Dementia in Canada

Methodology Notes

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Introduction

The Canadian Institute for Health Information (CIHI), in collaboration with the Public Health Agency of Canada (PHAC), has analyzed the health care interactions of seniors with dementia. The report *Dementia in Canada* covers a variety of topics, such as

- The epidemiological burden of dementia;
- Living at home with dementia and caregiver burden;
- Characteristics of and quality of care for residents of long-term care (LTC) facilities who have dementia;
- Characteristics of hospitalizations and emergency department (ED) visits by seniors with dementia; and
- Programs and policies designed to help Canadians reduce the risk of dementia and improve their quality of life after onset.

This work leverages data from PHAC's Canadian Chronic Disease Surveillance System (CCDSS) on dementia, including Alzheimer's disease, and explores the CIHI data holdings listed below to highlight dementia's impact on Canada's health systems and on family members or others who provide care at home. These data holdings are described in the next section.

- Hospital ED visits: National Ambulatory Care Reporting System (NACRS)
- Hospital admissions: Discharge Abstract Database/Hospital Morbidity Database (DAD/HMDB) and Ontario Mental Health Reporting System (OMHRS)
- Publicly funded home care services: Home Care Reporting System (HCRS)
- Publicly funded LTC services: Continuing Care Reporting System (CCRS)
- Drug claims: National Prescription Drug Utilization Information System (NPDUIS)

Use of PHAC's CCDSS estimates of dementia

This work relies extensively on PHAC's dementia surveillance activities, specifically the CCDSS dementia data. Data has been used

- To report, in the section How dementia impacts Canadians, dementia prevalence, incidence and all-cause mortality, and to compare prevalence of dementia with prevalence of other chronic diseases, based on publicly available data;
- To develop criteria to identify dementia in CIHI databases; and
- To provide baseline denominators for several measures, using short-term projections or in-progress data to maximize the timeliness of the data.

CCDSS methodology

The CCDSS is a collaborative network of provincial and territorial surveillance systems supported by PHAC. In each province and territory, the health insurance registry database is linked to the physician billing and hospitalization databases. In the case of dementia, the prescription drug database is also linked, in provinces and territories where such a database is available and linkable. PHAC regularly receives aggregate data on dementia prevalence, incidence and all-cause mortality by age group and sex.

In the CCDSS, diagnosed dementia was identified[1] if a person age 65 and older had

• At least 1 hospitalization record with an ICD-10-CA or ICD-9 code for dementia, including Alzheimer's disease; or

• At least 3 physician claims in a 2-year period (with at least 30 days between each claim) with an ICD-9 code for dementia, including Alzheimer's disease; or

• At least 1 prescription drug record for a cholinesterase inhibitor or an N-methyl-D-aspartate (NMDA) receptor antagonist.

CCDSS data is collected by fiscal year from 1995–1996 onward, and is reportable for dementia as of 2002–2003. Details on CCDSS methodology, definitions and provincial specifications are available in the Public Health Infobase.

Interpreting trends and geographical variations using CCDSS data

Variations in health status that are seen over time and between provinces and territories are partially a function of differences in drug database coverage and in access to cholinesterase inhibitor and NMDA receptor antagonist drugs across jurisdictions, as well as of other differences in data collection methods, coding/classification systems and clinical billing practices. These factors must be considered when interpreting any variations.

Obtaining CCDSS estimates of dementia

CCDSS Data Cubes were accessed to obtain prevalence, incidence and all-cause mortality estimates of dementia and of other conditions for comparison.

Adapting the CCDSS case definition to CIHI's databases

Given that CCDSS patient identifiers are not publicly available, CIHI adapted the CCDSS algorithm to identify seniors living with dementia and extract information on their health system interactions. CIHI adapted CCDSS criteria for diagnosed dementia for each of its databases and added CCRS data for the LTC component. Details are provided in Table 1.

Using CCDSS data as the baseline denominator for CIHI's measures

CIHI's analysis used prevalence counts or short-term projections (where the actual data was not available at the time of publication) for 2015–2016 as the baseline denominator.

CIHI used CCDSS dementia prevalence estimates for all jurisdictions, with the following exceptions:

- **Ontario:** Dementia prevalence estimates for all fiscal years were obtained from the Institute for Clinical Evaluative Sciences using the CCDSS case definition.
- **Saskatchewan:** Due to coding differences in physician-level billing data, Saskatchewan data is excluded from publicly reported CCDSS dementia prevalence for all years. To calculate health system interactions, CIHI obtained estimates and 2-year projections directly from the Saskatchewan Ministry of Health. A tailored algorithm was used.
- **New Brunswick, Alberta and Yukon:** 2015 estimates were not available at the time of the analysis; 2-year projections were used instead.

CIHI data sources

A full description of each CIHI database, including coverage, is available on [CIHI's website](#).

Discharge Abstract Database/Hospital Morbidity Database

The DAD captures administrative, clinical and demographic information on hospital discharges from facilities in all provinces and territories except Quebec. Data from Quebec is submitted to CIHI directly by the Ministère de la Santé et des Services sociaux du Québec. This data is appended to the DAD to create the HMDB. The DAD/HMDB uses ICD-10-CA/CCI to code diagnoses and interventions.

National Ambulatory Care Reporting System

NACRS captures information on client visits to hospitals and community-based ambulatory care. NACRS currently collects data on day surgeries, ED use and other ambulatory care visits; data varies by region. NACRS uses ICD-10-CA/CCI to code diagnoses and interventions.

Ontario Mental Health Reporting System

OMHRS contains information on all individuals receiving adult mental health services in Ontario, as well as on some individuals receiving services in youth inpatient beds and in selected facilities in other provinces. OMHRS includes information about mental and physical health, social supports and service use, as well as care planning, outcome measurement, quality improvement and case-mix funding applications.

Continuing Care Reporting System

CCRS contains demographic, administrative, clinical and resource utilization information on individuals who receive continuing care services in hospitals or LTC facilities in Canada. Participating organizations also provide information on facility characteristics to support comparative reporting and benchmarking. The clinical data standard for CCRS is the Resident Assessment Instrument–Minimum Data Set 2.0 (RAI-MDS 2.0), which was developed by interRAI, an international research network committed to improving care for people with complex medical needs. It was modified with permission by CIHI for Canadian use.

Home Care Reporting System

HCRS contains information from the Resident Assessment Instrument–Home Care (RAI-HC) developed by interRAI. The assessment instrument is designed to be used with adults in home and community-based settings. Along with administrative, demographic and resource utilization data, the RAI-HC data collected from publicly funded home care programs is submitted to HCRS and made available across Canada to plan and monitor care, understand populations, improve quality and allocate resources.

National Prescription Drug Utilization Information System

NPDUIS contains drug claims–level data collected from publicly financed drug benefit programs in 9 Canadian provinces. NPDUIS houses pan-Canadian information related to public program formularies, drug claims, policies and population statistics. It was designed to provide information that supports accurate, timely and comparative analytical and reporting requirements for the establishment of sound pharmaceutical policies and the effective management of Canada's public drug benefit programs.

Identifying seniors with dementia in CIHI's databases

Seniors with dementia were identified in each CIHI database using criteria aligned with the corresponding elements of the CCDSS definition of dementia, including Alzheimer's disease. Cases were also identified in the home care and LTC databases, but not from physician billings as was done in the CCDSS. Complete CCDSS case definition could not be implemented in CIHI data, as it was not possible to link the databases.

Table 1   Defining dementia in each data holding

Data holding	Description	Variables/codes
Hospital Morbidity Database, National Ambulatory Care Reporting System	Dementia in Alzheimer's disease	ICD-10-CA: F000, F001, F002, F009
	Vascular dementia	ICD-10-CA: F010, F011, F012, F013, F018, F019
	Dementia in other diseases classified elsewhere	ICD-10-CA: F020, F021, F022, F023, F024, F028
	Unspecified dementia	ICD-10-CA: F03
	Alzheimer's disease	ICD-10-CA: G300, G301, G308, G309
Ontario Mental Health Reporting System	Alzheimer's disease/ vascular dementia	DSM-IV: 290, 2904, 29040, 29041, 29042, 29043, 2941, 29410, 29411, 2948
Continuing Care Reporting System	Alzheimer's disease/ other dementia	RAI-MDS 2.0 Variables and response values: I1R = 1 or I1V = 1
Home Care Reporting System	Alzheimer's disease/ other dementia	RAI-HC Variables and response values: J1G = 1, 2 or J1H = 1, 2, where 1 = diagnosed but not part of focused treatment or monitoring by health professional and 2 = part of focused treatment
National Prescription Drug Utilization Information System	Individuals prescribed cholinesterase inhibitors or NMDA receptor antagonists	Donepezil, rivastigmine, galantamine, memantine

Note
For the HMDB and NACRS, codes include any diagnosis type.

General exclusion criteria

Certain exclusions were applied across all data holdings:

- Provincial/territorial coverage was not considered comprehensive for reporting.
- The information required for data linkage was missing/invalid:
  - Invalid health card number (HCN); and/or
  - Invalid province issuing HCN.
- HCN was issued by the government of Canada (e.g., military personnel, prisoners). This population is also excluded from CCDSS coverage.
- Gender reported was neither male nor female.
- Admissions/discharges had invalid dates.
- Cases were cadaveric donors (admission category code = R).
- Age was younger than 65. (Note: For the analysis of young-onset dementia, the age range was from 18 to 64.)

Dementia cohort creation

The following methods were used to identify individuals diagnosed with dementia in various care settings:

Core dementia cohort (acute care)

Data sources: HMDB, OMHRS

Years: 2012–2013 to 2015–2016

Inclusion criteria:

- Hospital discharge cases with at least one dementia code (see Table 1)
- Records from institution types 1 — acute care, 5 — psychiatric institutions and A — day surgery

We created a list of unique HCNs for all individuals identified.

ED dementia cohort

Data source: NACRS

Years: 2012–2013 to 2015–2016

Inclusion criteria:

- ED visits with at least one dementia code (see Table 1)
- Ontario and Alberta residents, as these provinces have full coverage in NACRS

We created a list of unique HCNs for all individuals identified.

We used the HCN to link this cohort to the core dementia cohort so we could include individuals diagnosed with dementia who did not have ED visits but who did have a hospital admission during the study period.

Continuing care (LTC) dementia cohort

Data source: CCRS

Years: 2012–2013 to 2015–2016

Inclusion criteria:

- Continuing care resident assessments with at least one dementia flag (see Table 1)
- Individuals from the 6 jurisdictions that have full coverage: Newfoundland and Labrador, Ontario, Saskatchewan, Alberta, British Columbia and Yukon

We used the HCN to link this cohort to the core dementia cohort so we could include individuals who did not have a dementia diagnosis in an LTC facility but who did have a dementia diagnosis in a hospital admission during the study period.

Exclusions:

- Hospital-based complex continuing care (sector code = 3), in order to extract residential-based continuing care only

Home care dementia cohort

Data source: HCRS

Years: 2012–2013 to 2015–2016

Inclusion criteria:

- Home care client assessments with at least one dementia flag (see Table 1)
- Individuals from the 4 jurisdictions that have full coverage — Newfoundland and Labrador, Ontario, Alberta and Yukon — as well as from 1 jurisdiction that has partial coverage — British Columbia

We used the HCN to link this cohort to the core dementia cohort so we could include individuals who did not have a dementia diagnosis in home care but who did have a dementia diagnosis in a hospital admission during the study period.

Methods

The methods used for the analysis are described after the following table:

Table 2   Databases and years used in the analysis

Topic	DAD/HMDB	OMHRS	NACRS	CCRS	HCRS	NPDUIS	CCDSS/ PHAC
Impact of dementia	n/a	n/a	n/a	n/a	n/a	n/a	2002–2003 to 2013–2014
Home and community care	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	2011–2012 to 2015–2016
Long-term care	2008–2009 to 2015–2016	2010–2011 to 2015–2016	n/a	2008–2009 to 2015–2016	n/a	n/a	n/a
Dementia in hospitals	2008–2009 to 2015–2016	2010–2011 to 2015–2016	2012–2013 to 2015–2016	n/a	n/a	n/a	2015–2016
Prevention	n/a	n/a	n/a	n/a	n/a	2011–2012 to 2015–2016	n/a
The impact of falls	2008–2009 to 2015–2016	2010–2011 to 2015–2016	2012–2013 to 2015–2016	2008–2009 to 2015–2016	2012–2013 to 2015–2016	n/a	2015–2016
Palliative care	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	2013–2014 (mortality only)
Young-onset dementia	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	n/a
Unpaid caregivers	2012–2013 to 2015–2016	2012–2013 to 2015–2016	n/a	n/a	2012–2013 to 2015–2016	n/a	n/a

Note
n/a: Not applicable.

Dementia in home and community care

Overview: Comparing where seniors with and without dementia live (i.e., LTC or not)

Data sources: CCRS, HCRS, CCDSS

Calculating the number of seniors with dementia who live outside of LTC

HCRS contains data only for recipients of publicly funded home care services, so identifying seniors with dementia who live at home and who do not receive home care services must be done another way: by using the prevalence of seniors with dementia from the CCDSS and deducting known seniors with dementia who live in LTC.

Data source: CCRS

Inclusion criteria:

• Individuals residing in an LTC facility between April 1, 2015, and March 31, 2016
• Individuals from the 5 jurisdictions that had full coverage: Newfoundland and Labrador, Ontario, Alberta, British Columbia and Yukon (Yukon was excluded due to inconsistencies when comparing with the CCDSS)

We used the HCN to link this cohort to the continuing care dementia cohort (to identify all individuals diagnosed with dementia regardless of whether or not they had a diagnosis of dementia in 2015–2016).

Exclusion criteria:

• Hospital-based complex continuing care (sector code = 3), in order to extract residential-based continuing care only

Analysis of home care recipients

Data source: HCRS

Inclusion criteria:

• Assessments done in home care between April 1, 2015, and March 31, 2016
• Keep only the last assessment for each individual

Exclusion criteria:

• Clients whose first assessment was done in the hospital

We analyzed the characteristics of home care clients for the outcome scales described in Appendix 3.

Factors that influence entering LTC following an initial assessment

The multivariate logistic regression model approach developed for CIHI's report *Seniors in Transition: Exploring Pathways Across the Care Continuum* was leveraged to focus specifically on seniors with dementia. All seniors in this model had an initial assessment in 2012–2013 that was used to establish eligibility for LTC and to assess health status and care needs. Following the initial assessment, seniors followed 1 of 3 care trajectories (see Table 3).

Table 3   Care trajectories for seniors with dementia

Trajectory	Initial setting	Assessment	Final setting
1	Long-term care	interRAI's Resident Assessment Instrument–Minimum Data Set 2.0	Long-term care
2	Home care	interRAI's Resident Assessment Instrument–Home Care	Home care
3	Home care	interRAI's Resident Assessment Instrument–Home Care	Long-term care

The model compared seniors in each of the 3 trajectories. The factors included in the model were based on information from the initial assessment. 32 factors were analyzed to identify those associated with an increased likelihood of having an LTC facility as an initial care setting for seniors living with dementia.

Table 4   Factors included in the logistic regression models

Factor	Definition
Patient factors	
Hospitalization	In hospital at time of initial assessment
High user	High user of hospital services in the 365 days prior to initial assessment, defined as 3 or more acute episodes of care and a cumulative minimum of 30 days in hospital
Age	Age in completed years as of assessment date
Male	Client is male
Income quintile	Neighbourhood income quintile (from Statistics Canada)
Urban	Urban location of residence at the time of the initial assessment, defined as Statistical Area Classification types 1 to 3

Living alone	Client lives alone:
	• Client does not live with a primary caregiver. RAI-HC assessment indicates that the client
	  – Has a primary caregiver who does not live with him or her; or
	  – Does not have a primary caregiver.

Factor	Definition
Patient factors (cont'd)	
Symptoms of caregiver distress	Symptoms of caregiver distress, anger or depression
Caregiver unable to continue	Caregiver is unable to continue providing care, where 0 = no and 1 = yes
Behaviours and impairments	
Requires physical assistance	Measured with the Activities of Daily Living Hierarchy Scale, where 0 = no functional impairment and 6 = total dependence
Cognitive impairment	Measured with the Cognitive Performance Scale, where 0 = intact and 6 = very severe impairment
Responsive behaviours	Responsive behaviours, including at least one instance of verbally abusive, physically abusive, socially inappropriate or disruptive behaviour or of resisting care, where the behaviour occurred in the last 3 days
Wandering	Wandering in the last 3 days
Any health instability	Medical instability measured using the CHESS (Changes in Health, End-Stage Disease and Signs and Symptoms) Scale, with instability indicated with a CHESS score greater than or equal to 1
Falls	One or more falls recorded in the last 90 days
Bladder incontinence	Measured as occasionally or more frequently incontinent
Bowel incontinence	Measured as occasionally or more frequently incontinent
Oxygen	Oxygen scheduled as part of care plan
Daily pain	Any indication of daily pain
Diseases and disorders	
Signs of depression	Signs of depression measured using the Depression Rating Scale, with a value of 3 or greater indicating the client has more numerous and/or frequent symptoms
Any psychiatric diagnosis	Any psychiatric diagnosis present
Diabetes	Diabetes present
Heart disease	Heart disease present
Congestive heart failure	Congestive heart failure present
Emphysema/ COPD/asthma	Emphysema, chronic obstructive pulmonary disease (COPD) or asthma present
Hypertension	Hypertension present
Stroke	Cerebrovascular accident (stroke) present
Parkinson's disease	Parkinson's disease present
Cancer	Cancer, not including skin cancer, present
Arthritis	Arthritis present
Hip fracture	Hip fracture present
Osteoporosis	Osteoporosis present

Dementia in long-term care

Overview: Use of physical restraints and potentially inappropriate antipsychotics among seniors with dementia who reside in an LTC facility, including trending and comparison with seniors without dementia

Data source: CCRS

Inclusion criteria:

- Age 65 and older
- Received care in an LTC facility between April 1, 2015, and March 31, 2016
- Individuals from the 6 jurisdictions with full coverage: Newfoundland and Labrador, Ontario, Saskatchewan, Alberta, British Columbia and Yukon

Exclusion criteria:

- Hospital-based complex continuing care in Ontario, in order to focus on residential-based continuing care only

Table 5   Selection criteria for LTC cohorts

Cohort	Selection criteria
All active episodes of care	• Residents with an entry date before March 31, 2016, and discharge date either missing or after April 1, 2015 • Last episode only for each resident
Admission episodes selected for resident characteristics	• Residents with an entry date between April 1, 2015, and March 31, 2016 • Remove episodes if there was a prior discharge within 92 days of admission of interest
Assessments selected for resident characteristics in LTC	• Residents with assessments between April 1, 2015, and March 31, 2016 • Last assessment only for each resident
Assessments selected for quality indicator reporting	• Assessments between April 1, 2015, and March 31, 2016 • Quality indicator denominator identifier = 1

Dementia in hospitals

Overview: Comparing seniors with and without dementia in terms of admission rates, reason for admission, length of stay (including in ED) and hospital harm

Data sources: HMDB, NACRS, CCDSS

ED visits

Inclusion criteria:

- From the ED dementia cohort (described above)
- All visits to the ED between April 1, 2015, and March 31, 2016

Hospital admissions

Inclusion criteria:

- From the core dementia cohort (described above)
- All discharges between April 1, 2015, and March 31, 2016

Hospital harm

Inclusion criteria:

- From the core dementia cohort (described above)
- Discharges between April 1, 2015, and March 31, 2016

Exclusion criteria:

- Discharges from Quebec acute care institutions
- Discharges of patients age 15 and older with selected mental health diagnoses (i.e., most responsible diagnosis code of F10 to F99)

The definition of hospital harm was based on CIHI's existing Hospital Harm indicator (please see the Indicator Library for details). A multivariate logistic regression model was used to identify the factors associated with hospital harm in seniors with dementia. The variables that were significant and were therefore included in the model were total length of stay, transfer from other health care facilities/programs and presence of pre-admit comorbidities measured by the Charlson Index.

Young-onset dementia

Overview: Comparison of individuals diagnosed with dementia before age 65 with those diagnosed as seniors, in terms of hospitalizations, LTC and home care

Data sources: HMDB, OMHRS, CCRS, HCRS

Hospital admissions

Inclusion criteria:

- Discharges in HMDB and OMHRS from all acute care institutions (analytical institution type = 1)
- Discharges occurring between April 1, 2015, and March 31, 2016
- Individuals age 18 to 64

Long-term care

Inclusion criteria:

- Same criteria as those used for the continuing care cohort
- Residents of LTC facilities with an assessment between April 1, 2015, and March 31, 2016
- Individuals age 18 to 64

Home care

Inclusion criteria:

- Same criteria as those used for the home care cohort
- Clients who received home care services and had an assessment recorded between April 1, 2015, and March 31, 2016
- Individuals age 18 to 64

We analyzed the characteristics of home care clients for the outcome scales described in Appendix 3.

Dementia and falls

Overview: Rate of fall-related ED visits and hospitalizations among seniors with and without dementia, at home or in LTC, with comparison by income level

Data sources: DAD/HMDB, NACRS, CCRS, HCRS, Postal Code Conversion File Plus

Fall-related ED visits

Using the ED visits cohort (described above), the following inclusion criteria were applied:

- Visits to EDs in Ontario and Alberta
- Visits between April 1, 2015, and March 31, 2016
- Presence of at least one ICD-10-CA code for falls from the range W00 to W19 with a corresponding problem identified as secondary

Fall-related hospital admissions

Using the core dementia cohort (described above), the following inclusion criteria were applied:

- Discharges from all acute care institutions (analytical institution type = 1)
- Discharges occurring between April 1, 2015, and March 31, 2016
- Presence of at least one ICD-10-CA code for falls from the range W00 to W19 with a corresponding diagnosis type = 9 (external cause of injury code)

Statistics Canada's Postal Code Conversion File Plus (PCCF+, version 6D) was used to assign patients to income quintiles. Income-related inequality measures were examined by 5 levels (quintiles) that were determined using average neighbourhood-level income.

Falls in LTC facilities

Using the continuing care dementia cohort (described above), identified LTC residents with falls in the last 30 days, per the RAI-MDS 2.0 assessment.

Falls among home care clients

Using the home care dementia cohort (described above), identified home care clients with falls in the last 90 days, per the RAI-HC assessment.

Palliative and end-of-life care

Overview: Palliative care provided to seniors with dementia in the last year of life in various care settings, including comparison between those with and without cancer

Data sources: DAD, OMHRS, CCRS, HCRS

Table 6   Criteria for selecting palliative care recipients

Care setting	Data source	Criteria for selecting palliative care recipients
Acute care	DAD, OMHRS	• Discharges from all acute care institutions (analytical institution type = 1) • Discharges occurring between April 1, 2015, and March 31, 2016 • Admissions to hospitals outside of Quebec (due to palliative care coding differences) • Individuals with health cards issued outside of Quebec • Individuals who died in hospital between April 1, 2015, and March 31, 2016 • Individuals were flagged as having palliative needs if they had at least one occurrence of any of the following in the 12 months prior to death: – ICD-10-CA palliative care code Z51.5 on the hospital abstract – Main patient service = Palliative care – Intervention service code = Palliative medicine – Service provider = Palliative medicine
Long-term care	CCRS	• Had a RAI-MDS 2.0 assessment conducted in the last year of life that indicated "hospice care"
Home care	HCRS	• Belonged to the end-of-life client group; or • Had a RAI-HC assessment conducted in the last year of life that indicated any of the following: – Palliative goals of care – Hospice care was scheduled – A prognosis of less than 6 months to live

Further information on the definition of palliative care is available from the Ontario Palliative Care Network.

Cancer analysis

• Acute care: Individuals who had at least one occurrence of an ICD-10-CA code from the range C00 to C97 (any diagnosis type) within the 12 months prior to their death

• LTC and home care: A cancer flag from the interRAI assessments

Dementia prevention and treatment

Overview: Trending of anti-dementia medication prescribed to seniors with dementia

Data source: NPDUIS

Inclusion criteria:

- Records from Newfoundland and Labrador, Prince Edward Island, Manitoba, Alberta and British Columbia; Yukon was excluded due to the unavailability of necessary CCDSS estimates
- Individuals prescribed the anti-dementia drugs donepezil, rivastigmine, galantamine or memantine
- Prescriptions occurring in 2011–2012 (April 1, 2011, to March 31, 2012) and 2015–2016 (April 1, 2015, to March 31, 2016)

Unpaid caregiver challenges and supports

Overview: Comparison of unpaid caregivers of seniors with and without dementia, and factors associated with caregiver distress

Data source: HCRS

Inclusion criteria:

- Home care dementia cohort (described above)
- Distress identified when one or both of the following were present on the RAI-HC assessment:
  - A caregiver is unable to continue in caring activities
  - The primary caregiver expresses feeling of distress, anger or depression

Factors associated with caregiver distress

A multivariate logistic regression model was used to identify factors associated with an increased likelihood of having a caregiver in distress. More than 30 factors in 6 broad categories (demographics, function, health status, mood and behaviour, service utilization and informal support) were considered. The selection of these factors is based on a previous CIHI analysis.

Table 7   Factors included in the logistic regression model

Factor	Definition
Client demographics	
Urban residency	Urban location of residence at the time of the assessment, defined as Statistical Area Classification types 1 to 3
Male	Client is male
Age	Age in completed years as of April 1, 2015
Function	
Moderate to severe cognitive impairment	Measured with Cognitive Performance Scale (range 0 to 6); a score of 3+ indicates moderate to severe cognitive impairment
Some to great difficulty in self-performance of daily living tasks	Measured with Instrumental Activities of Daily Living (IADL) Difficulty Scale (range 0 to 21); a score of 3+ indicates some to great difficulties in self-performance of IADL tasks
Requires physical assistance	Measured with Activities of Daily Living Hierarchy Scale (range 0 to 6); a score of 1+ indicates some to total dependency and requirement for physical assistance
Health status	
Any medical instability	Measured with CHESS Scale (range 0 to 5); a score of 1+ indicates instability
Poor self-rated health	Clients self-rated health as poor
Falls	One or more falls recorded in the last 90 days
Renal failure	Renal failure present
Any incontinence	Bladder or bowel incontinence measured as occasionally or more frequently incontinent
Mood and behaviour	
Possible depression	Measured with Depression Rating Scale (range 0 to 14); a score of 3+ may indicate a potential or actual problem with depression
Responsive behaviours present	At least one of verbally abusive, physically abusive, socially inappropriate or disruptive behaviour or of resisting care occurred in the last 3 days
Expresses anger/conflict with family	Expressions of anger/conflict with family present
Delusions or hallucinations	Delusions or hallucinations present
Wandering	Wandering occurred in the last 3 days
Service utilization	
Respite care/day care/day hospital services user	Being a respite care/day care/day hospital services user
No visiting nursing/home health aides/physical therapy services	Does not receive visiting nursing/home health aides/physical therapy services
Any hospital stays or ED visits	Number of overnight hospital admissions or ED visits is greater than 0
No homemaking services	Does not receive homemaking services

Factor	Definition
Informal support	
Hours of informal care	Hours of care provided by unpaid caregiver per week
Spousal relationship to primary caregiver	Primary caregiver is a spouse
Receives assistance with ADLs	Receives assistance with activities of daily living

Limitations

Jurisdictional differences in availability of care for seniors and terminology

Canada's continuing care systems are administered uniquely within each province and territory. This results in noteworthy differences in the type and range of services offered, the administrative systems used to deliver services, eligibility criteria and the terminology used to describe available services. Please see CIHI's *Seniors in Transition: Exploring Pathways Across the Care Continuum — Methodology Notes* for more details. For consistency, the term "long-term care or nursing homes" is used in the digital report to refer to the residential care setting. Provincial comparisons of the results should be done with caution.

Jurisdictional differences in data availability

Not all provinces and territories submit data to the CIHI data holdings used for analysis; therefore, full jurisdictional comparisons are not always possible. In these cases, assumptions were made that the results were representative of all jurisdictions in Canada.

Projection of dementia prevalence

2015–2016 CCDSS estimates for New Brunswick, Alberta and Yukon were not available at the time of the analysis; projections were used instead.

Capturing diagnosed dementia

For seniors with dementia to be included in the analyses, they had to

• Interact with the health system; and

• Have a record of dementia, such as a diagnosis, flag or dementia medication.

Seniors with dementia who did not interact with the health system in the study period and/or for whom dementia was not recorded were not included in the analyses. The actual number of seniors with dementia is likely underestimated.

Using CCDSS data has advantages when describing the current burden of dementia and monitoring changes over time, such as the annual data collection cycle; the availability of prevalence, incidence and all-cause mortality indicators; and trends over time. Although CCDSS estimates may seem to be conservative compared with those from other data sources, the algorithm and the underlying methodology were selected to maximize the validity and national comparability of data.[1] CCDSS algorithm sensitivity may also increase over time as the coverage of the drug databases improves at the provincial/territorial level.

Appendix 1: Acronyms

ADLs   activities of daily living

CA   census agglomeration

CCDSS   Canadian Chronic Disease Surveillance System

CCI   Canadian Classification of Health Interventions

CHESS   Changes in Health, End-Stage Disease and Signs and Symptoms

CIHI   Canadian Institute for Health Information

CMA   census metropolitan area

COPD   chronic obstructive pulmonary disease

CCRS   Continuing Care Reporting System

DAD   Discharge Abstract Database

DSM-IV   Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition

ED   emergency department

HCN   health card number

HCRS   Home Care Reporting System

HMDB   Hospital Morbidity Database

IADLs   instrumental activities of daily living

ICD-9	International Statistical Classification of Diseases and Related Health Problems, 9th Revision
ICD-10-CA	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Canada
LTC	long-term care
NACRS	National Ambulatory Care Reporting System
NPDUIS	National Prescription Drug Utilization Information System
OMHRS	Ontario Mental Health Reporting System
PCCF+	Postal Code Conversion File Plus
PHAC	Public Health Agency of Canada
RAI-HC	Resident Assessment Instrument–Home Care
RAI-MDS 2.0	Resident Assessment Instrument–Minimum Data Set 2.0

Appendix 2: Glossary

activities of daily living: Activities done as part of normal daily living, including self-care and mobility.

Alzheimer's disease: A type of dementia that causes problems with memory, thinking and behaviour. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks. It is the most common form of dementia and accounts for 60% to 80% of dementia cases.[2]

Continuing Care Reporting System quality indicators: Indicators developed by interRAI to provide organizations with measures of quality across key domains, including physical and cognitive function, safety and quality of life. Each indicator is adjusted for resident characteristics that are related to the outcome and are independent of quality of care.

Clinical Assessment Protocols: Suite of clinical and management interRAI tools identifying areas in which a resident has a higher-than-expected rate of decline, an increased potential to improve and symptoms that could be alleviated if a problem was addressed.

Cognitive Performance Scale: An assessment scale combining information on memory impairment, level of consciousness and executive function, with scores ranging from 0 (intact) to 6 (very severe impairment).[3]

community care: Includes a broad range of services that can be dichotomized as short-term home care services (usually defined as less than 60 days) and long-term home care services (can be provided in the client's home or community-based living).

dementia: An overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language that are severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour. Dementia is not a specific disease. Many diseases can cause dementia, including Alzheimer's disease, vascular dementia, Lewy body disease, head trauma, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease and Huntington's disease. These conditions can have similar and overlapping symptoms.[4]

length of stay: Number of days from admission to discharge, reported as an integer.

most responsible diagnosis: The one diagnosis or condition that is considered the most responsible for the patient's stay in hospital.

Organisation for Economic Co-operation and Development: A multidisciplinary international body made up of 30 member countries that offers a structure/forum for governments to consult and co-operate with each other in order to develop and refine economic and social policy.[5]

palliative care: A type of health care for patients and families facing life-threatening illness. Palliative care helps patients achieve the best possible quality of life right up until the end of life. It is also called end-of-life or comfort care.[6]

person with dementia: A person who has been diagnosed with dementia.

remote: Areas that are distant from large urban centres and have weak/no social and economic integration with larger urban centres.

responsive behaviours: This term originates from, and is preferred by, persons with dementia to represent how their actions, words and gestures are a response, often intentional, to something important to them.

residential care: Care that serves diverse populations who need access to 24-hour nursing care, personal care and other therapeutic and support services (either short or long term). It encompasses a range of living options for people, primarily seniors, with different support needs. Residential care facilities can include lodges, assisted living, supportive housing and LTC homes.

rural: All areas lying outside but relatively close to urban areas with a population of less than 10,000 persons.

socio-economic status: Estimated by combining the International Socio-Economic Index of Occupational Status with information on the highest level of education among a student's parents, family assets, educational resources at home and family cultural assets.[7]

unpaid caregiver: Also referred to as a "carer" or "family caregiver," a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness.[8]

urban: Any area that can be defined as a census metropolitan area (CMA) or a census agglomeration (CA); that is, an area consisting of one or more neighbouring municipalities situated around a major urban core. A CMA must have a total population of at least 100,000, of which 50,000 or more live in the urban core. A CA must have an urban core population of at least 10,000.

Appendix 3: Outcome scales

Embedded within each interRAI instrument are various scales and indices that can be used to evaluate an individual's current clinical status. If longitudinal data is collected, changes in clinical status over time can also be evaluated and compared. These scales have been carefully researched to ensure that they are comparable to industry gold standard measures. Additional information may be found on interRAI's website.

Table A1   List of outcome scales included in the analysis

Outcome scale	Description	Score range
Depression Rating Scale	This scale can be used as a clinical screen for depression.	0–14, with higher values indicating the resident has more numerous and/or frequent symptoms
Changes in Health, End-Stage Disease and Signs and Symptoms Scale	This scale detects frailty and health instability.	0–5, with 0 indicating no instability and 5 indicating the highest level of instability
Activities of Daily Living Self-Performance Hierarchy Scale	This scale reflects the disablement process by grouping ADL performance levels into discrete stage of loss: early loss: personal hygiene; middle loss: toileting and locomotion; late loss: eating.	0–6, with higher scores indicating greater decline in ADL performance
Cognitive Performance Scale	This scale describes the cognitive status of a resident.	0–6, with higher scores indicating more severe cognitive impairment
Aggressive Behaviour Scale	This scale describes the degree of aggressive behaviours, including verbally abusive behaviour, physically abusive behaviour, socially inappropriate or disruptive behaviour and resisting care.	0–12, with higher values indicating a higher degree of aggressive behaviour

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