Report summary

Prevalence and monetary costs of dementia in Canada (2016)[1]: a report by the Alzheimer Society of Canada

Alzheimer Society of Canada

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Background

Dementia prevalence estimates vary among population-based studies, depending on the definitions of dementia, methodologies and data sources and types of costs they use. A common approach is needed to avoid confusion and increase public and stakeholder confidence in the estimates.

Since 1994, five major studies have yielded widely differing estimates of dementia prevalence and monetary costs of dementia in Canada:

- Canadian Study of Health and Aging, 1994[2]
- Alzheimer Society of Canada. Rising Tide: The Impact of Dementia on Canadian Society, 2010[3]
- Mental Health Commission of Canada: Making the Case for Investing in Mental Health in Canada, 2011[4]
- Economic Burden of Illness in Canada, 2014[5]
- National Population Health Study of Neurological Conditions, 2014[6]

These studies variously estimated the prevalence of dementia for the year 2011 as low as 340 170 and as high as 747 000. The main reason for this difference was that mild cognitive impairment (MCI) was not consistently included in the projections. The estimated monetary costs of dementia for the same year also varied, from $910 million to $33 billion. This discrepancy is largely due to three factors: (1) the lack of agreed-upon methods for estimating financial costs; (2) the unavailability of prevalence estimates for the various stages of dementia (mild, moderate and severe), which directly affect the amount of money spent; and (3) the absence of tools to measure direct, indirect and intangible costs more accurately.

Given the increasing challenges of dementia in Canada and around the globe, reconciling these differences is critical for developing standards to generate reliable information for public consumption and to shape public policy and service development.

Methods

In May 2015, following a review of these and other studies, the Alzheimer Society of Canada convened a panel of Canadian and international epidemiologists, health economists and policy analysts, as well as representatives from provincial Alzheimer Societies. Our goal was to provide advice on how best to estimate current and future prevalence and monetary costs of dementia in Canada. *Prevalence and Monetary Costs of Dementia in Canada (2016)*[1] is the result of this collaborative work.

Panel findings

Prevalence estimates

There was consensus among panel members that the Canadian Study of Health and Aging (1994)[2] remains the best and most reliable population data source to use for building present and future prevalence estimates.

The authors of this study derived the data from questionnaires and interviews conducted with 9008 individuals aged 65 years and older who were living in the community, and 1255 individuals living in long-term care homes. For the individuals who were interviewed, researchers then carried out clinical, neurological and neuropsychological examinations of 2914 people who had low cognitive scores, and a random sample of those with normal scores. A team made up of a physician, a nurse and a neuropsychologist then assessed whether these individuals should be classified as having probable or definite dementia, and further determined the type of dementia. This method is consistent with the way diagnosis is currently achieved in a clinical setting, using multiple data sources and input from multiple health care professionals. Autopsies are seldom done, despite the fact that they are the most accurate means of diagnosing dementia.

Prevalence estimates drawn from health administrative data are not based on standardized clinical assessment as in the Canadian Study of Health and Aging or in autopsies.

Based on projections using the Canadian Study of Health and Aging (1994)[2] data, as of 2016 there are an estimated 564 000 Canadians living with dementia. By 2031, this number is expected to rise to 937 000, an increase of 66%. Of the current number of Canadians with dementia, more than 65% are women.

Monetary cost estimates

When estimating the present and future costs of dementia, three key factors must be taken into account:

1. perspective, which focusses on who incurs the cost, e.g. the public health care system only or society as whole, including people with dementia, their caregivers and employers;
2. scope, which is concerned with what costs are included, e.g. direct and indirect, informal and intangible costs; and
3. valuation, which involves the method of attributing a cost to dementia that would not otherwise exist.

Because the financial impact of dementia goes well beyond the health care system and takes a tremendous toll not only on those living with dementia, but also their families, caregivers and employers, the Panel recommended taking a societal perspective in estimating the economic consequences of the condition. It also recommended that the scope should include direct, indirect, informal and intangible costs, and that these costs should be compared between populations living with dementia and those without the condition.

The Panel concluded that the National Population Health Study of Neurological Conditions (2014)[6] met these requirements and provided the best foundation for projecting the monetary costs of dementia. According to this study, the combined Canadian health care system costs and out-of-pocket caregiver costs amounted to $10.4 billion in 2016. By 2031, this figure is expected to increase to $16.6 billion.

Generally, costs for people with dementia are estimated to be five-and-a-half times greater than for those who do not have the condition. Home care and long-term care are the largest contributors to direct costs. In 2011, family caregivers provided 19.2 million unpaid hours of care. This number is projected to double by 2031.

Applicability

Accurate and reliable data on dementia are particularly important because Canada's population is aging, and there is still no cure and pharmacological treatments are helpful only for limited times in the course of the condition for some patients. Evidence from economically developed countries shows that incidences of dementia may be declining because of higher levels of education, greater health awareness and in some cases better control of vascular risk factors.

Public health uses for these data include

- improving public awareness and understanding of the social and personal impact of dementia on Canadians living with the condition and their caregivers;
- documenting financial costs of care, loss of income and loss of productivity;
- providing benchmarks against which future progress can be measured and evaluated; and
- informing service planning and policy development, such as a national dementia strategy, human resources policies across workplaces, government projections and budgets.

The Public Health Agency of Canada, in collaboration with provincial and territorial ministries of health, has developed the first national case definition that will be used to consistently report the epidemiology of Alzheimer's disease and other dementias (prevalence, incidence and all-cause mortality) among Canadians aged 65 years and older. Data will be disaggregated by sex, age group, fiscal year and province or territory. Annual reporting of these data is expected to begin in 2017/18.

Conclusion

Prevalence and Monetary Costs of Dementia in Canada (2016) provides useful and more reliable information about the prevalence of dementia and its economic impact on Canadian society. It serves to help Alzheimer Societies across Canada as well as other like-minded organizations to develop awareness campaigns and other public initiatives, create new programs and services and influence policy development and service planning now and in the future.

To read the full report online, visit http://www.alzheimer.ca/~/media/Files/national/Statistics/PrevalenceandCostsofDementia_EN.pdf

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