

Analysis in Brief

August 2010 **Types of Care**



Caring for Seniors With Alzheimer's Disease and Other Forms of Dementia

Executive Summary

This study showcases two emerging CIHI data holdings that inform health system planning for the care needs of a growing number of Canadians with Alzheimer's disease and other forms of dementia. This population is expected to double within the next 30 years, to 1.1 million or nearly 3% of Canadians. Key findings include the following:

- One in five seniors (20%) receiving publicly funded long-term home care had a diagnosis of Alzheimer's disease and/or other dementia. The rate was nearly three in five (57%) for seniors living in a residential care facility, such as a nursing home or long-term care home.
- There was an overlap in the populations served by these two sectors. One in six (17%) seniors with dementia and high impairment—those experiencing moderate to severe difficulty with basic cognitive and self-care functions—were living at home with home care. At the other end of the spectrum, the same proportion of seniors with dementia and low impairment—or little difficulty with cognition and self care—was living in residential care.
- Among the low-impairment (higher-functioning) seniors with dementia, those newly admitted to residential care were twice as likely to be unmarried (defined as widowed, separated, divorced or never having been married). This highlights the critical role of the spouse in helping seniors with dementia stay at home.
- Wandering, with an odds ratio of almost seven, was the most powerful factor explaining why a person with dementia and low impairment would be in a residential care facility rather than at home with home care. A recent hospital admission, resisting care and physically abusive behaviour were also important factors.

These findings suggest that there are important reasons why some seniors with dementia, even those with relatively mild symptoms of impairment, are unable to stay at home. Many of these same factors were highlighted in a recent CIHI study on the factors associated with informal caregiver distress, a common reason for seniors' admission to residential care.¹

Who We Are

Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada's health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

Our Vision

To help improve Canada's health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.

Federal Identity Program

Production of this report is made possible by financial contributions from Health Canada and provincial and territorial governments. The views expressed herein do not necessarily represent the views of Health Canada or any provincial or territorial government.

As this special population grows, planners and policy-makers will want to balance investments in residential care with those in other care settings. Growing pressure on residential care beds may shift the care of more seniors with dementia to home care, seniors' housing or assisted living.

This and future studies can influence the shape of the Canadian health care system of the future by providing in-depth profiles and trends in important populations, such as seniors with Alzheimer's and other dementias.

Introduction

Dementia refers to “a large class of disorders characterized by the progressive deterioration of thinking ability and memory as the brain becomes damaged.”² In addition to the progressive deterioration in cognition, other symptoms include changes in the ability to perform activities of daily living, as well as varying mood and behaviour. In 2008, nearly 500,000 Canadians suffered from dementia, representing 1.5% of the population.² It is the most significant cause of disability among Canadians age 65 and older.² With population aging, the prevalence of dementia is expected to reach 1.1 million Canadians by 2038, nearly 3% of the population.²

As the disorder progresses, a person's need for support and care increases. Depending on the availability of family support and the level of care required, he or she may be able to remain at home with home care services or may require admission to a residential care facility (such as a nursing or long-term care home).³ In fact, dementia is currently the main cause of institutionalization among the elderly.⁴

Changes in health care in Canada have included a shift toward more community services.⁵ There are also projects under way to build more residential care facilities across the country. It will be increasingly important to understand the population's needs and the key factors that may allow individuals with dementia to remain at home and prevent or delay institutionalization.

This study looks at nearly 185,000 seniors who were either at home receiving publicly funded home care services or living in a residential care facility. We focused on three questions:

- How common is dementia among seniors in these two care settings?
- What are the key characteristics and health issues of seniors with dementia in each care setting?
- What factors are associated with admission to residential care among seniors with dementia and low levels of functional impairment?

Methods

CIHI Home and Continuing Care Reporting Systems

The Home and Continuing Care program at CIHI provides clinicians, managers, policy-makers and the public with information for planning, quality improvement and accountability. The Home Care Reporting System (HCRS) provides information on publicly funded home care programs. The Continuing Care Reporting System (CCRS) includes information on hospital-based and residential continuing care (facilities that provide 24-hour nursing care). Both systems provide comparative reports that include standard clinical measures, quality indicators and resource utilization. Collaboration with interRAI, an international research network in 30 countries, supports the foundation data standards for these reporting systems.

interRAI Assessment Instruments

The Resident Assessment Instrument—Home Care (RAI-HC)^{©i} and Resident Assessment Instrument—Minimum Data Set (RAI-MDS) 2.0^{©ii} are comprehensive, standardized assessment instruments developed by interRAI for evaluating an individual's needs, preferences and strengths. Both instruments record measures of physical, cognitive and social function along with indicators of clinical status and services received. The instruments have undergone reliability and validity testing in a number of countries worldwide, including Canada.^{6–18}

The RAI-HC (HCRS) is used to assess long-term home care clients—those expected to require services for more than 60 days. The RAI-MDS 2.0 (CCRS) is completed upon admission to a residential care facility (such as a long-term care or nursing home) and every three months thereafter, or more frequently if the person experiences a significant change in clinical status. The assessments are captured electronically and provide real-time feedback for clinicians to support care planning and monitoring. They also provide organization- and jurisdiction-level data to support system management, quality improvement and policy-making.

Defining Dementia

Two dementia-related diagnoses are available on both the RAI-HC and the RAI-MDS 2.0 assessments. For this analysis, a person was considered to have a diagnosis of dementia if Alzheimer's disease and/or dementia other than Alzheimer's disease were documented. Alzheimer's disease is a degenerative brain disease that primarily impacts the ability to remember names and recent events in its early stages. As the disease progresses, further deterioration occurs, resulting in challenges such as confusion and communication difficulties. Other forms of dementia include vascular dementia, often the result of a stroke. These other forms may involve more or less severe cognitive impairment.¹⁹

Framework and Measures

Our analysis of seniors with dementia receiving services in one of two settings is guided by a conceptual framework developed from a literature review that includes demographic, functional, health status and resource utilization factors. The conceptual framework is provided in Appendix A. Descriptions of the interRAI clinical and functional scales used in the analysis may be found in Appendix B.

The Data

The data set for this analysis included assessments from 131,246 long-term home care clients (those expected to be on service for more than 60 days) age 65 and older who were receiving publicly funded home care services in Nova Scotia, Ontario, the Winnipeg Regional Health Authority and the Yukon in 2007–2008.

The data set also included assessments from 53,420 residents age 65 and older living in publicly funded residential care facilities in Nova Scotia, Ontario, the Winnipeg Regional Health Authority, Saskatchewan and the Yukon in 2008–2009. In residential care, emergency department visits and hospital admissions are captured only on admission and annual assessments. Therefore, the residential care population used in this analysis for calculating rates of acute care service use was a subset of 32,197 residents.

To shed light on some of the factors associated with admission to residential care, seniors with dementia in the two settings were compared by levels of impairment. For this analysis and for the subsequent logistic regression, admission assessments for the seniors in residential care were selected, while for home care clients the most recent assessments were used. This was to reflect the level of function of the residents as close as possible to the time of the decision that the person was unable to remain at home.

i. RAI-HC © interRAI Corporation, 2001. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information. Canadianized items and their descriptions are protected by copyright: © 2002 Canadian Institute for Health Information.

ii. RAI-MDS 2.0 © interRAI Corporation, Washington, D.C., 1997, 1999. Modified with permission for Canadian use under licence to the Canadian Institute for Health Information.

Statistical Considerations

The RAI-HC and RAI-MDS 2.0 assessments are designed to be compatible but do have some slight differences due to the different populations. These differences are documented where appropriate in a comparison table found in Appendix C. The RAI-HC is designed for seniors receiving long-term home care services; therefore, those receiving short-term home care services that were expected to last fewer than 60 days were excluded from this analysis.

The analysis is a cross-sectional snapshot of both care settings rather than a study of seniors over time; therefore, causal conclusions cannot be made.

Logistic regression was used to determine the factors most strongly associated with care setting among seniors with dementia who had low levels of functional impairment (to be defined later in the report). Factors from each domain in the conceptual framework were included, and the results are presented following the comparative profiles of seniors with dementia.

Results

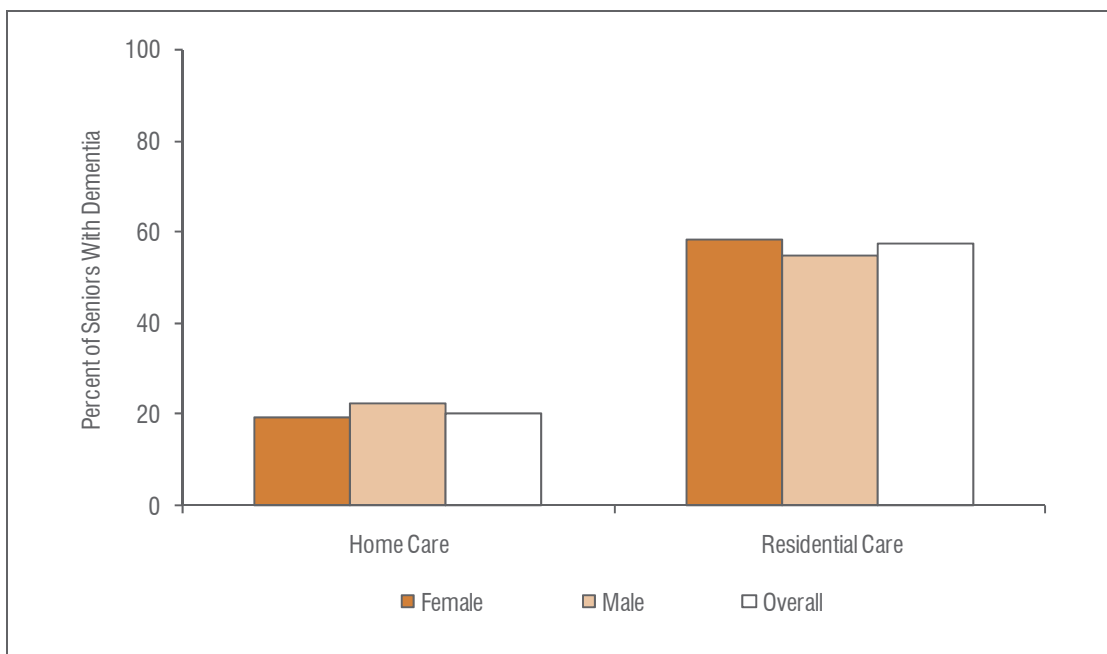
Characteristics of Seniors With Dementia

Figure 1 illustrates that one in five seniors (20%) receiving long-term home care and nearly three in five (57%) living in residential care had a diagnosis of Alzheimer’s disease and/or another type of dementia.

Seniors with dementia in residential care tended to be older than those receiving home care services. In residential care, 59% of residents with dementia were age 85 and older, compared to 42% in home care. There was a slightly higher proportion of males with dementia in home care, with the reverse seen in residential care.

Figure 1

Prevalence of Dementia by Care Setting and Sex



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

There was a smaller proportion of married individuals with dementia in residential care compared to those receiving home care services (26% and 42%, respectively). Almost all home care clients with a diagnosis of dementia (99%) had at least one informal caregiver—a family member, friend or neighbour helping out with key activities such as shopping, transportation, medications, meals, personal care and providing emotional support.

Among those clients with an informal caregiver, 30% had a caregiver expressing distress related to the caregiving role. For further information on caregiver distress, please see the report *Supporting Informal Caregivers—The Heart of Home Care* on the CIHI website.¹

Functional Status

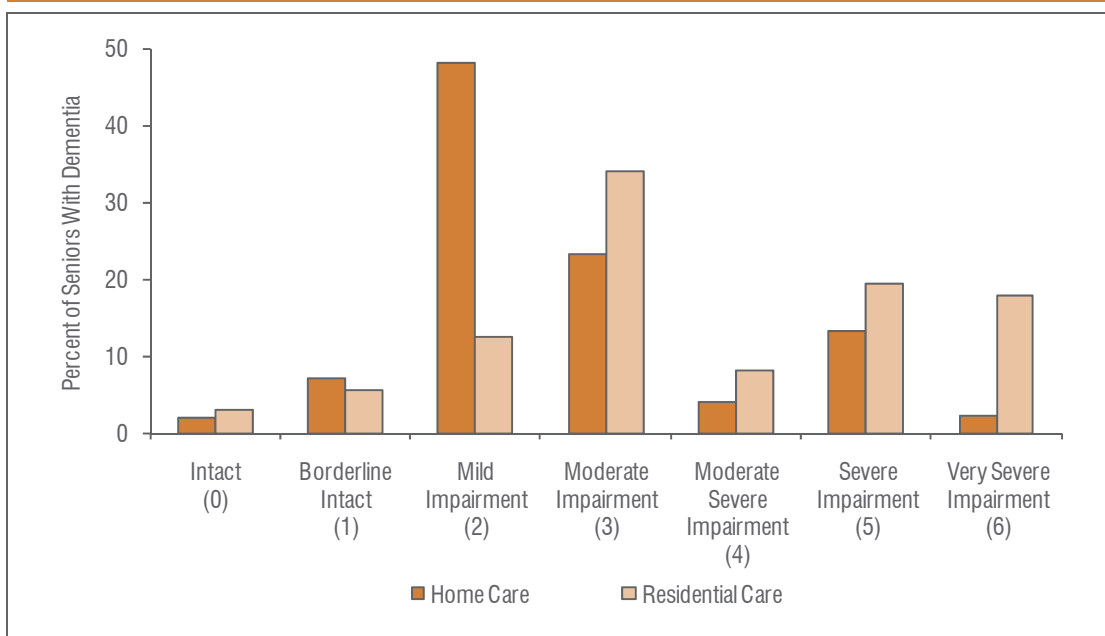
As dementia progresses, there is increasing difficulty with memory and other cognitive skills. Early short-term memory difficulties mean that recent events are forgotten, and seniors may have difficulty managing their finances or medications. With further deterioration, people have more difficulty with everyday tasks and eventually with their own personal care. Family and friends once familiar to the senior are not recognized. The person may become confused and unable to make simple decisions.

For this analysis, cognitive impairment was measured using the Cognitive Performance Scale (CPS) derived from the interRAI assessments. Components include memory, decision-making skills, communication and eating. Higher scores reflect greater impairment. A score of 0 (intact) reflects people who are experiencing no difficulties in these areas. A score of 6 (very severe impairment) indicates that people have very severe memory problems and are unable to make daily decisions, make themselves understood or feed themselves. A comatose person would receive a score of 6. More information on the CPS and other scales may be found in Appendix B.

Figure 2 illustrates the levels of cognitive impairment among seniors with dementia in the two care settings. As expected, those in residential care tended to have higher levels of cognitive impairment. Nearly two in five seniors (37%) in this setting had either severe or very severe impairment. Still, one in six seniors (16%) living at home with home care suffered from severe or very severe cognitive impairment.

Figure 2

Cognitive Impairment by Care Setting Among Seniors With Dementia



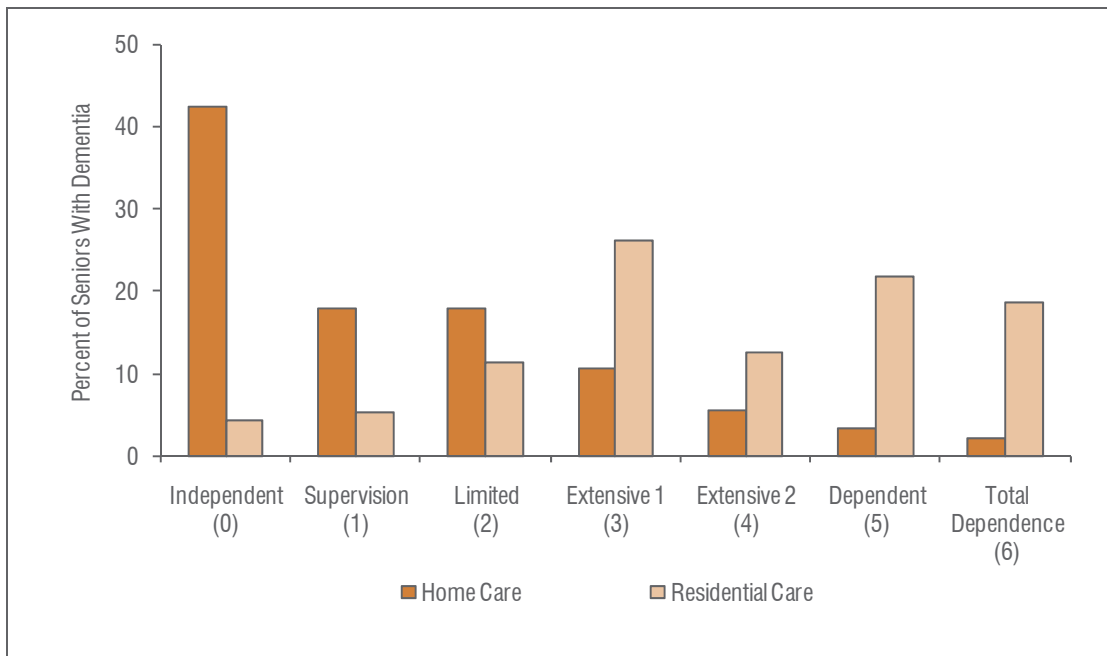
Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Often in conjunction with progressive cognitive impairment, people with dementia have difficulty with activities of daily living (ADLs). Figure 3 illustrates the levels of impairment in ADLs among seniors with dementia by care setting. ADL impairment is measured by the ADL Self-Performance Hierarchy Scale. Higher scores on this scale mean greater impairment. A score of 0 (independent) means that a person has no difficulty performing ADLs, while a score of 6 (total dependence) means that a person is completely dependent in locomotion, eating, toilet use and personal hygiene. Seniors with dementia in residential care tended to have higher levels of ADL impairment, with almost one in five (19%) being totally dependent in ADLs.

Figure 3

Impairment in Activities of Daily Living by Care Setting Among Seniors With Dementia



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Health Status

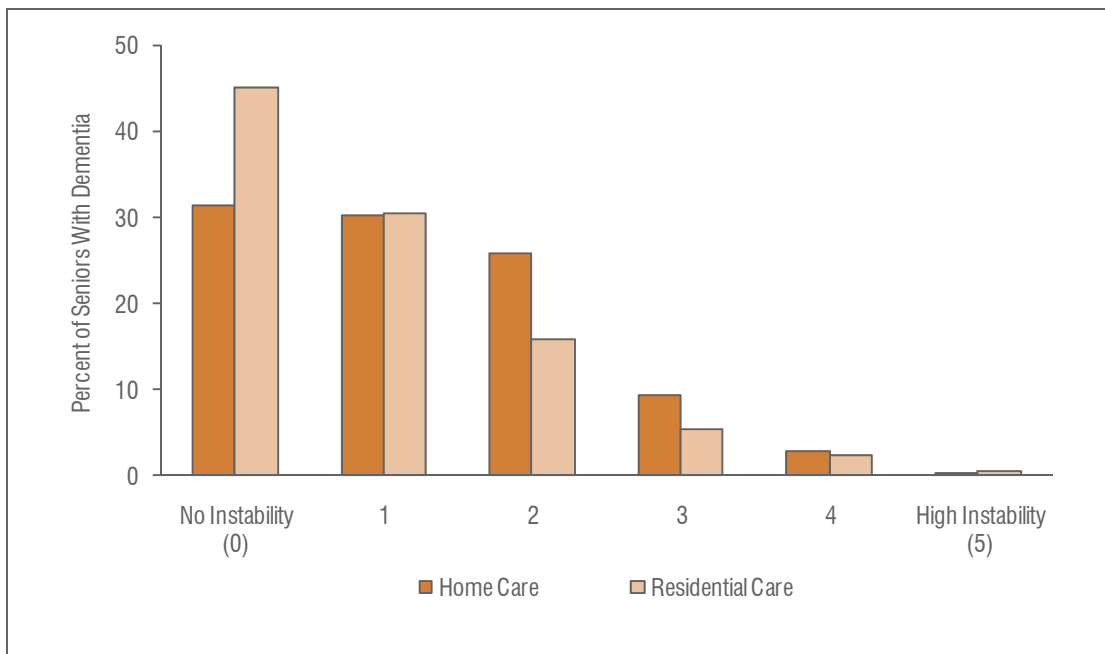
Dementia is associated with other important health issues that affect the quality of life for the person and his or her support network.

The interRAI Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS) Scale is derived from the assessments used in both care settings. It is a measure of health instability and identifies people at risk of adverse outcomes, including death. It ranges from 0 (no instability) to 5 (high instability) and includes measures such as recent ADL decline, vomiting and shortness of breath. Details may be found in Appendix B.

Figure 4 illustrates that among seniors with dementia, a greater proportion of those receiving home care services were assessed as having some health instability (69%) than were seniors in residential care (55%). There may be a number of individual, family and system factors driving this difference that require further in-depth analysis.

Figure 4

Health Instability by Care Setting Among Seniors With Dementia



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Figure 5 illustrates three other important health issues and their prevalence among those with dementia in the two care settings. A recent CIHI study confirmed that depression is a serious problem among seniors, particularly those living in residential care.²⁰ The Depression Rating Scale (DRS) is used to measure the occurrence of depressive symptoms in both home and residential care. Scores of 3 or higher on the DRS have been shown to be indicative of possible depression, based on diagnoses made by a geriatric psychiatrist.^{6,21} A higher proportion of seniors in residential care had possible depression compared to those receiving home care services (29% and 17%, respectively).

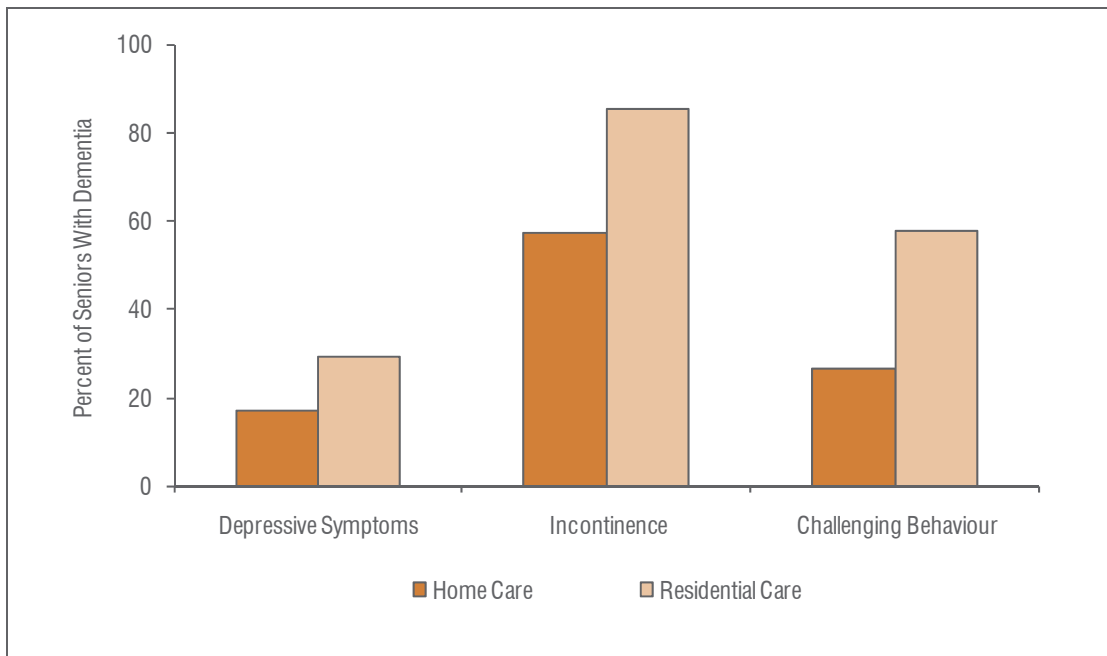
More than 85% of seniors with dementia in residential care were incontinent, compared to 57% in home care.

For the purpose of this analysis, challenging behaviours included wandering, verbal abuse, physical abuse, socially inappropriate/disruptive behaviour and resisting care. The proportion of seniors with dementia exhibiting any challenging behaviour in residential care (58%) was more than double the rate seen in home care (27%). The most common behaviour was resisting care (41% in residential care, 16% in home care).

Wandering is a particular concern for those caring for seniors with dementia, given the serious safety concerns associated with this behaviour. Wandering occurred among a higher proportion of seniors in residential care (23%) than in home care (10%).

Figure 5

Health Issues by Care Setting Among Seniors With Dementia



Sources

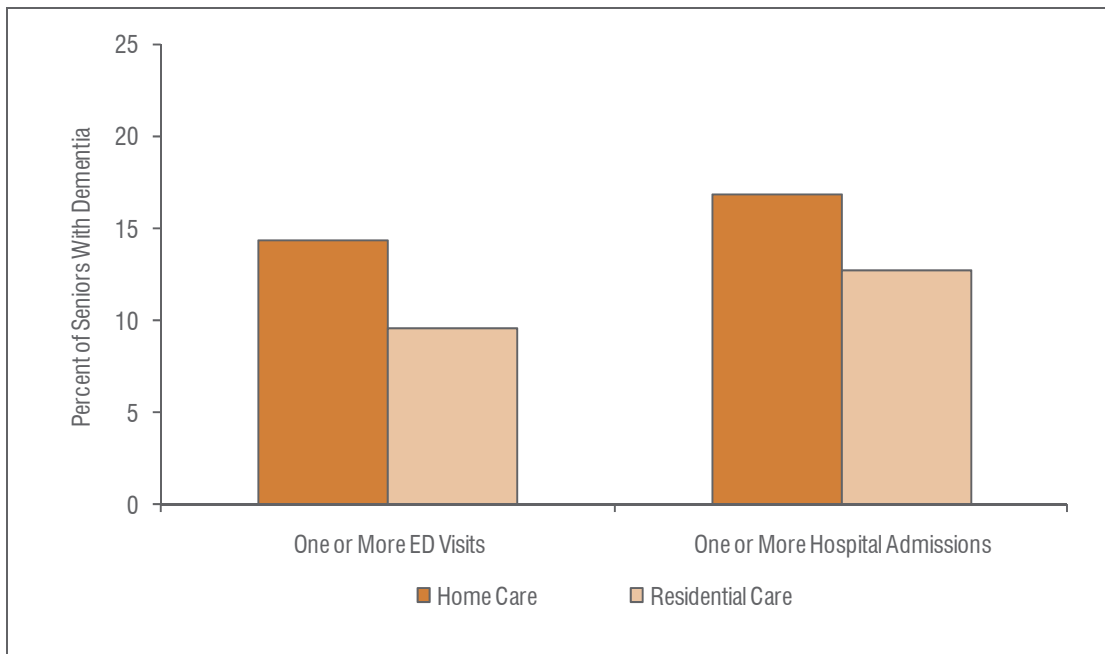
Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Resource Utilization

A higher proportion of seniors with dementia receiving home care services had emergency room visits and hospital admissions than those living in residential care, as illustrated in Figure 6. This finding is not surprising given the previously noted higher proportion of seniors with health instability in the home care population.

Figure 6

Resource Utilization by Care Setting Among Seniors With Dementia



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Seniors With Dementia and Low Levels of Impairment

A 2010 report by the Ontario Health Quality Council suggested that one in four people in residential care have relatively lighter care needs and that other care settings might be an option for some.²² The following analysis looks at seniors with dementia grouped by two important dimensions of everyday function that play a role in the amount of care a senior may need—cognition and ADLs. We then selected those with the lowest levels of impairment and compared their characteristics across the two settings to try to determine why some seniors with similar functional profiles were at home while others were institutionalized.

For this analysis and the subsequent logistic regression, assessments from the seniors in home care were the most recent assessments, while those in residential care were limited to admission assessments. This was to reflect, as closely as possible, the level of function of the residents when the decision was made that that the person was unable to remain at home.

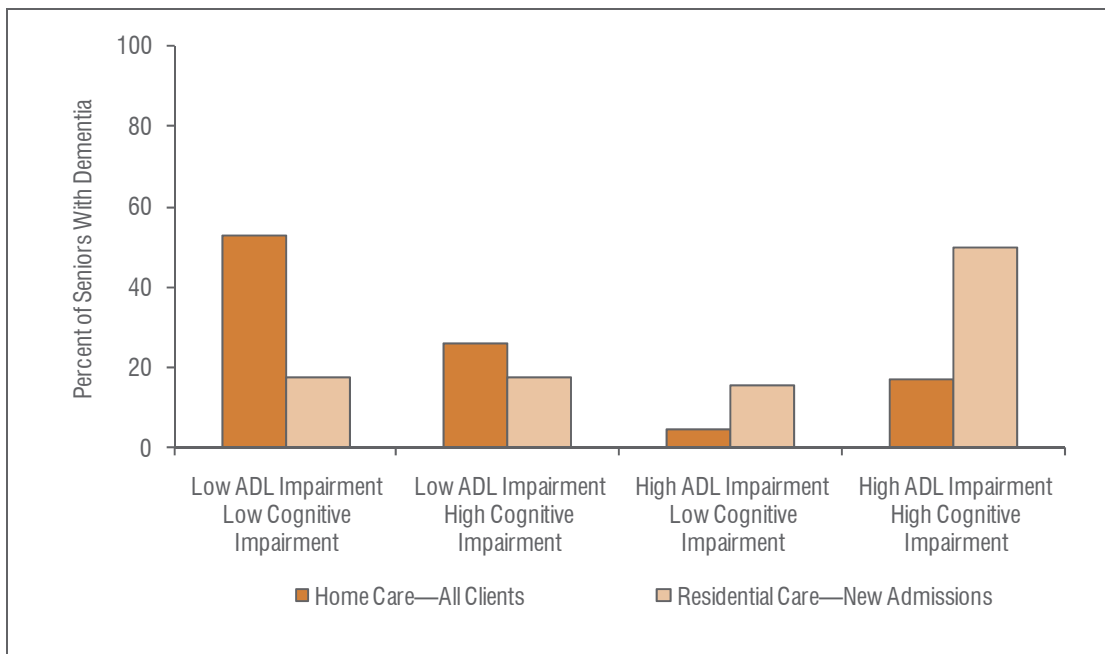
The seniors with dementia in each setting were clustered into four groups by low and high impairment in ADLs and cognitive function. Low ADL impairment was defined as having no or limited difficulty with ADLs. High impairment was defined as requiring extensive assistance to being totally dependent in ADLs.

Low cognitive impairment was defined as being cognitively intact or experiencing only minimal difficulty with memory, decision-making or communication. High cognitive impairment was defined as experiencing moderate to severe difficulty with these functions.

Figure 7 illustrates the distribution of seniors by impairment groups. More than half (53%) of the home care clients with dementia had relatively low levels of ADL and cognitive impairment, compared to one in six (17%) seniors who were newly admitted to residential care. The pattern was reversed at high levels of ADL and cognitive impairment, with the greatest proportion of these seniors found in residential care.

Figure 7

ADL and Cognitive Impairment by Care Setting Among Seniors With Dementia



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

There was an overlap observed in the groups of seniors served by home and residential care. This finding is consistent with previously reported research which suggests that care settings do not serve entirely unique populations.²³

As expected, the overall proportion of seniors with low levels of impairment was higher in home care; however, a key question remains:

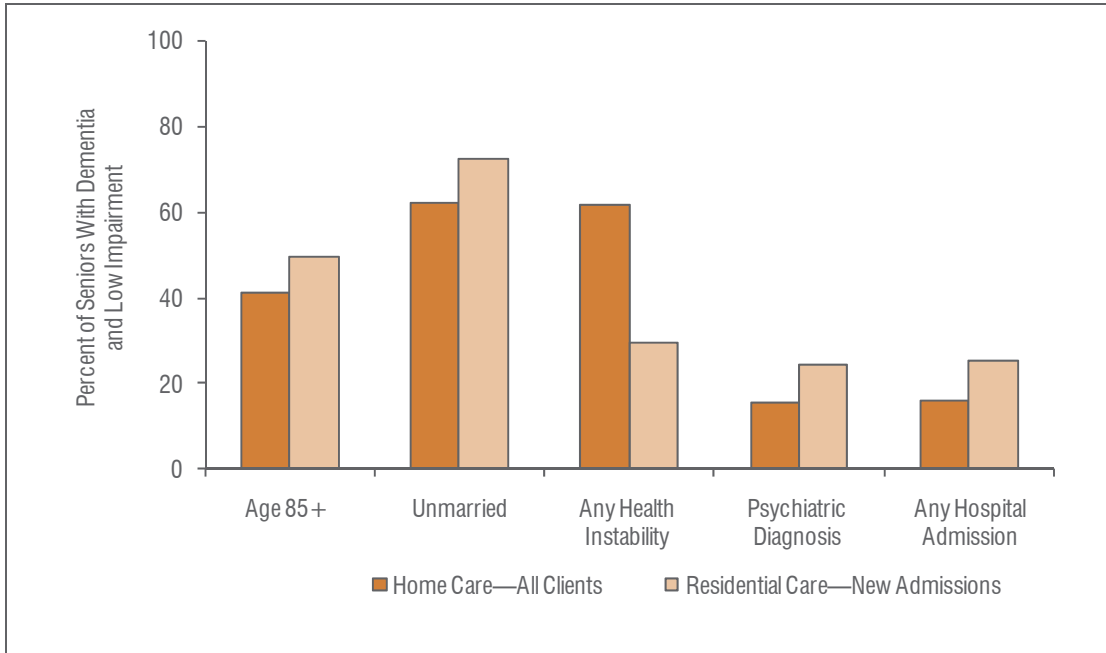
What factors help to explain why one in six seniors with low impairment might be living in residential care rather than in their own homes with home care services?

Figures 8 and 9 illustrate some of the differences between low-impairment seniors with dementia, that is, those with low levels of both ADL and cognitive impairment. Those recently admitted to residential care tended to be older and were more likely to be unmarried (defined as widowed, separated, divorced or never having been married). These seniors were also more likely to have a psychiatric diagnosis and to have been admitted to a hospital in the 90 days prior to assessment.

Challenging behaviours were more common among low-impairment seniors who were newly admitted to residential care. In particular, wandering and resisting care were much more likely to be a problem for seniors in this care setting than among those living at home.

Figure 8

Characteristics of Seniors With Dementia and Low ADL and Cognitive Impairment by Care Setting

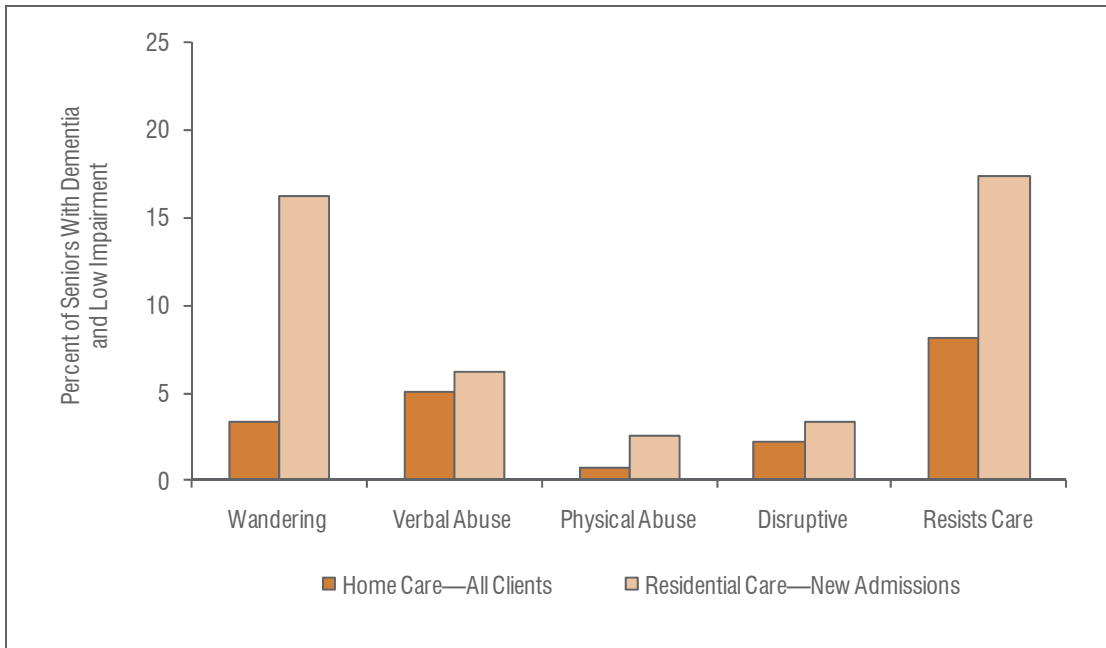


Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Figure 9

Behaviours of Seniors With Dementia and Low ADL and Cognitive Impairment by Care Setting



Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

There are many diverse factors associated with nursing home admission, including many of the factors discussed above as well as health conditions such as cancer, diabetes and stroke.²⁴ A logistic regression model was developed to determine the key factors associated with care setting. This model predicted the odds of low-impairment seniors with dementia being in residential care rather than home care, controlling for a variety of factors identified in the conceptual framework (Appendix A). The results are presented in Figure 10, with additional detail found in Appendix D.

The selected model did not include the CPS or ADLs, as these were used to select the low-impairment group. Further, there were close associations between a person's ability to communicate and cognitive and ADL impairment. Therefore, this measure was also excluded from the model. Informal caregiver distress was excluded because the information was not available for those seniors living in residential care.

The results suggest that the strongest predictor of being in residential care rather than home care among seniors with dementia and low impairment was wandering. After controlling for factors in other domains, the odds of being newly admitted to residential care rather than home care were nearly seven times higher for those who wandered compared to those who did not.

The reverse was true for those with health instability. These seniors had higher odds of being in home care rather than residential care, controlling for other factors. While this may be associated with residential care admission criteria or availability of beds for those with unstable or declining health, further study is required to understand this finding.

The odds were also more than double for those with a hospital admission within the previous 90 days, suggesting that this might have been a precipitating event for the admission to residential care. Resisting care and physically abusive behaviour were associated with being in residential care (odds more than two to one).

Unmarried seniors had nearly two-to-one odds of being in residential care compared to their married counterparts, highlighting the critical role of the spouse as caregiver. A person had more than one and a half times the odds of being in residential care if he or she had a psychiatric condition.

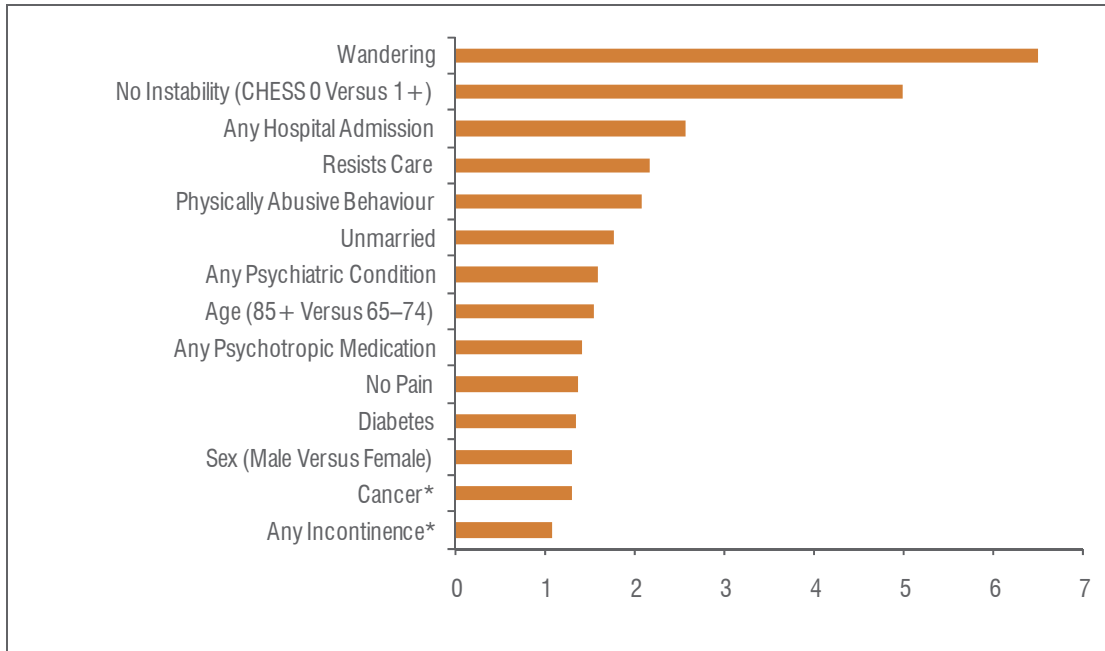
It is interesting to note that not all age categories were a significant predictor of care setting among those with low impairment. Only the odds ratio comparing those age 85 and older to those age 65 to 74 was significant, at odds of 1.6.

Psychotropic medications, diabetes and cancer were also significantly associated with being in residential care, although they were less powerful predictors. Pain was significant but in the opposite direction. Those living in residential care had slightly higher odds of having no pain compared to those at home, which may suggest better pain management in institutional settings. The odds of males being in residential care were slightly higher compared to females, controlling for other factors.

Incontinence, a very prevalent condition, particularly in residential care, was not significantly associated with a person being in residential care versus home care, nor was the presence of falls or stroke.

Figure 10

Odds Ratios for Predicting Being in Residential Care Rather Than Home Care Among Seniors With Dementia and Low ADL and Cognitive Impairment



Note

* Not significant.

Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Discussion

This study sheds light on the characteristics of seniors with dementia who are receiving services at home with home care and compares them with seniors with dementia living in residential care. There was an overlap in the populations served by these two sectors. Some very impaired seniors with dementia were living at home with home care while nearly one in six seniors with dementia in residential care had relatively low levels of difficulty with basic functions.

The most powerful factors explaining the institutional setting for seniors with dementia and low impairment were wandering, a recent hospital admission, resisting care, physically abusive behaviour, being unmarried, having a psychiatric diagnosis and being on a psychotropic medication.

These findings suggest that there are important reasons why some seniors with dementia, even those with relatively mild symptoms of impairment, are unable to stay at home. Many of these same issues were highlighted in a recent CIHI study on the factors associated with informal caregiver distress, a common reason for seniors' admissions to residential care.¹

Conclusion

This study of nearly 185,000 seniors showcases two emerging CIHI data holdings that can inform health system planning for a growing number of Canadians with Alzheimer's disease and other forms of dementia.

The overlap in populations of seniors with dementia who receive home care services and those who live in residential care raises important questions, including why seniors with dementia and low impairment are living in residential care and how seniors with high impairment can cope at home with home care. This study sheds light on the first question. Future analysis will inform the question of factors contributing to seniors with dementia managing at home.

As this special population grows, planners and policy-makers will want to balance investments in residential care with those in other care settings. Growing pressure on residential care beds may shift the care of more seniors with dementia to home care, seniors' housing or assisted living. This and future studies can influence the shape of the Canadian health care system of the future by providing in-depth profiles and trends in important populations, such as seniors with Alzheimer's and other dementias.

As the CIHI data holdings expand to include more jurisdictions, we can begin to look at similarities and differences in populations with dementia across the country as well as trends in the use of home care and residential care services. CIHI will continue to study these issues over time.

In the meantime, this report represents an important first step toward the goal of evidence-informed planning to achieve quality care in the most appropriate setting for seniors with dementia and a sustainable health care system for all Canadians.

Appendix A: Conceptual Framework

| Domain | Factors |
|-----------------------------|---|
| Demographic | Age Marital status Sex |
| Functional Status | Activities of daily living impairment (ADL Self-Performance Hierarchy Scale) Cognitive impairment (CPS) Communication |
| Health Status | Health instability (CHESS) Comorbid conditions Falls Incontinence Medication use Caregiver distress Challenging behaviours Depressive symptoms (DRS) Pain |
| Resource Utilization | ED visits Hospital admissions |

Appendix B: Outcome Scales and Algorithms

| Outcome Scale | Description | RAI-HC Assessment Items | Score Range |
|--|--|---|--|
| ADL Self-Performance Hierarchy Scale¹⁶ | This scale reflects the disablement process by grouping ADL performance levels into discrete stages of loss (that is, early loss: personal hygiene; middle loss: toileting and locomotion; late loss: eating). | Four ADL Self-Performance Hierarchy Scale items: <ul style="list-style-type: none"> • Personal hygiene • Toilet use • Locomotion • Eating | 0–6 Higher scores indicate greater decline (progressive loss) in ADL performance. |
| CHES Changes in Health, End-Stage Disease and Signs and Symptoms ¹⁰ | This scale detects frailty and health instability and was designed to identify individuals at risk of serious decline. | Nine CHES items: <ul style="list-style-type: none"> • Worsening of decision-making • Decline in ADL • Vomiting • Edema • Shortness of breath • End-stage disease • Weight loss • Dehydration • Leaving food uneaten | 0–5 Higher scores indicate higher levels of medical complexity and are associated with adverse outcomes such as mortality, hospitalization, pain, caregiver stress and poor self-rated health. |
| CPS Cognitive Performance Scale ^{8, 15} | This scale describes the cognitive status of an individual. Validated against the Mini-Mental State Examination (MMSE) and the Test for Severe Impairment (TSI) . | Four Cognitive Performance Scale items: <ul style="list-style-type: none"> • Short-term memory recall • Cognitive skills for daily decision-making • Expressive communication—making self understood • Eating impairment <p>In the RAI-MDS 2.0 an additional item is used: comatose. People who are comatose receive a score of 6 on the CPS.</p> | 0–6 Higher scores indicate more severe cognitive impairment. |
| DRS Depression Rating Scale ⁶ | This scale can be used as a clinical screen for depression. Validated against the Hamilton Depression Rating Scale (HDRS) , the Cornell Scale for Depression in Dementia (CSDD) and the Calgary Depression Scale (CDS) . | Seven Depression Rating Scale items: <ul style="list-style-type: none"> • Feeling of sadness or being depressed • Persistent anger • Expressions of unrealistic fears • Repetitive health complaints • Repetitive anxious complaints • Sad or worried facial expression • Tearfulness | 0–14 A score of 3 or more may indicate a potential or actual problem with depression. |
| Pain Scale⁷ | This scale summarizes the presence and intensity of pain. Validates well against the Visual Analogue Scale . | Two Pain Scale items: <ul style="list-style-type: none"> • Pain frequency • Pain intensity | 0–3 Higher scores indicate a more severe pain experience. |

Appendix C: Characteristics of Seniors With Dementia by Care Setting

| Characteristic | Home Care (N = 26,514) | | Residential Care (N = 30,645) | | p-Value |
|---|---------------------------|------|----------------------------------|------|---------|
| | N | % | N | % | |
| Demographic | | | | | |
| Age | | | | | <0.0001 |
| 65–74 | 2,926 | 11.0 | 2,179 | 7.1 | |
| 75–84 | 12,411 | 46.8 | 10,476 | 34.2 | |
| 85–94 | 10,303 | 38.9 | 14,963 | 48.8 | |
| 95+ | 874 | 3.3 | 3,027 | 9.9 | |
| Sex | | | | | <0.0001 |
| Female | 17,171 | 64.8 | 21,980 | 71.8 | |
| Male | 9,343 | 35.2 | 8,646 | 28.2 | |
| Marital Status | | | | | <0.0001 |
| Never married | 913 | 3.4 | 1,959 | 6.7 | |
| Married | 11,074 | 41.8 | 7,563 | 25.7 | |
| Widowed | 13,081 | 49.3 | 17,860 | 60.7 | |
| Separated | 331 | 1.3 | 438 | 1.5 | |
| Divorced | 807 | 3.0 | 1,183 | 4.0 | |
| Other/unknown | 308 | 1.2 | 426 | 1.5 | |
| Functional Status | | | | | |
| Activities of Daily Living Hierarchy | | | | | <0.0001 |
| Independent (0) | 11,274 | 42.5 | 1,352 | 4.4 | |
| Limited impairment (1–2) | 9,501 | 35.8 | 5,083 | 16.6 | |
| Extensive assistance (3–4) | 4,289 | 16.2 | 11,829 | 38.6 | |
| Dependent (5–6) | 1,450 | 5.5 | 12,381 | 40.4 | |
| Cognitive Performance Scale (CPS) | | | | | <0.0001 |
| Relatively intact (0–1) | 2,419 | 9.1 | 2,562 | 8.4 | |
| Mild/moderate (2–3) | 18,919 | 71.4 | 14,198 | 46.3 | |
| Severe (4–6) | 5,175 | 19.5 | 13,885 | 45.3 | |
| Communication | | | | | <0.0001 |
| No problem | 8,406 | 31.7 | 6,991 | 22.8 | |
| Any problem | 18,107 | 68.3 | 23,619 | 77.2 | |
| Health Status | | | | | |
| CHES | | | | | <0.0001 |
| No instability (0) | 8,320 | 31.4 | 12,348 | 45.1 | |
| 1 | 8,026 | 30.3 | 8,357 | 30.5 | |
| 2 | 6,873 | 25.9 | 4,368 | 16.0 | |
| 3 | 2,470 | 9.3 | 1,494 | 5.5 | |
| 4 | 799 | 3.0 | 668 | 2.4 | |
| High instability (5) | 26 | 0.1 | 133 | 0.5 | |
| Bladder Incontinence | | | | | <0.0001 |
| Continent* | 12,340 | 46.5 | 5,227 | 17.1 | |
| Usually continent | 3,345 | 12.6 | 2,022 | 6.6 | |
| Occasionally incontinent | 3,090 | 11.7 | 2,117 | 6.9 | |
| Frequently incontinent | 4,387 | 16.6 | 5,648 | 18.4 | |
| Incontinent | 3,352 | 12.6 | 15,631 | 51.0 | |
| Bowel Incontinence | | | | | <0.0001 |
| Continent† | 19,172 | 72.3 | 9,903 | 32.3 | |
| Usually continent | 2,420 | 9.1 | 3,236 | 10.6 | |
| Occasionally incontinent | 1,654 | 6.2 | 2,583 | 8.4 | |
| Frequently incontinent | 1,425 | 5.4 | 3,853 | 12.6 | |
| Incontinent | 1,843 | 7.0 | 11,070 | 36.1 | |
| Any incontinence | 15,205 | 57.4 | 26,200 | 85.5 | <0.0001 |

| Characteristic | Home Care (N = 26,514) | | Residential Care (N = 30,645) | | p-Value |
|---|---------------------------|------|----------------------------------|------|---------|
| | N | % | N | % | |
| Falls[†] | 8,093 | 30.5 | 10,257 | 33.5 | <0.0001 |
| Comorbidities | | | | | |
| Diabetes | 5,364 | 20.2 | 5,659 | 18.5 | <0.0001 |
| Stroke | 5,500 | 20.7 | 5,428 | 17.7 | <0.0001 |
| Cancer | 2,243 | 8.5 | 2,559 | 8.4 | 0.64 |
| Psychotropic Medication | | | | | |
| Antipsychotic | 5,533 | 20.9 | 12,198 | 39.8 | <0.0001 |
| Antianxiety | 3,771 | 14.2 | 4,306 | 14.1 | 0.56 |
| Antidepressant | 7,436 | 28.1 | 13,603 | 44.4 | <0.0001 |
| Hypnotic | 2,438 | 9.2 | 2,227 | 7.3 | <0.0001 |
| Any | 13,309 | 50.2 | 21,017 | 68.6 | <0.0001 |
| Challenging Behaviours[§] | | | | | |
| Wandering | 2,584 | 9.8 | 6,952 | 22.7 | <0.0001 |
| Verbal abuse | 2,380 | 9.0 | 6,097 | 19.9 | <0.0001 |
| Physical abuse | 744 | 2.8 | 4,643 | 15.2 | <0.0001 |
| Socially inappropriate/disruptive | 1,414 | 5.3 | 6,175 | 20.2 | <0.0001 |
| Resists care | 4,133 | 15.6 | 12,414 | 40.5 | <0.0001 |
| Any | 7,020 | 26.5 | 17,736 | 57.9 | <0.0001 |
| Caregiver Distress^{**} | 7,797 | 29.7 | — | — | |
| Depression Rating Scale | | | | | <0.0001 |
| No or mild symptoms of depression (0–2) | 22,044 | 83.1 | 21,662 | 70.8 | |
| Signs of possible depression (3+) | 4,470 | 16.9 | 8,948 | 29.2 | |
| Pain Scale | | | | | <0.0001 |
| No pain (0) | 14,194 | 53.5 | 18,710 | 61.1 | |
| Less than daily pain (1) | 3,983 | 15.0 | 6,542 | 21.4 | |
| Daily pain but not severe (2) | 7,188 | 27.1 | 4,748 | 15.5 | |
| Severe daily pain (3) | 1,149 | 4.3 | 645 | 2.1 | |
| Resource Utilization | | | | | |
| ED Visits in Last 90 Days^{††} | | | | | <0.0001 |
| 0 | 22,700 | 85.6 | 16,427 | 90.4 | |
| 1+ | 3,814 | 14.4 | 1,748 | 9.6 | |
| Hospital Admissions in Last 90 Days^{††} | | | | | <0.0001 |
| 0 | 22,038 | 83.1 | 15,863 | 87.3 | |
| 1+ | 4,476 | 16.9 | 2,312 | 12.7 | |

- Notes**
- p-Value refers to significance of chi-square test.
- * Includes those who are continent with catheter.
- † Includes those who are continent with ostomy.
- ‡ The look-back period for falls was 90 days in home care and 180 days in residential care.
- § The look-back period for behaviours was 3 days in home care and 7 days in long-term care.
- ** A client had a distressed caregiver if either of the following was true: caregiver is unable to continue in caring activities and/or primary caregiver expresses distress, anger or depression.
- †† Emergency department visits and hospital admissions are available only on full RAI-MDS 2.0 assessments. For these two categories, quarterly RAI-MDS 2.0 assessments were excluded.
- Data not collected.

Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

Appendix D: Logistic Regression Results

Table 1

Multivariate Logistic Regression Results Predicting Odds of Being in Residential Care Among Seniors With Dementia and Low Cognitive and Functional Impairment

| Variable | Odds Ratio | Confidence Limits | |
|--|------------|-------------------|------|
| Demographics | | | |
| Unmarried | 1.77 | 1.43 | 2.20 |
| Age (85+ versus 65–74) | 1.55 | 1.12 | 2.15 |
| Age (75–84 versus 65–74)* | 1.05 | 0.76 | 1.45 |
| Sex (male versus female) | 1.30 | 1.06 | 1.59 |
| Health Status | | | |
| Wandering | 6.51 | 4.90 | 8.65 |
| No instability | 5.00 | 4.07 | 6.15 |
| Physically abusive behaviour | 2.07 | 1.01 | 4.26 |
| Resists care | 2.16 | 1.65 | 2.83 |
| Any psychiatric condition | 1.60 | 1.27 | 2.01 |
| Any psychotropic medication | 1.42 | 1.17 | 1.73 |
| No pain | 1.38 | 1.14 | 1.67 |
| Diabetes | 1.34 | 1.08 | 1.67 |
| Cancer* | 1.31 | 0.96 | 1.78 |
| No or few depressive symptoms (DRS 3+ versus 0–2)* | 1.27 | 0.94 | 1.72 |
| Any incontinence* | 1.08 | 0.90 | 1.30 |
| No verbally abusive behaviour* | 1.17 | 0.76 | 1.80 |
| No disruptive behaviour* | 1.16 | 0.67 | 2.00 |
| No falls* | 1.08 | 0.87 | 1.34 |
| No stroke* | 1.26 | 0.99 | 1.62 |
| Resource Utilization | | | |
| Any hospital admission | 2.58 | 2.06 | 3.22 |
| Any emergency room visits* | 1.23 | 0.94 | 1.60 |

Note

* Not statistically significant.

Sources

Home Care Reporting System, 2007–2008, and Continuing Care Reporting System, 2008–2009, Canadian Institute for Health Information.

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References

1. Canadian Institute for Health Information, *Supporting Informal Caregivers—The Heart of Home Care* (Ottawa, Ont.: CIHI, 2010), accessed from <<http://www.cihi.ca>>.
2. Alzheimer Society, *Rising Tide: The Impact of Dementia on Canadian Society* (Toronto, Ont.: Alzheimer Society of Canada, 2010), accessed May 5, 2010, from <http://www.alzheimer.ca/docs/RisingTide/Rising%20Tide_Full%20Report_Eng_FINAL_Secured%20version.pdf>.
3. M. Luppá et al., “Prediction of Institutionalisation in Dementia. A Systematic Review,” *Dementia & Geriatric Cognitive Disorders* 26, 1 (2008): pp. 65–78.
4. M. Brod et al., “Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL),” *Gerontologist* 39, 1 (1999): pp. 25–35.
5. J. P. Hirdes et al., “Integrated Health Information Systems Based on the RAI/MDS Series of Instruments,” *Healthcare Management Forum* 12, 4 (1999): pp. 30–40.
6. A. B. Burrows et al., “Development of a Minimum Data Set–Based Depression Rating Scale for Use in Nursing Homes,” *Age & Ageing* 29, 2 (2000): pp. 165–172.
7. B. E. Fries et al., “Pain in U.S. Nursing Homes: Validating a Pain Scale for the Minimum Data Set,” *Gerontologist* 41, 2 (2001): pp. 173–179.
8. S. Hartmaier et al., “Validation of the Minimum Data Set Cognitive Performance Scale: Agreement With the Mini-Mental State Examination,” *Journal of Gerontology: Medical Sciences* 50A (1995): pp. M128–M133.
9. C. Hawes et al., “Reliability Estimates for the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS),” *Gerontologist* 35 (1995): pp. 172–178.
10. J. P. Hirdes et al., “The MDS-CHESS Scale: A New Measure to Predict Mortality in Institutionalized Older People,” *Journal of the American Geriatrics Society* 51, 1 (2003): pp. 96–100.
11. J. P. Hirdes et al., “The Method for Assigning Priority Levels (MAPLe): A New Decision-Support System for Allocating Home Care Resources,” *BMC Medicine* 6 (2008): p. 9.
12. M. P. Lawton et al., “Psychometric Characteristics of the Minimum Data Set II: Validity,” *Journal of the American Geriatrics Society* 46 (1998): pp. 736–744.
13. V. Mor et al., “The Structure of Social Engagement Among Nursing Home Residents,” *Gerontologist* 50B (1995): pp. 1–8.
14. J. Morris et al., “A Commitment to Change: Revision of HCFA’s RAI,” *Journal of the American Geriatrics Society* 45 (1997): pp. 1011–1016.
15. J. N. Morris et al., “MDS Cognitive Performance Scale,” *Journal of Gerontology* 49, 4 (1994): pp. M174–M182.
16. J. N. Morris et al., “Scaling ADLs Within the MDS,” *Journals of Gerontology Series A—Biological Sciences & Medical Sciences* 54, 11 (1999): pp. M546–M553.
17. M. Schroll et al., “An International Study of Social Engagement Among Nursing Home Residents,” *Age & Ageing* 26 Suppl. 2 (1997): pp. 55–59.
18. M. Snowden et al., “Validity and Responsiveness of the Minimum Data Set,” *Journal of the American Geriatrics Society* 47 (1999): pp. 1000–1004.
19. Alzheimer’s Association, *Alzheimer’s Disease Facts and Figures* (Chicago, Illinois: Alzheimer’s Association, 2010), accessed May 5, 2010, from <http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf>.

20. Canadian Institute for Health Information, *Depression Among Seniors in Residential Care* (Ottawa, Ont.: CIHI, 2010), accessed July 5, 2010, from <http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=PG_2935_E&cw_topic=2935&cw_rel=AR_2129_E#media/>.
21. M. Koehler et al., "Measuring Depression in Nursing Home Residents With the MDS and GDS: An Observational Psychometric Study," *BMC Geriatrics* 5 (2005), accessed July 22, 2010, from <<http://www.biomedcentral.com/1471-2318/5/1>>.
22. Ontario Health Quality Council, *2010 Yearly Report* (Toronto, Ont.: OHQC, 2010), accessed July 19, 2010, from <<http://www.ohqc.ca/en/yearlyreport.php>>.
23. J. P. Hirdes, "Addressing the Health Needs of Frail Elderly People: Ontario's Experience With an Integrated Health Information System," *Age & Ageing* 35, 4 (2006): pp. 329–331.
24. J. E. Gaugler et al., "Predicting Nursing Home Admission in the U.S.: A Meta-Analysis," *BMC Geriatrics* 7, 13 (2007): pp. 1–14.