



A snapshot of Canadians caring for persons with dementia: The toll it takes

Making a meaningful difference in the lives of older adults and their families by bridging research, policies and practice

Summary

As the population ages, there is a growing number of Canadians living with dementia. Their ability to continue to live in the community relies on the support of family members and friends. By knowing who supports Canadians with dementia and the consequences they experience, we can better support these caregivers through difficult times and reduce the stigma associated with the disease. Using Statistics Canada’s 2012 General Social Survey (GSS), we compare the characteristics of Canadians providing care to persons with dementia and non-dementia and the health, social, and financial consequences they face. We found:

- 480,000 Canadians provided care to someone with dementia, 6% of all caregivers.
- Canadians caring for someone with dementia are older, less likely than other caregivers to have minor children at home, more likely to be caring for parents (in-law), and less likely to live with the care receiver but to live nearby or within commuting distance.
- Canadians caring for someone with dementia spend an average of 13.6 hours per week providing care—nearly 1.5 times the average of 9.6 hours per week that other caregivers provide. Among dementia caregivers, women spend more time on average providing care than men, and are more likely to provide intense amounts of care.
- Collectively, dementia caregivers provide 342 million hours of care per year, the equivalent of over 171,000 full-time employees.
- Caring for someone with dementia takes a heavier toll on caregivers’ health, social and financial well-being compared to other caregivers. Women dementia caregivers are more likely than their male counterparts to experience these negative consequences.
- Significantly more dementia than non-dementia caregivers reduced hours worked or exited the labour force to provide care. At an aggregate level, caring for someone with dementia results in 58 million fewer hours of paid employment per year and the loss of over 34,000 dementia caregivers from the paid labour force.
- Nearly half of dementia caregivers incurred extra expenses.
- As a result of the above, 25% of women and 14% of men dementia caregivers— 98,784 Canadians—experienced financial hardship because of their caring obligations.



As the population ages, more Canadians are living with dementia. Most are over age 65, but people in their 40s and 50s can also develop dementia. Those affected often rely on family members and friends to support them to live well, be active, and remain connected to their communities. According to the Alzheimer Society of Canada, 3 in 4 Canadians know someone affected by dementia.

Federal, provincial and territorial governments and the Alzheimer Society of Canada are working on a pan-Canadian Dementia Strategy that aims to raise awareness of the impact of dementia on those diagnosed and their families. Knowing who supports Canadians with dementia, and at what cost, can help better support dementia caregivers and reduce the stigma associated with the disease.

Research Objectives

To describe family caregivers caring for persons with dementia and the consequences they incur.

480,000 Canadians care for someone with dementia

Of the 8.1 million Canadians (28%) who care for a family member or friend, nearly half a million (6%) are caring for

someone with dementia. Almost as many men as women are caregivers overall, but more women than men provide care to a loved one with dementia (W59%, M41%).

Dementia caregivers differ from other caregivers

Dementia caregivers are older, less likely to have children under age 15 at home, more likely to be caring for parents (in-law), less likely to live with the care receiver and more likely to live nearby or within commuting distance (< 3 hours by car) than other caregivers.

Dementia caregivers spend 14 hours/week on care

Caregivers to someone with dementia spend more time on care than other caregivers (13.6 v. 9.6 hr/wk on average). While more than two-thirds of caregivers provide less than 9 hours of care per week, dementia caregivers are significantly more likely to spend more than 29 hours per week on care than all other caregivers.

Women dementia caregivers spend the most time caring (16.2 v. 10.2 hr/wk on average). Collectively, Canadians caring for persons with dementia provide over 342 million hours

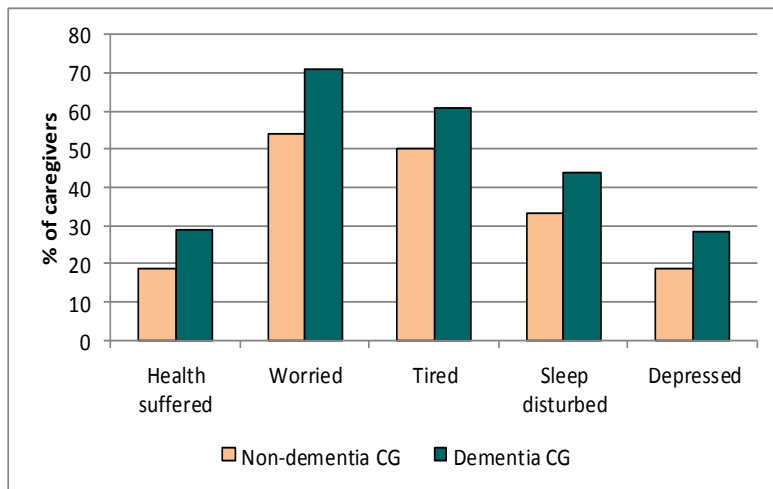
of care per year, the equivalent of over 171,000 full time employees, contributing meaningfully to society in valuable yet often hidden ways.

Caring takes a toll on health

The vast majority of caregivers, including dementia caregivers, report being in good, very good or excellent physical and mental health. Yet caring for a loved one with dementia takes a heavier toll on caregivers' health (see Figure 1). Those caring for someone with dementia, especially women, are significantly more likely than all other caregivers to feel worried (W78%, M60%), tired (W73%, M43%), overwhelmed (W57%, M27%), and depressed (W32%, M22%). Nearly 1/2 of women and 1/3 of men also report sleep disturbances because of dementia care. These indicators may explain why significantly more dementia caregivers (W36%, M19%) than all other caregivers (W25%, M11%) report that their overall health suffers because of their care responsibilities. Again, women are particularly vulnerable to poor care-related health outcomes.

Caring for someone with dementia impacts healthy behaviors too. Dementia

Figure 1. Impact on health



caregivers are significantly more likely than other caregivers to exercise less (40%) and eat a less healthy diet (24%).

Caring impacts social well-being and isolation

Caring for someone with dementia negatively impacts caregivers’ social well-being more than it does for non-dementia caregivers. A significantly higher proportion of dementia than non-dementia caregivers have less time to spend with their partner, children and friends and to report strained relationships (see Figure 2).

As well, dementia caregivers spend less time than other caregivers on social activities, hobbies, volunteering and relaxing. Dementia caregivers are also more likely to change or not make holiday plans at all.

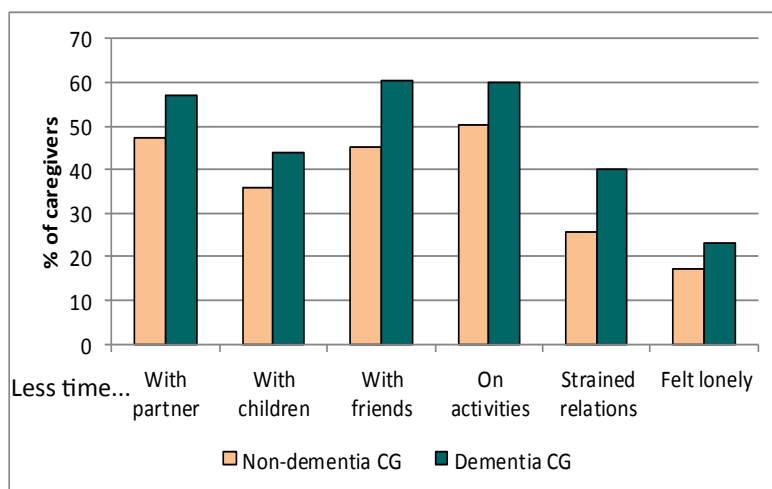
Little wonder that significantly more dementia than non-dementia caregivers feel tired and lonely because of caring.

Women dementia caregivers have the least time for social engagement. As a result, while slightly more men than women report strained relationships (W38%, M42%), more women felt lonely (W27%, M18%).

Caring impacts finances

Dementia and non-dementia caregivers are equally likely to have paid jobs (most of them full time) in addition to their care work, but dementia caregivers incur more employment and other financial consequences (see Figure 3). There is little difference in care-related absenteeism reported by the two groups: more than 40% missed at least one day of work in the past year. But significantly more dementia than non-dementia caregivers reduce their hours of work and leave their jobs. About 1 in 5 dementia caregivers reduce their paid work hours to provide care, cutting back their hours by 10.6 hrs/wk on average compared to 9.1 hrs/wk for non-dementia caregivers. Few caregivers leave the labour force altogether, but the proportion of

Figure 2. Impact on social well-being and isolation



dementia caregivers who exit is nearly double that of non-dementia caregivers. At an aggregate level, these consequences represent an enormous loss of productivity to employers and the labour market. Caring for someone with dementia results in 58 million fewer hours of paid employment per year and loss of 34,000 Canadians from the labour force.

In addition to the loss of income and benefits associated with paid work, dementia caregivers are significantly more likely than other caregivers to incur extra care-related expenses (49% v. 43%). Equal proportions of dementia and non-dementia caregivers experience financial hardship, however more women than men dementia caregivers were affected (W25%, M14%).

Collectively, 98,784 people caring for someone with dementia incurred financial hardship, often modifying spending or deferring savings to cover care-related expenses.

Implications for public policies

Canadians caring for family members or friends with dementia are at greater risk of negative health, social and financial outcomes than other caregivers. These negative outcomes also spill over onto other stakeholders: productivity losses for employers; threats to labour market sustainability (absenteeism, turnover and benefit expenses); lost income tax revenues; additional health care costs when caregivers become ill or injured, or when they are unable to continue

caring for their loved one at home. Addressing these negative consequences is increasingly urgent in the face of growing care demands due to population aging and rising rates of disability. Public and workplace policies that improve quality of and access to community services, enhance workplace flexibility, and compensate for financial losses can play a role in reducing risks to caregivers, employers and society at large.



Research Methods

Descriptive analyses were conducted on two sub-samples of Statistics Canada’s 2012 General Social Survey on caregiving and care receiving: 624 respondents aged 15+ whose primary care receiver had dementia; and 8,680 respondents caring for someone with a disability, chronic illness or age-related condition that was not dementia. Care included assistance with: indoor domestic tasks, home maintenance, outdoor work, transportation, errands, personal or medical care, care management, or emotional support.

Data were weighted to ensure findings are representative of the Canadian population. All analyses were conducted separately for men and women.

Figure 3. Financial consequences of care

