What is a Defendable Estimate of Dementia Prevalence and Monetary Costs?

Presentation at the 30th International Conference of Alzheimer's Disease International, Perth Australia

Friday, April 17, 2015
4:00PM – 5:30PM
River View Room 7

Mimi Lowi-Young, M.H.A, Dip Bus. Admin., FACHE, FCCHL
Chief Executive Officer, Alzheimer Society of Canada
Objectives of Presentation

- Why defendable estimates of dementia prevalence and costs?
- How does one reconcile major differences in prevalence of dementia now to 2031 across studies?
- What costs and outcomes of prevention, treatment, care and support should be included in projections to 2031?
- What are the ‘preferred’ ‘dependable’ single estimates for Canada that the Alzheimer Society of Canada should report?
- How should defendable estimates for provinces be produced?
- What knowledge gaps require future research?
Why defendable estimates of dementia prevalence?

Real World of Dementia

(collection, coding)

Data

(processing, interpretation, presentation)

Information

(politics, commitment)

Action
Why Defendable Estimate of Dementia Prevalence and Monetary Costs?

1. Support public policy and advocacy initiatives with governments

2. Improve work plans, budgets and projections
   - user friendly (e.g. single number not a range of numbers inform service planning at all levels)
   - robust so all sectors can use them with confidence

3. Increase public awareness about:
   - severity experienced by those living with dementia
   - costs of care
   - loss of income
   - availability and burden on family caregivers
   - other challenges
Prevalence of Dementia
Canada 1991-92

Rate per 1,000

Source: Can Med Assoc J 1994;150:899-913
CONTEXT – By 2031, Canada’s population is projected to grow to ~40 million and to see a shift in age structure.
Projected Prevalence of Dementia (x 1,000)
Canada, 1991 - 2031

Source: CMAJ 1994; 150: 899-913
Canada’s most Authoritative and Reliable Estimates of Dementia Prevalence: the Canadian Study of Health and Aging 1991-2001

• Interviews and questionnaires with 9,008 people 65 years and over living in community and in long term care facilities.

• Clinical, neurological and neuropsychological examinations (2,914 of people with low cognitive scores and random sample with “normal” scores).

• Physical measurements of mobility and blood pressure.

• Laboratory tests were undertaken, and blood samples or genetic and other analyses.

• Abstracted information from death certificates and provincial health care utilization records for the study period.
Three Recent Major Reports on Present and Future Dementia Prevalence and Monetary Costs

- Mental Health Commission of Canada, 2012 (Government of Canada)
- Rising Tide, 2010 (Alzheimer Society of Canada)
- National Population Health Study of Neurological Conditions, 2014 (Government of Canada)
Existence of Varied Prevalence Estimates Leads to Confusion and Impacts Credibility of Sources

<table>
<thead>
<tr>
<th>Time</th>
<th>MHCC</th>
<th>Rising Tide</th>
<th>PHSNC</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>747,129</td>
<td>521,280</td>
<td>340,170</td>
</tr>
<tr>
<td>2021</td>
<td>1,024,465</td>
<td>687,552</td>
<td>461,651</td>
</tr>
<tr>
<td>2031</td>
<td>1,435,923</td>
<td>923,763</td>
<td>673,991</td>
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</tbody>
</table>

MHCC = Mental Health Commission of Canada, 2012
Rising Tide = Rising Tide: Impact of Dementia on Canadian Society, 2010
PHSNC = National Population Health Study of Neurological Conditions, 2014
Future Study: Canadian Longitudinal Study of Aging but incidence data
Issues in Estimating Dementia Prevalence

• Varied prevalence estimates lead to confusion and impacts credibility of agencies providing estimates

• Two important determinants of differences in estimates of dementia prevalence are:
  – Decisions on what *level of severity* of dementia to include, that is, should mild cognitive impairment be included
  – different *data sources* have strengths and limitations
What level of dementia severity should be used in prevalence estimates?

- Canadian Study of Health and Aging
  - 8% of persons over 65 years of age had “definite or probable” dementia,
  - but another 8% had “mild cognitive impairment”
  → adding people with mild cognitive impairment can double estimate of “dementia” in population
# Inclusion of People with Mild Cognitive Impairment in three Reports

<table>
<thead>
<tr>
<th>Report</th>
<th>Severity of Dementia</th>
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</thead>
<tbody>
<tr>
<td>Mental Health Commission of Canada, 2012</td>
<td>Included people with dementia and people with mild cognitive impairment</td>
</tr>
<tr>
<td>Rising Tide, 2010</td>
<td>Did not include people with mild cognitive impairment</td>
</tr>
<tr>
<td>National Population Health Study of Neurological Conditions, 2014</td>
<td>Did not include people with mild cognitive impairment</td>
</tr>
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Source of Data and Dementia Prevalence

• Studies show that community surveys find twice as many cases of dementia than health administrative data
# Data Source and Prevalence of Dementia

<table>
<thead>
<tr>
<th>Report</th>
<th>Sources of Data</th>
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<tbody>
<tr>
<td>Mental Health Commission of Canada, 2012</td>
<td>Health services data, access and supply, utilization, costs (Province of Manitoba)</td>
</tr>
<tr>
<td>Rising Tide, 2010</td>
<td>National survey (Canadian Study of Health and Aging) and surveys from other countries (EURODEM)</td>
</tr>
<tr>
<td>National Population Health Study of Neurological Conditions, 2014</td>
<td>Health services data, access and supply, utilization, costs. Data from other agencies, social care, housing (Province of British Columbia including MDS InterRAI in long term home and residential care).</td>
</tr>
</tbody>
</table>
## Annual Estimated Direct Costs of Dementia in 2031 in Three Reports

<table>
<thead>
<tr>
<th>Report</th>
<th>In $Millions</th>
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</thead>
<tbody>
<tr>
<td>Mental Health Commission of Canada</td>
<td>$92,863</td>
</tr>
<tr>
<td>Rising Tide</td>
<td>$55,351</td>
</tr>
<tr>
<td>National Population Health Study of Neurological Conditions</td>
<td>$16,000?</td>
</tr>
</tbody>
</table>
Issues in Estimating Dementia Monetary Costs

- Costs from societal perspective preferred
- Cost estimates are sensitive to:
  - Inclusion of different types of housing
  - Number of persons with dementia within each housing type
  - Length of time in each stage of severity of dementia
Total out-of-pocket costs to caregivers of individuals with Alzheimer's disease and other dementias

Costs in Billions of Dollars ($)

Year

2011
2016
2021
2026
2031
Continuum of Care and Services for Seniors and those requiring Continuing Care

Independent Older Adult

Primary Care

Continuing Care Retirement Communities

Independent Living / Supportive Housing

Home Health / Personal Care Assistance

Assisted Living

Adult Day Programs

Nursing Home / Long-Term Care

Hospital Care

Dependent Older Adult
Percentage of Individuals with Dementia in Community vs. Institution

<table>
<thead>
<tr>
<th>Stage of Dementia</th>
<th>Community</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free</td>
<td>97%</td>
<td>3%</td>
</tr>
<tr>
<td>Mild</td>
<td>91.7%</td>
<td>8.4%</td>
</tr>
<tr>
<td>Moderate</td>
<td>50.4%</td>
<td>49.6%</td>
</tr>
<tr>
<td>Severe</td>
<td>13.9%</td>
<td>86.1%</td>
</tr>
</tbody>
</table>
Continuum of Care and Services for Seniors and those requiring Continuing Care:
Estimated % with Cognitive Impairment

Legend
= Estimated % of persons with cognitive impairment
Data Required on Length of Time in Stages of Dementia

Stages of Dementia

- Free
- Mild
- Moderate
- Severe
- Death

Average Time

Total Average Time - 8 years
The Canadian Longitudinal Study on Aging (CLSA)

- A key strategic initiative of the Canadian Institutes of Health Research (CIHR)
- More than 160 researchers - 26 institutions
- Follow 50,000 Canadians for 20 years
- Multidisciplinary - biology, genetics, medicine, psychology, sociology, demography, economics, epidemiology, nursing, nutrition, health services, biostatistics, population health
Next Steps: Workshop of Researchers and Policy Makers

- Members of Canadian and international research teams
- Policy makers from governments and the Alzheimer Society
- Use Workshop to:
  - Produce single estimate in Canada to be used by the Alzheimer Society of Canada
  - Advise provinces and territories of Canada on how to derive estimates using national estimates
  - Identify priorities for future research
Workshop Process

Commissioned Report “On the Prevalence and Costs of Dementia in Canada: A Review of the Evidence” sent to Workshop Participants

Completion of Cost and Prevalence of Dementia Questionnaire by Workshop Participants

Dementia Prevalence and Monetary Costs Workshop May 8 & 9, 2015

Review Draft Workshop Report by Experts and Provincial Societies who did not attend Workshop

Final Workshop Report Disseminated
Summary of Presentation

• Alzheimer Society requires defendable estimates of dementia prevalence and costs
• Must acknowledge unavoidable uncertainty associated with estimating both prevalence and costs of dementia
• Workshop “process” will be used to create the “message” about dementia prevalence and costs for consumption by media, public and policy makers
• Workshop “process” also will identify knowledge gaps for future research priorities
Société Alzheimer Society