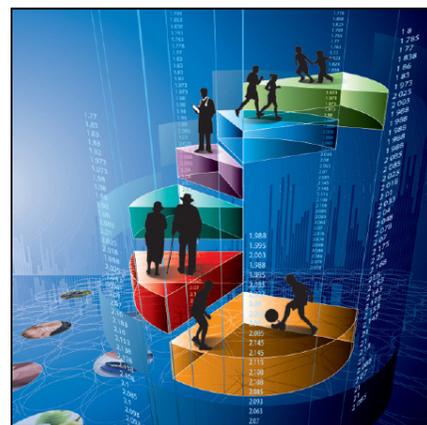


Health Reports

Alzheimer's disease and other dementias in Canada

by Suzy L. Wong, Heather Gilmour and Pamela L. Ramage-Morin

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- . not available for any reference period
- .. not available for a specific reference period
- ... not applicable
- 0 true zero or a value rounded to zero
- 0^s value rounded to 0 (zero) where there is a meaningful distinction between true zero and the value that was rounded
- ^P preliminary
- ^r revised
- X suppressed to meet the confidentiality requirements of the *Statistics Act*
- ^E use with caution
- F too unreliable to be published
- * significantly different from reference category ($p < 0.05$)

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Abstract

This article provides information on Alzheimer's disease and other dementias, using the 2010/2011 Canadian Community Health Survey, the 2011/2012 Survey of Neurological Conditions in Institutions in Canada, and the 2011 Survey on Living with Neurological Conditions in Canada. Among Canadians aged 45 or older, an estimated 0.8% in private households and 45% in long-term residential care facilities had a diagnosis of dementia. Prevalence rose with age. The vast majority of people with dementia in private households received assistance with medical care (81%), housework and home maintenance (83%), meal preparation (88%), emotional support (90%), transportation (92%), and managing care (92%). Among those receiving assistance, 85% relied, at least in part, on family, friends or neighbours. The primary caregiver tended to be a spouse (46%) or an adult child (44%), most of whom were daughters (71%). The majority of primary caregivers lived in the same household (83%) and provided daily care (86%).

Keywords: Caregivers, informal assistance, neurological disease

Dementia is the most common type of neurodegenerative disorder.¹ In 2010, an estimated 35.6 million people worldwide were living with dementia, a number that is expected to double in 20 years.²

Dementia is a general term used to describe a range of symptoms associated with a decline in mental function severe enough to reduce a person's ability to perform everyday activities.³ It is caused by a variety of diseases and injuries that affect the brain. Alzheimer's disease is the most common, followed by vascular dementia, dementia with Lewy bodies, and frontotemporal dementia; individuals can also have a combination of different types of dementia.⁴ Dementia mainly affects older people, but it is not a normal part of healthy aging.

Mental functions that may be impaired include memory, communication and language, ability to focus and pay attention, reasoning and judgment, and visual perception.³ Emotional control, social behaviour and motivation may also deteriorate. As the condition progresses, the need for assistance increases, and eventually, almost constant supervision is required.

Thus, dementia may be overwhelming not only for those who have it, but also for their caregivers and families. The impact on caregivers, family, and society can be physical, psychological, social and economic.³ Total estimated worldwide costs of dementia (direct costs such as medical and social care, and indirect costs such as unpaid caregiving by families and friends) were US\$604 billion in 2010.⁵

Estimates of the prevalence of dementia in Canada vary. According to a 2012 study commissioned by the Alzheimer's Society of Canada,⁶ 747,000 Canadians were living with cognitive impairment, which included, but was not limited to, dementia. In a 2010 report,⁷ the estimated prevalence of

dementia alone was 500,000, based on previous studies in Canada and Europe. By contrast, based on administrative data from British Columbia,⁸ the estimated prevalence in Canada in 2011 was 340,000.

Using data from nationally representative self-report surveys, this study examines Canadians aged 45 or older living with Alzheimer's disease or any other dementia (see The data). Separate estimates are presented for residents of long-term health care facilities (Survey of Neurological Conditions in Institutions in Canada) and for those living in private households (Canadian Community Health Survey Neurological Conditions Prevalence File). Additional details, including the types of assistance received and information about caregivers, are examined for people with dementia in private households.⁹ For context, some characteristics are compared with other household populations—specifically, people without dementia (2011 Canadian Community Health Survey) and those with Parkinson's disease, (Survey on Living with Neurological Conditions in Canada) the second most common neurodegenerative disorder.

Dementia in long-term residential care facilities

An estimated 45% (118,000) of people aged 45 or older in long-term residential care facilities had a diagnosis of dementia. Dementia was more common at older ages: 12% at ages 45 to 64, 42% at ages 65 to 79, and 56% at age 80 or older (Table 1).

In the older age groups, the number of women in long-term care with dementia substantially exceeded the number of men (Figure 1). This may reflect women's longer life expectancy¹⁰ or their lack of caregivers in the community.

Dementia in the household population

Among people aged 45 or older in private households, an estimated 0.8% (109,500) had a diagnosis of dementia. As was true in institutions, prevalence rose with age: 0.1% at ages 45 to 64, compared with 5% at age 80 or older (Table 1). About the same number of men and women in the household population had dementia (Figure 1). Among those aged 45 to 75 with dementia, nearly all (99%) were not working; 54% cited their neurological condition(s) as the reason.

Assistance

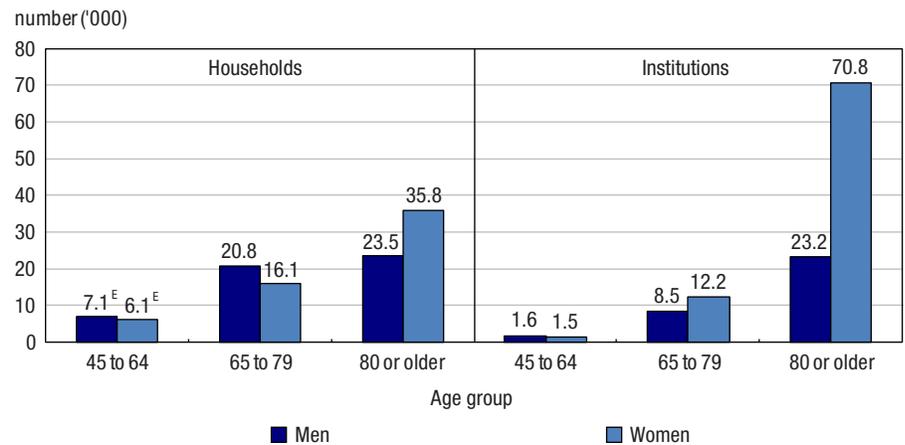
The majority of household residents with dementia received formal or informal assistance. *Formal* assistance is provided by organizations with paid or volunteer workers; *informal* assistance, or caregiving, is provided by family, friends or neighbours. Among those with

dementia, 85% relied, at least in part, on family, friends or neighbours for assistance—43% also received some formal assistance; the remaining 41% relied solely on informal assistance. An additional 15% received neither formal nor

informal assistance. Sources of assistance may be influenced by the availability of caregivers, volunteer and paid services, as well as financial resources.

Informal assistance was provided for a variety of tasks (Figure 2). The vast

Figure 1
Number with dementia in private households (2010/2011) and long-term health care institutions (2011/2012), by age group and sex, population aged 45 or older, Canada excluding territories



^E interpret with caution

Sources: 2010/2011 Canadian Community Health Survey—Neurological Prevalence File (households); 2011/2012 Survey of Neurological Conditions in Institutions in Canada (institutions).

Table 1
Prevalence of dementia in private households (2010/2011) and long-term care institutions (2011/2012), by sex and age group, population aged 45 or older, Canada

Age group	Men			Women		
	%	95% confidence interval from	to	%	95% confidence interval from	to
Households						
45 to 64	0.2 ^{E†}	0.1	0.3	0.1 ^{E†}	0.1	0.2
65 to 79	1.3 [‡]	1.1	1.6	0.9	0.7	1.2
80 or older	5.2 [‡]	4.4	6.3	5.2 [‡]	4.3	6.1
Institutions						
45 to 64	11.3 [‡]	10.6	12.1	12.6 [‡]	11.9	13.3
65 to 79	39.8 [‡]	38.6	40.9	43.0	41.7	44.3
80 or older	53.1 ^{††}	52.0	54.3	56.8 [‡]	55.7	57.9

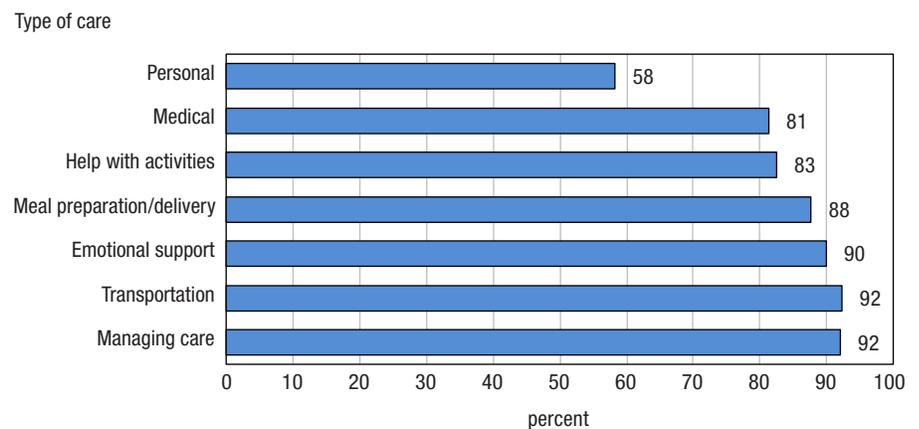
^E interpret with caution

[†] significantly different from women ($p < 0.05$)

[‡] significantly different from 65-to-79 age group ($p < 0.01$)

Sources: 2010/2011 Canadian Community Health Survey—Neurological Prevalence File (private households); 2011/2012 Survey of Neurological Conditions in Institutions in Canada (institutions).

Figure 2
Percentage with dementia receiving informal assistance, by type of care, household population aged 45 or older, Canada excluding territories, 2011



Source: 2011 Survey on Living with Neurological Conditions in Canada.

majority of people with dementia received help with medical care such as taking medicine or nursing care (81%); housework, home maintenance or outdoor work (83%); meal preparation or delivery (88%); emotional support (90%); transportation including trips to the doctor or for shopping (92%); and managing care such as making appointments or managing personal finances (92%). Fewer needed help with personal care such as eating, dressing, bathing or toileting (58%). Previous research has shown that seniors who need assistance with personal care are more likely to move to institutions.¹¹

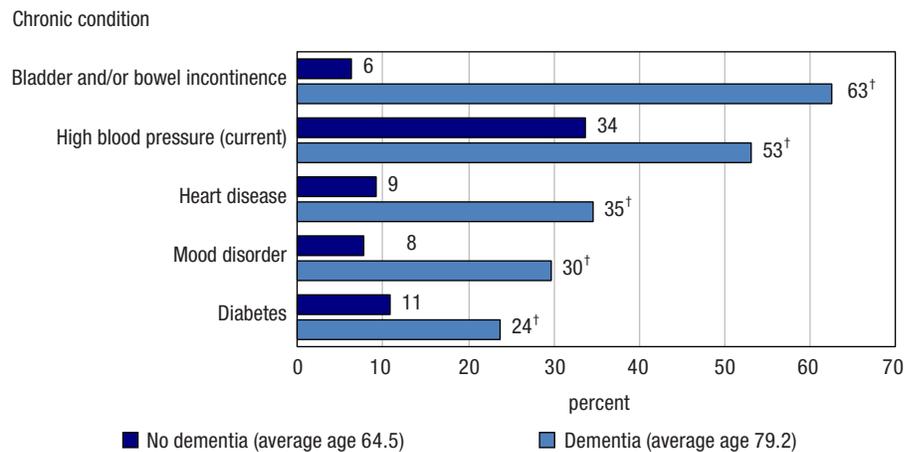
People with dementia often had other medical conditions that could increase their need for assistance and make caring for them more complex. Almost a third (32%) had at least one of the other neurological conditions that were examined in the survey; 63% had incontinence; and 53% had high blood pressure (Figure 3). Between a third and a quarter had heart disease, a mood disorder or diabetes.

People without dementia also have these conditions, although not to the same extent (Figure 3). For example, in 2011, 6% of the general population without dementia reported incontinence; the likelihood of a person with dementia having incontinence was 10-fold higher. Age contributes to these differences. Among people with at least one of the chronic conditions, those with dementia were, on average, almost 15 years older than those without dementia: 79 versus 65. When age was taken into account, those with dementia were significantly more likely to also have heart disease, a mood disorder, or incontinence, but were no more likely to have diabetes or high blood pressure than those without dementia (data not shown).

Caregiver characteristics

Usually, the primary informal caregiver for people with dementia was a spouse (46%) or an adult child (44%), typically, a daughter (71%) (Table 2).

Figure 3
Prevalence of selected chronic conditions, by presence of dementia, household population aged 45 or older, Canada excluding territories, 2011



[†] significantly different from no dementia ($p < 0.05$)

Sources: 2011 Survey on Living with Neurological Conditions in Canada; 2011 Canadian Community Health Survey.

Table 2
Selected characteristics of informal caregivers of household population aged 45 or older with dementia, by relationship to care recipient, Canada excluding territories, 2011

Characteristics	Relationship to care recipient						
	%	Spouse (married, common-law, same-sex partner, ex-spouse)			Son or daughter		
		95% confidence interval	95% confidence interval	95% confidence interval	95% confidence interval	95% confidence interval	95% confidence interval
	%	from	to	%	from	to	
Total	46.4	37.9	55.2	44.3	35.4	53.5	
Mean age (years)	74.2 [†]	54.1	
Sex							
Male	41.7	31.5	52.5	28.5 ^E	17.4	43.0	
Female	58.3	47.5	68.5	71.5 [†]	57.0	82.6	
Lives in same household	98.6 [†]	95.9	99.6	71.1	57.2	81.9	
Provides daily care	96.6 [†]	89.1	99.0	77.1	63.6	86.7	
Employment status							
Full-time	F	F	F	43.7 ^E	29.5	59.0	
Part-time	F	F	F	16.4 ^E	8.4	29.4	
Not employed	85.5 [†]	76.3	91.5	40.0 ^E	26.1	55.6	
Reduced hours or stopped work for 3 or more months[§]	67.5 [†]	47.9	82.4	35.3 ^E	20.1	54.2	

... not applicable

^E interpret with caution

F unreliable

[§] among caregivers currently employed or who had worked in past and provided assistance while working

[†] significantly different from son or daughter ($p < 0.05$)

[‡] significantly different from males ($p < 0.05$)

Source: 2011 Survey on Living with Neurological Conditions in Canada.

A smaller percentage of informal caregivers were other relatives, friends or neighbours (9%) (data not shown in table). Most spouse caregivers lived in the same household as the person with dementia (99%) and provided daily care (97%). Their average age was 74, and 15% were employed at a job or business. Among adult child caregivers, the majority (71%) lived in the same household as their parent and provided daily care (77%). Their average age was 54, and 60% were employed.

Similar percentages of those with dementia and Parkinson's disease received informal care, mostly by caregivers in the same household who provided daily care.¹² However, the demands on caregivers of people with dementia were likely greater, since nearly twice as many received assistance with all seven types of tasks, compared to those with Parkinson's (43% versus 22%, $p < 0.05$).

Conclusion

This study highlights the prevalence and impact of dementia in Canada. An estimated 0.8% of Canadians aged 45 or older living in private households, and 45% of those in long-term residential care facilities, had a diagnosis of dementia. Prevalence rose with age. Most people with dementia received assistance from family, friends or neighbours for a variety of tasks. Primary caregivers tended to be spouses or adult children, and nearly all caregivers provided care on a daily basis.

Acknowledgements

Statistics Canada thanks participants for their input and advice during development of the neurological content for the Canadian Community Health Survey, the Survey on Living with Neurological Conditions in Canada, and the Survey of Neurological Conditions in Institutions in Canada. The content was developed

jointly by the Health Statistics Division at Statistics Canada and the Public Health Agency of Canada (PHAC), with significant input from PHAC's expert advisory group members who specialize in the study of the neurological conditions. Content selection was based on objectives and data requirements specified by PHAC. Sponsorship was provided by PHAC as part of the National Population Health Study of Neurological Conditions.

The data

Data sources

The study was based on the Neurological Conditions Prevalence File, which was derived from the 2010/2011 Canadian Community Health Survey – Annual Component, the 2011 Survey on Living with Neurological Conditions in Canada, and the 2011/2012 Survey of Neurological Conditions in Institutions in Canada. Detailed documentation for these surveys is available at www.statcan.gc.ca.

Canadian Community Health Survey

The Canadian Community Health Survey (CCHS) is a cross-sectional survey that collects health information for people aged 12 or older in private households, excluding full-time members of the Canadian Forces, and residents of institutions, Aboriginal settlements in the provinces, and some remote areas. Sample sizes/Response rates were 63,542/69.8% (2011) and 62,103/67% (2012). Data from 36,347 CCHS (2011) respondents 45 or older were analyzed to provide comparable estimates for the population who did not have dementia. Respondents who agreed to share their data with the survey's share partners were included in the Neurological Conditions Prevalence File. The final sample size was 285,971. The response rate was 70.6%.

Survey on Living with Neurological Conditions in Canada

The 2011 Survey on Living with Neurological Conditions in Canada (SLNCC) was a cross-sectional survey that collected information for people aged 15 or older living in private households, excluding those previously described for the CCHS and residents of the three territories. The sample size was 4,569, with a response rate of 81.6%. This study used a subsample of 461 respondents (242 men, 219 women) aged 45 or older with dementia, representing an estimated 67,300 Canadians. Their average age was 78.7, and 56.6% were women.

Survey of Neurological Conditions in Institutions in Canada

The 2011 Survey of Neurological Conditions in Institutions in Canada (SNCIC) was a census to determine the number of people diagnosed with selected neurological conditions, including dementia, who lived in long-term residential care facilities with four or more beds and which were approved, funded or licensed by provincial/territorial departments of health and/or social services. The sample consisted of 4,245 institutions with a response rate of 63.5%.¹³

Definitions

Respondents were asked to report on Alzheimer's disease or any other dementia—referred to as “dementia” in the text—and other chronic neurological conditions (amyotrophic lateral sclerosis, brain injury, brain tumour, cerebral palsy, dystonia, effects of a stroke, epilepsy, Huntington's disease, hydrocephalus, migraine, multiple sclerosis, muscular dystrophy, Parkinson's disease, spina bifida, spinal cord injury, spinal cord tumour, Tourette's syndrome) that had lasted or were expected to last six months or more and that had been diagnosed by a health professional. The presence of other selected chronic conditions was similarly reported. *Bladder and/or bowel incontinence* were combined. Current *high blood pressure* was limited to those with the condition who had taken blood pressure medication in the past month. *Heart disease, diabetes* and *mood disorder* were established with single questions. Respondents were not classified as having diabetes if it had occurred only during pregnancy. Depression, bipolar disorder, mania and dysthymia were listed as examples in the mood disorder question.

Respondents were asked about specific types of assistance they received in the past 12 months at home, work or school because of their neurological condition.

The *caregiver* was the family member, friend or neighbour who had dedicated the most time and resources to providing informal assistance in the past 12 months. *Spouse* caregivers included married, common-law, same-sex partner, and ex-spouse relationships. Based on caregivers' work status in the week before the interview, they were classified as *currently working* if they had worked at a job or been absent from work that week. The frequency of care from the caregiver was categorized as *daily* or *less than daily*. This refers to the frequency of care provided by the caregiver, not the total frequency of assistance received.

Statistical analysis included weighted frequencies, cross-tabulations and means. To account for survey design effects, standard errors and coefficients of variation were estimated using the bootstrap technique.^{14,15}

Limitations

Neurological and other chronic conditions were self-reported by individuals (household) or by proxy respondents (institutions) and not verified by another source. Only prevalence data were available for people in institutions. Most of the study pertains to the population in private households and does not represent people in long-term residential care facilities.

CCHS respondents were asked if they, or someone in their household, had been diagnosed with selected neurological conditions. People who were reported to have a neurological condition were selected to participate in the SLNCC and were asked again about the selected neurological conditions. A total of 314 respondents had dementia based on CCHS, but not based on the SLNCC. Conversely, 40 respondents did not have dementia based on the CCHS, but did based on the SLNCC. Additional details are available elsewhere.⁹

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