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# **NOTE TO READERS**

This third series of *Aging Vignettes* has been designed by the National Advisory Council on Aging (NACA) to provide a statistical portrait of dementia in Canada. They are produced as part of NACA's mandate to disseminate information and are intended for people who are interested in dementia and aging, and who care about seniors.

In these Vignettes, the word 'seniors' refers to people aged 65 and over (65+). This is not meant to suggest that the population group 65+ represents a homogeneous group. The Council recognizes that seniors are as heterogeneous and often more so than other age groups.

As a rule the latest data available were cited. Because the sources are varied and cover a number of years, the year the data were collected is referenced. As was the case with the first series of Vignettes that provided a general portrait of seniors and the second that focused on health data, the reader will note that no effort was made to analyze or interpret the facts stated in this series.

The Council welcomes your comments on these *Aging Vignettes* and suggestions for future editions.

#### A Quick Portrait of Dementia in Canada

#### What is Dementia?

- Dementia refers to a group of diseases characterized by a progressive and usually irreversible decline of mental functions. The symptoms are memory loss, disorientation, cognitive decline and inappropriate social behaviour. As the disease progresses, the patient usually becomes dependent on others to manage even very simple physical activities.
- Around the beginning of the 20th Century several distinct descriptions of dementia began to appear based on differing clinical symptoms, course, or pathologic findings.
- Some of the most common types of dementia are:

Alzheimer's disease
Vascular dementia
Mixed dementia
Gerstmann-Straussler syndrome
AIDS dementia
Parkinson's disease
Alcoholic dementia.

#### Sources:

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

Ostbye, T. and E. Crosse. Net economic costs of dementia in Canada. *Canadian Medical Association Journal*, 151, (1994): 1457-1464.

Veterans Affairs Canada. Dementia: guidelines for diagnosis and treatment. Ottawa, 1989: 1B 18-3.

## A Quick Portrait of Dementia in Canada

## **How Many People are Affected?**

- In 1991, 8% of the Canadian population 65+ suffered from dementia.
- It is expected that the number of Canadians with dementia will triple between 1991 and 2031, whereas the population 65+ will double in this time period.

YEAR	NUMBER OF DEMENTIA CASES IN CANADA
1991	253,000
2001	364,000
2011	475,000
2021	592,000
2031	778,000

## **How Old are Those Affected?**

The probability of suffering from dementia rises with age, the rates being

2.4% among those 65 to 74

11. 1 % among those 75 to 84

34.5% among those 85+ (1991 data).

- The rate of dementia increases with age, with prevalence doubling every 5.1 years after the age of 65.
- In 1991, of those Canadian seniors suffering from dementia

18% were 65-74 (44,700 seniors) 44% were 75-84 (1 10,200 seniors) 39% were 85+ (97,700 seniors)

#### Sources:

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913

Dalziel, W.B. Dementia: no longer the silent epidemic. *Canadian Medical Association Journal*, 151, (1994):1407-1409.

Ebly, E.M. et al. Prevalence and types of dementia in the very old: results from the Canadian Study of Health and Aging. *Neurology*, 44, (1994): 1593-1600.

#### A Quick Portrait of Dementia in Canada

## Are there Differences between Men and Women?

- In 1991, women accounted for 68% of dementia cases. The greater number of women
  with dementia mainly reflects the greater number of women in older age groups (in
  older age groups the likelihood of dementia is higher).
- In Canada in 1991, 81,200 males and 171,400 females had dementia.
- Of those seniors aged 65 to 84 suffering from dementia, 44% were male 56% were female (1991 data).
- Of those seniors aged 85+ suffering from dementia, 30% were male 70% were female (1991 data).

#### Source:

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

## A Quick Portrait of Dementia in Canada

## Where Do Seniors with Dementia Live?

- In 1991, approximately 50% of seniors with dementia (123,900) were living in the community; the remaining 128,700 were living in an institutional setting.
- It is estimated that of those seniors suffering from dementia who live in the community,
  - 45.5% have mild dementia
  - 44.5% have moderate dementia
  - 10.0% have severe dementia.
- It is estimated that of those seniors suffering from dementia who live in an institution,
  - 10.9% have mild dementia
  - 33.7% have moderate dementia
  - 55.4% have severe dementia.
- In 1991, 67% of seniors aged 85+ who had a form of dementia were living in an institution.
- Overall, the prevalence of dementia is similar across the different regions of Canada. However, in 1991,
  - in the Atlantic provinces and Quebec, more people with dementia lived in the community
  - in Ontario and the Prairie provinces, more people with dementia lived institutions in British Columbia, people were equally distributed between the community and institutions.

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canadian *Journal on Aging, 13,* (1994): 470-487.

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

## A Quick Portrait of Dementia in Canada

## What are the Economic Costs of Dementia?

- In 1991, it was estimated that the net economic cost of dementia in Canada was \$3.9 billion. Amounts spent include:
  - \$1.25 billion for dementia patients in the community
  - \$2.18 billion for dementia patients in long-term care institutions
  - \$74 million for drugs, hospitalization, and diagnosis
  - \$10 million for research
  - \$389 million for dementia patients under the age of 65
  - \$3.5 billion for dementia patients aged 65+.
- In 1991, dementia costs accounted for 5.8% of Canada's total health care cost (\$67 billion) for that year.
- By 2031, the annual cost of dementia will rise to approximately \$12 billion if there are no advances in prevention or treatment.
- The net economic cost of each dementia patient is \$13,900 (1991 data).
- The net economic cost of caring for a dementia patient in the community is \$10,100, compared with \$19,100 in an institution (1991 data).
- In 1991, unpaid caregivers contributed \$250 million of the total costs related to people with dementia living in the community.
- The cost of dementia-related research was calculated to be only .25% of the total cost of dementia.

#### Sources:

Ostbye, T. and E. Crosse. Net economic costs of dementia in Canada. *Canadian Medical Association Journal*, 151, (1994): 1457-1464.

Dalziel, W.B. Dementia: no longer the silent epidemic. *Canadian Medical Association Journal*, 151, (1994): 1407-1409.

## A Quick Portrait of Dementia in Canada

## What are the Common Symptoms of Dementia?

Of those people with dementia,

97% are confused or have trouble making decisions

97% forget names of people and places

87% have problems with physical ambulation

86% do or say things repeatedly

85% have problems completing tasks like housework or grocery shopping

85% act restless or agitated

83% sit doing nothing

73% are stubborn or uncooperative

63% talk to themselves or talk nonsense (1991 data).

Other less common symptoms are often present among those affected individuals:

52% have disturbed sleep patterns

50% see things that aren't there

50% are fearful or suspicious of people

18% have anti-social behaviour

14% threaten to hurt themselves or others.

#### Sources:

Gottlieb, B.H. and J. Johnson. Impact of day programs on family caregivers of persons with dementia. *Respite Care Project.* Guelph: University of Guelph, 1995.

Rockwood, K. et al. Screening for cognitive impairment in the elderly: impact of physical function measures added to cognitive screening instruments. *Aging and Cognition*, 1, (1994): 261-270.

#### A Quick Portrait of Dementia in Canada

## What are the Mortality Rates?

- In Canada, 10,000 deaths per year can be attributed directly to dementia. As many as 100,000 to 300,000 deaths per year may be caused by dementia to a varying degree (1985 data).
- Alzheimer's disease is the fourth or fifth most common cause of death in Canada's seniors after cancer, heart disease and stroke. This data is difficult to verify because Alzheimer's disease is not always listed as an official cause of death on death certificates (1985 data).
- Seniors diagnosed with Alzheimer's disease have mortality rates 2.5 times that of the expected mortality rate (1994 data).
- The approximate life expectancy for patients with Alzheimer's disease is 8 years from the time of onset of symptoms; however, some patients have survived for more than 20 years after that.
- Some 37.1 % of patients with Alzheimer's disease have died within 5 years of their diagnosis.
- Persons diagnosed as having vascular dementia, overall, have fewer years of life remaining after diagnosis than those with Alzheimer's disease.
- Definite diagnosis of Alzheimer's disease can only be made at the time of autopsy when microscopic examination of the brain tissue reveals the characteristic pathology of the illness.

#### Sources:

Health and Welfare Canada. Mental Health Division. *Alzheimer's disease: a family information handbook*. Ottawa: 1985.

Hogan, D.B. et al. Progression and outcome of patients in a Canadian dementia clinic. *Canadian Journal of Neurological Science*, 21, (1994): 331-338.

Department of Veterans Affairs. Dementia: guidelines for diagnosis and treatment. Ottawa, 1989: 1B 18-3.

#### A Quick Portrait of Dementia in Canada

## What about Dementia Among Persons Aged 85+?

- In 1991, 34.5% of the Canadian population aged 85+ were suffering from dementia.
- It is estimated that dementia is present in

23% of seniors aged 85 to 89 years old

40% of seniors aged 90 to 94 years old

55% of seniors aged 95 to 99 years old

85% of seniors aged 100 to 106 years old.

In 1991, of those seniors aged 85+ suffering from dementia,

67% lived in institutions and

33% lived in the community.

• Of those persons aged 85+.

20% suffer from mild dementia

37% suffer from moderate dementia

42% suffer from severe dementia (1991 data).

• Of those dementia patients aged 85+ living in the community,

41.4% suffer from mild dementia

10.6% suffer from severe dementia (1991 data).

Of those dementia patients aged 85+ living in an institution,

9.8% suffer from mild dementia

56.6% suffer from severe dementia (1991 data).

Alzheimer's disease accounts for 75.2% of all dementias in individuals aged 85+.
 Vascular dementia, which is the second most common type of dementia in those aged 85+, accounts for approximately 13.9% of all cases.

#### Sources:

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

Ebly, E. et al. Prevalence and types of dementia in the very old: results from the Canadian Study of Health and Aging. *Neurology*, 44, (1994): 1593-1600.

Rockwood, K. and K. Stadnyk. The prevalence of dementia in the elderly: a review. *Canadian Journal of Psychiatry*, 39, (1994): 253-257.

## A Quick Portrait of Dementia in Canada

## What is the Prevalence of Alzheimer's Disease?

• In 1991, it was estimated that 5.1 % of the Canadian population 65+ was suffering from Alzheimer's disease.

YEAR	NUMBER OF ALZHEIMER'S CASES IN CANADA
1991	161,000
2001	238,000
2011	314,000
2021	387,000
2031	509,000

- Alzheimer's disease accounts for approximately two-thirds of all dementia cases.
- · The probability of suffering from Alzheimer's rises with age at a rate of

1.0% among those aged 65 to 74

6.9% among those aged 75 to 84

26.0% among those aged 85+.

 In a world report on the prevalence of Alzheimer's disease it is estimated that 8.5% of the world population 65+ and 28% of the world population 85+ suffer from Alzheimer's.

#### Sources:

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

Rockwood, K. and K. Stadnyk. The prevalence of dementia in the elderly: a review. *Canadian Journal of Psychiatry*, 39, (1994): 253-257.

#### A Quick Portrait of Dementia in Canada

## At Risk of Developing Alzheimer's Disease?

- A person's chances of developing Alzheimer's disease are increased by 2.5 times if they have a close relative with the disease. This finding supports the theory that genetics plays a role in the risk of developing the disease.
- The probability of Alzheimer's disease occurring within the same family is about 1 in 6 if one's parents had the disease, and 1 in 12 if one's siblings had the disease.
- The risk of developing Alzheimer's disease is higher in those who have had a previous head injury, in those who have worked in a job exposing them to glue, pesticides and fertilizers, and in those with less education.
- Little evidence supports the notion that the use of antiperspirants or antacids containing aluminum increases one's risk of developing Alzheimer's disease.

## What are the Symptoms?

At the time of diagnosis of Alzheimer's disease,

99% of patients suffer from memory impairment

83% of patients have problems with calculation

67% of patients have problems writing

60% of patients have problems with oral language

53% of patients have problems recognizing people.

#### Sources:

Health Canada. Division of Aging and Seniors. The Canadian Study of Health and Aging. *Seniors Info Exchange*, (Spring 1995): 9.

Herrmann, N. Confusion and dementia in the elderly. In *Mental Health and Aging*. National Advisory Council on Aging (ed.). Ottawa, 1991: 35-47.

The Canadian Study of Health and Aging. Canadian Study of Health and Aging: risk factors for Alzheimer's disease in Canada. *Neurology*, 44, (1994): 2073-2080.

Hogan, D.B. et al. Progression and outcome of patients in a Canadian dementia clinic. *Canadian Journal of Neurological Science*, 21, (1994): 331-338.

## A Quick Portrait of Dementia in Canada

## Vascular and other Dementias?

- In 1991, 1.5% of the population 65+ had some form of vascular dementia.
- Vascular dementia is the second most common type of dementia in Canada, accounting for approximately 20% of all cases.
- The projected prevalence of vascular dementia is expected to triple in the next 40 years.

YEAR	NUMBER OF VASCULAR DEMENTIA CASES IN CANADA
1991	49,000
2001	68,000
2011	86,000
2021	109,000
2031	144,000

- In 1991, the estimated number of cases of vascular dementia was 40% higher among men than among women.
- In 1991, 42,900 Canadians were diagnosed as having other types of dementia, such as alcoholic dementia, Picks' disease, or dementia associated with a neurological illness (Parkinson's, Multiple Sclerosis).

#### Sources:

Herrmann, N. Confusion and dementia in the elderly. In *Mental Health and Aging*. National Advisory Council on Aging (ed.). Ottawa, 1991: 35-47.

Canadian Study of Health and Aging Working Group. Canadian Study of Health and Aging: study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150, (1994): 899-913.

## A Quick Portrait of Dementia in Canada

## **How Important are Informal Caregivers?**

 The majority of dementia patients in Canada, approximately 98%, have a caregiver, most having more than one:

2% of patients have no caregiver

3% of patients have only a primary caregiver

3% of patients have only one person to count on beyond the primary caregiver 92% of patients have two or more friends or relatives beyond the primary caregiver provide them with assistance.

- In 1991, 34,800 Canadians with dementia lived alone (1991 data).
- In 1991, 3,000 Canadians with dementia had no caregiver.
- Of those demented persons in the community with no caregiver, 81% are suffering from moderate or severe dementia (1991 data).
- Persons suffering from dementia have fewer friends and relatives to count on for support than those without dementia.
- It is estimated that

caregivers of people with mild to moderate dementia put in 3.2 hours of care per day, and

caregivers of people with severe dementia put in 8.06 hours of care per day.

#### Sources:

The Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canadian *Journal on Aging*, 13, (1994): 470-487.

Health Canada. Division of Aging and Seniors. The Canadian Study of Health and Aging. *Seniors Info Exchange*, (Spring 1995): 9.

Ostbye, T. and E. Crosse. Net economic costs of dementia in Canada. *Canadian Medical Association Journal*, 151, (1994): 1457-1464.

## A Quick Portrait of Dementia in Canada

## What is the Profile of the Caregiver?

In 1991, of unpaid caregivers looking after a dementia patient living in the community,

37% were a spouse

28% were a child

24% were an other family member or a friend.

In 1991, of unpaid caregivers looking after a dementia patient living in an institution,

13% were a spouse

64% were a child

23% were an other family member or a friend.

- In 1991, 75.4% of dementia patients living in the community had a female caregiver.
- Wives are most likely to be the informal caregiver of a dementia patient living in the community, while daughters are most likely to be the informal caregiver of a patient living in an institution.
- In 1991, 36% of community informal caregivers of dementia patients and 19% of institutional caregivers of dementia patients were aged 70+.
- In 1991, 36% of all informal caregivers are employed. Among them, 33% report disturbances in their work due to caregiving responsibilities.
- These disturbances were twice as frequent in caregivers of person's with dementia than those without.
- On average, informal caregivers spend 2.5 years providing care to a particular dementia patient.

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, (1994): 470-487.

Gottlieb, B.H. and J. Johnson. Impact of day programs on family caregivers of persons with dementia. *Respite Care Project.* Guelph: University of Guelph, 1995.

#### A Quick Portrait of Dementia in Canada

## **How are Support Services Used?**

- Overall, use of community support services by a caregiver is low. However, use of community support services is higher among those caring for someone with dementia than for those caring for someone without it.
- In 1991, among caregivers of dementia patients,

37% were using 1 or 2 support services

18% were using 3 or more support services

44% were using none (1991 data).

 Spouses caring for a dementia patient were using fewer services than children caregivers:

69% of spouses used no support services

46% of children used none

2% of spouses used 3 or more services

16% of children used 3 or more (1991 data).

- Support service use increases as the level of disability from dementia increases.
- Of those caregivers using one or more community support services,

71 % use a homemaker service

41% use in-home nursing care

36% use home help for personal tasks

19% use home delivered meals

12% use day care

9% use counselling

7% use respite care

6% use self-help or support groups (1991 data).

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, (1994): 470-487.

Penning, M. Cognitive impairment, caregiver burden, and the utilization of home health services. *Journal of Aging and Health*, 7, (1995): 233-253.

Durand, P.J. et al. Predictors of caregivers' dissatisfaction with community long-term care services for seniors: results from the Canadian Study of Health and Aging. *Canadian Journal of Public Health*, 86, (1995): 325-332

#### A Quick Portrait of Dementia in Canada

## **Do Support Services Have an Impact on Caregivers?**

 In general, caregivers report high satisfaction with the support services they are receiving.

SERVICE	% OF CAREGIVER SATISFACTION
homemaker	81%
in-home nursing care	85%
home help with personal tasks	87%
home delivered meals	65%
day centres	81%
counselling	81%
respite care	61%
self-help or support groups	64%

 73% of caregivers using support services reported no problems with them. Caregivers already using support services are 2.4 times more likely to request additional services.

# **How Do Caregivers Use Day Centre Programs?**

- A study of 103 family caregivers of persons with dementia in South-central Ontario revealed that:
- Caregivers using a day centre brought their patient to it an average 1.5 days/week.
   After 5 months of day centre use, caregivers reported less global stress and less emotional distress.
- 27% of dementia patients were placed in long-term care within 5 months of enrolment in a day centre program (1994 data).

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, (1994): 470-487

Durand, P.J. et al. Predictors of caregivers' dissatisfaction With community long-term care services for seniors: results from the Canadian Study of Health and Aging. *Canadian Journal of Public Health*, 86, (1995): 325-332.

Gottlieb, B.H. and J. Johnson. Impact of day programs on family caregivers of persons with dementia. *Respite Care Project.* Guelph: University of Guelph, 1995.

#### A Quick Portrait of Dementia in Canada

## **How Healthy are Caregivers?**

- Depression is twice as common in someone who cares for a dementia patient than in someone who cares for a person without dementia.
- The more severe the case of dementia, the more likely the caregiver is to experience depression. Approximately 16% of persons caring for someone in the community with mild dementia and 40% of persons caring for someone in the community with severe dementia report symptoms of depression.
- Informal caregivers of dementia patients living in institutions experience less depression than those who care for individuals living in the community, even though dementia severity is higher in institutions.
- Of informal caregivers who provide care to individuals living in the community, the mean number of chronic health problems is
  - 2.6 for caregivers of dementia patients
  - 1.9 for caregivers of non-dementia patients.

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, (1994): 470-487.

#### A Quick Portrait of Dementia in Canada

## What of Institutional Placement of Dementia Patients?

- In 1991, 12% of all community caregivers had considered placing the senior they were caring for in an institution. Among those who considered placement,
  - 53% were caregivers for people with dementia
  - 11 % were caregivers for people without dementia.
- As reasons for institutionalization, 40% of caregivers of people with dementia cited behaviour problems and the family feeling overwhelmed.
- Within 5 years of diagnosis, 79% of Alzheimer's patients had been institutionalized.

#### Sources:

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13, (1994): 470-487.

Hogan, D.B. et al. Progression and outcome of patients in a Canadian dementia clinic. *Canadian Journal of Neurological Science*, 21, (1994): 331-338.