

## Health Reports

# The association between rurality, places of care and the location of death of long-term care home residents with dementia: A population-based study

by Hanbyoul Park, Christina Milani, Peter Tanuseputro and Colleen Webber

Release date: July 17, 2024



---

## How to obtain more information

For information about this product or the wide range of services and data available from Statistics Canada, visit our website, [www.statcan.gc.ca](http://www.statcan.gc.ca).

You can also contact us by

**Email at** [infostats@statcan.gc.ca](mailto:infostats@statcan.gc.ca)

**Telephone**, from Monday to Friday, 8:30 a.m. to 4:30 p.m., at the following numbers:

- Statistical Information Service 1-800-263-1136
- National telecommunications device for the hearing impaired 1-800-363-7629
- Fax line 1-514-283-9350

## Standards of service to the public

Statistics Canada is committed to serving its clients in a prompt, reliable and courteous manner. To this end, Statistics Canada has developed standards of service that its employees observe. To obtain a copy of these service standards, please contact Statistics Canada toll-free at 1-800-263-1136. The service standards are also published on [www.statcan.gc.ca](http://www.statcan.gc.ca) under “Contact us” > “[Standards of service to the public](#).”

## Note of appreciation

Canada owes the success of its statistical system to a long-standing partnership between Statistics Canada, the citizens of Canada, its businesses, governments and other institutions. Accurate and timely statistical information could not be produced without their continued co-operation and goodwill.

Published by authority of the Minister responsible for Statistics Canada

© His Majesty the King in Right of Canada, as represented by the Minister of Industry, 2024

Use of this publication is governed by the Statistics Canada [Open Licence Agreement](#).

**An [HTML version](#) is also available.**

*Cette publication est aussi disponible en français.*

---

# The association between rurality, places of care and the location of death of long-term care home residents with dementia: A population-based study

by Hanbyoul Park, Christina Milani, Peter Tanuseputro and Colleen Webber

**DOI:** <https://www.doi.org/10.25318/82-003-x202400700001-eng>

## ABSTRACT

### Background

Most individuals prefer to spend their final moments of life outside a hospital setting. This study compares the places of care and death of long-term care (LTC) home residents in Ontario in the last 90 days of life, according to LTC home rurality.

### Data and methods

This retrospective cohort study was conducted using health administrative data from ICES (formerly known as the Institute for Clinical Evaluative Sciences). The study population, which was identified through algorithms, included all Ontario LTC home residents with a dementia diagnosis who died between April 1, 2014, and March 31, 2019. The location of death was categorized as in an acute care hospital, an LTC home, a subacute care facility, or the community. Places of care included emergency department visits and hospitalizations in the last 90 days of life. Statistical tests were used to evaluate differences in location of death and places of care by rurality.

### Results

Of the 65,375 LTC home residents with dementia, 49,432 (75.6%) died in an LTC home. Residents of LTC homes in the most urban areas were less likely to die in an LTC home than those in more rural homes (adjusted relative risk: 0.84; 95% confidence interval: 0.83 to 0.85). A higher proportion of residents of the most urban LTC homes had at least one hospitalization in the last 90 days of life compared with rural residents (23.7% versus 9.9% palliative hospitalizations and 28.3% versus 15.9% non-palliative hospitalizations [ $p < 0.001$ ]).

### Interpretation

Individuals with dementia residing in urban LTC homes are more likely to receive care in the hospital and to die outside a LTC home than their counterparts living in rural LTC homes. The findings of this work will inform efforts to improve end-of-life care for older adults with dementia living in LTC homes.

### Keywords

nursing home, rural health, dementia, end-of-life care, care transitions

## AUTHORS

Hanbyoul Park and Peter Tanuseputro are with the Faculty of Medicine, University of Ottawa. Christina Milani, Peter Tanuseputro and Colleen Webber are with the Bruyère Research Institute, Ottawa. Peter Tanuseputro and Colleen Webber are also with the Ottawa Hospital Research Institute, Ottawa.

***What is already known on this subject?***

- Most individuals prefer to die outside a hospital setting, yet many Canadians die outside home and community settings.
- Evidence suggests that individuals in rural areas often face additional barriers at the end of life because of remoteness, limited access to resources, and staff shortage. However, it is unclear how often rural residents die outside hospitals, compared with their urban counterparts.

***What does this study add?***

- This study found urban–rural differences in end-of-life care. Residents with dementia in long-term care (LTC) homes in the most urban areas are more likely to die outside their LTC home, be hospitalized, and visit the emergency department, compared with residents of less urban LTC homes.
- This research will contribute to the better understanding of the differences in end-of-life care for LTC home residents living with dementia in rural and urban areas of Ontario. The findings from this study will help inform future end-of-life strategies in Canadian LTC homes.

Individuals who are nearing death report a preference to be cared for and die outside the hospital.<sup>1</sup> The reasons for this preference are complex and multifactorial. When hospitalized near the end of life, individuals may experience potentially aggressive or inappropriate care that may cause unnecessary pain and negatively affect their quality of life.<sup>2</sup> Individuals' preferences to die outside a hospital setting may also be related to support from their family and social network, cultural values, and the extent to which their wishes and those of their caregivers could be supported in different care settings.<sup>3</sup> Despite these preferences, many Canadians still die in settings that are not their home or community, with 54.5% dying at home or in a community setting in 2020.<sup>4</sup> Canadians living in rural areas face numerous health care barriers that may affect their end-of-life care, such as the quality of the care they receive and where they die. These barriers include the requirement to travel long distances to access health care services because of the lower density of hospitals, limited local availability of physicians, and reduced access to home care support in rural areas.<sup>5,6</sup> Palliative care, an approach to care that supports the needs of individuals who are facing a serious and life-limiting illness, including those who are at the end of life, is also more difficult to access in rural areas.<sup>7-9</sup> Likely owing to these barriers, individuals in rural areas have an increased risk of hospitalization in the last weeks and months of life and are more likely to die in the hospital than those in urban areas.<sup>9-11</sup> Less is known about urban–rural differences in end-of-life care among residents of long-term care (LTC) homes (i.e., nursing homes). LTC homes provide 24-hour nursing, medical, and personal care for individuals whose care needs cannot typically be met in the community. Given a median survival of 18 months after admission to an LTC home, the need to plan for the end-of-life care needs of these residents is vital.<sup>12</sup> In a rural setting, the challenges associated with end-of-life care for residents of LTC homes may differ from those experienced by individuals not residing in an LTC home.<sup>13</sup> While health care access may be

more limited in rural areas, the level of care and support provided in LTC homes may enable residents to stay in their homes throughout the end of life.<sup>14</sup> Rural LTC homes have also been found to have higher physician retention and therefore greater continuity of care.<sup>15</sup> These features of rural LTC homes may help improve the quality of end-of-life care provided to residents.

This study examined differences in the use of end-of-life acute care and the location of death among residents with dementia in rural LTC homes, compared with those in urban LTC homes, in Ontario, Canada. The study focused on LTC home residents with dementia for two reasons. First, dementia is highly prevalent in LTC homes, with up to two-thirds of LTC home residents having a dementia diagnosis.<sup>16</sup> Second, the symptoms and disease trajectory of dementia may pose unique barriers to the provision of high-quality end-of-life care. For example, communication challenges may make it difficult for individuals with dementia to express their needs and preferences.<sup>13</sup> Further, unlike other terminal illnesses such as cancer, death from dementia may be harder to anticipate, making it harder to determine when a palliative approach should be initiated.<sup>17</sup>

**Data and methods****Study design and population**

A population-based retrospective cohort study was conducted using linked administrative data held at ICES which contain information on all Ontarians registered for the universal, publicly funded provincial Ontario Health Insurance Plan (OHIP). OHIP covers all medically necessary physician and hospital care. The costs of LTC are also paid for by the provincial government, with residents paying a co-payment based on their income. The study population included all individuals with a dementia diagnosis who died between April

1, 2014, and March 31, 2019, and who were living in an LTC home in Ontario at least 90 days before their death. A dementia diagnosis was ascertained using a validated algorithm applied to health administrative data. Specifically, dementia was present if an individual met any of the following criteria: (1) one or more hospitalizations with a dementia diagnosis on the discharge record; (2) three or more physician visits in a two-year period, with at least 30 days between each visit and a dementia diagnosis on the visit record; or (3) a prescription dispensed for a cholinesterase inhibitor. The diagnosis date is the earliest occurrence of these criteria.<sup>18</sup>

**Data sources and variables**

Ontario health administrative data held at ICES were used in this study. ICES is an independent, non-profit research institute whose legal status under Ontario’s health information privacy law allows it to collect and analyze health care and demographic data, without consent, for the evaluation and improvement of the health system. A list of databases and their descriptions can

included the Continuing Care Reporting System (CCRS), which contains detailed demographic, clinical, and functional information on all residents of LTC homes in the province. The Canadian Institute for Health Information’s Discharge Abstract Database (DAD) and the National Ambulatory Care Reporting System (NACRS) contain records of acute care hospitalizations and emergency department (ED) visits, respectively. Further information on the place of death was obtained from the National Rehabilitation Reporting System (NRS), the CCRS, the Same Day Surgery (SDS) Database, the Ontario Mental Health Reporting System (OMHRS), and the Home Care Database. Physician billing claims were used to capture physician encounters, and the Registered Persons Database provided demographic and vital status information about all residents.

The rurality of LTC homes was defined using Statistics Canada’s definition, based on the Postal Code Conversion File.<sup>19</sup> The postal codes of LTC homes were classified as urban if they were within a census metropolitan area (CMA) or a

**Table 1**  
**Characteristics of Ontario long-term care home residents with dementia, overall and stratified by rurality**

Variable	Total N=65,375	Urban 1 (population 1,500,000 or more) N=19,754	Urban 2 (population 500,000 to 1,499,999) N=11,847	Urban 3 (population 100,000 to 499,999) N=16,736	Urban 4 (population 10,001 to 99,999) N=8,519	Rural (population 10,000 or less) N=8,519
<b>Sex</b>						
Female (%)	65.6	65.6	65.0	66.7	65.8	64.0
<b>Age at death</b>						
Mean	87.8	88.2	87.8	87.64	87.6	87.4
SD	7.3	7.3	7.2	7.3	7.1	7.3
<b>Neighbourhood income quintile prior to LTC home entry</b>						
Missing income (%)	0.7	0.6	0.5	0.9	1.2	0.4
First quintile (%)	28.9	32.2	22.5	27.8	30.9	29.8
Second quintile (%)	21.9	23.0	23.4	22.7	16.2	21.6
Third quintile (%)	17.8	15.6	21.7	17.4	17.4	18.7
Fourth quintile (%)	16.7	14.6	15.7	17.0	21.4	17.7
Fifth quintile (%)	14.0	13.9	16.3	14.2	12.9	11.7
<b>Cancer (%)</b>	54.9	54.0	55.8	56.2	54.3	53.9
<b>Congestive heart failure (%)</b>	27.0	27.9	25.7	26.4	27.5	27.8
<b>Number of prevalent conditions</b>						
None (%)	0.8	0.6	1.1	0.8	0.8	1.1
One (%)	2.6	2.1	3.1	2.5	2.9	3.2
Two (%)	6.3	5.0	7.2	6.6	6.9	7.0
Three (%)	11.4	9.5	12.5	12.2	12.2	12.2
Four (%)	15.6	14.1	16.3	16.2	16.7	16.8
Five (%)	17.3	17.2	17.6	17.1	17.1	17.5
Six or more (%)	45.9	51.6	42.2	44.7	43.8	42.2
<b>Advance directives:</b>						
<b>resuscitating (DNR) (%)</b>	10.2	14.2	8.4	8.6	8.8	8.2
<b>Advance directives:</b>						
<b>hospitalizing (DNH) (%)</b>	5.2	17.2	4.8	4.4	3.3	3.4

Notes: SD = standard deviation, LTC = long-term care, DNR = do not resuscitate, and DNH = do not hospitalize. All variables are significantly associated with rurality (p < 0.001).

Sources: Continuing Care Reporting System and Registered Persons Database.

be found in Table A.1. Briefly, the databases used in this study census agglomeration (CA). CMAs and CAs comprise one or

**Table 2**  
**Location of death for people living with dementia in Ontario long-term care homes**

Variable	Total N=65,375	Urban 1 (population 1,500,000 or more) N=19,754	Urban 2 (population 500,000 to 1,499,999) N=11,847	Urban 3 (population 100,000 to 499,999) N=16,736	Urban 4 (population 10,001 to 99,999) N=8,519	Rural (population 10,000 or less) N=8,519
<b>Location of death</b>						
Long-term care home (%)	75.6	66.3	80.7	78.4	80.6	79.5
Acute care hospital (%)	21.5	30.4	17.1	18.6	16.7	17.5
Subacute care facility (%)	0.7	1.2	0.5	0.5	0.2	0.3
Community (%)	2.2	2.1	1.7	2.4	2.4	2.7

**Note:** All variables are significantly associated with rurality ( $p < 0.001$ ).

**Sources:** Canadian Institute for Health Information Discharge Abstract Database, National Ambulatory Care Reporting System, National Rehabilitation Reporting System, Continuing Care Reporting System, Same Day Surgery Database, Ontario Mental Health Reporting System, and Home Care Database.

more adjacent municipalities centred around a densely populated core. CMAs have a total population of at least 100,000, of which at least 50,000 must live in the core, while CAs must have a core population of at least 10,000.<sup>19</sup> In this study, urban LTC homes were further classified into four categories of urbanicity based on the CMA or CA population size: urban 1 (most urban) (population 1,500,000 or more), urban 2 (population 500,000 to 1,499,999), urban 3 (population 100,000 to 499,999), and urban 4 (least urban) (population 10,001 to 99,999). LTC homes outside CMAs or CAs were classified as rural.

The primary outcome was the location of death. As a secondary outcome, the place of care in the last 90 days of life, measured by acute care use (hospitalizations and ED visits), was also examined. The location of death was categorized as acute care hospital (included deaths in the hospital and the ED via the DAD, the NACRS, and the SDS) or subacute care facility (included deaths in complex continuing care facilities, rehabilitation facilities, or mental health facilities via the CCRS, the NRS, and the OMHRS). All other deaths were in the community. Hospitalizations were classified as palliative or non-palliative, based on the presence of a palliative diagnosis code or service provider on the DAD record, or palliative care billing by a physician for the individual while in the hospital.<sup>18</sup> Hospitalization length of stay (LOS) was defined by a difference between admission and discharge days, with a minimum of one day in the hospital. ED visits in the last 90 days of life were captured using the NACRS.

Additional study variables included age at death, sex, neighbourhood income quintile, type and number of comorbidities, and do-not-hospitalize (DNH) and do-not-resuscitate (DNR) orders. The neighbourhood income quintile was measured before residents' entry to an LTC home and based on the postal code of their previous primary residence. Comorbid conditions were defined using a series of algorithms that identified the presence of 17 conditions using hospitalization data, physician billing records, and prescription claims data.<sup>20-29</sup> Conditions included acute myocardial infarction, arrhythmia, asthma, cancer, congestive heart failure, chronic obstructive pulmonary disease, coronary heart disease,

diabetes, hypertension, inflammatory bowel disease, non-psychotic mood and anxiety disorders, other mental health conditions, osteoarthritis, osteoporosis, renal disease, rheumatoid arthritis, and stroke. The number of comorbidities was measured via a count of these chronic conditions.<sup>20-29</sup> Whether residents had a DNR or DNH order on their LTC assessment was captured using the CCRS database.

### Statistical analysis

Descriptive statistics, including the mean and standard deviation, the median and interquartile range, and counts and proportions, were used to describe the study population overall and stratified by degree of rurality. The place of care and the location of death were described overall and according to the degree of rurality. Differences in the location of death, categorized as being in or out of an LTC home, between rurality categories were evaluated via a chi-square test and a multivariable log-binomial regression model. The adjusted regression model included confounders selected a priori, including age, sex, income quintile, and the number of prevalent conditions. Differences in hospitalizations and ED visits between rurality groups were evaluated using chi-square tests, and the difference in hospitalization LOS between rurality groups was evaluated using the Kruskal–Wallis test. A p-value of less than 0.05 was used to identify statistically significant results. All analyses were conducted using SAS version 9.4 (SAS Institute Incorporated, Cary, North Carolina).

### Ethical considerations

The use of the data in this project is authorized under section 45 of Ontario's *Personal Health Information Protection Act* and does not require a review by a Research Ethics Board.

## Results

### Characteristics of the study population

Between April 1, 2014, and March 31, 2019, 65,558 LTC home residents with dementia died in Ontario. Of these, 183 were residing in homes with unknown or missing rurality data and

excluded from this study, leaving a total of 65,375 residents for analysis (Table 1). Of the 65,375 residents, 19,754 (30.2%) lived in the most urban LTC homes (urban 1), 11,847 (18.1%) lived in LTC homes in the urban 2 category, 16,736 (25.6%) lived in LTC homes in the urban 3 category, 8,519 (13.0%) lived in the least urban LTC homes (urban 4 category), and 8,519 (13.0%) lived in rural LTC homes (Table 1).

The mean age of the population was 87.8 years (standard deviation [SD] 7.3), ranging from 87.4 (SD 7.3) in rural LTC homes to 88.2 (SD 7.3) in the most urban LTC homes ( $p < 0.001$ ). Roughly two-thirds (65.6%) of residents of LTC homes were female. The sex distribution differed across rurality groups. The most rural LTC homes had the lowest proportion of female residents (64.0%), while the LTC homes in the urban 3 category had the highest (66.7%) ( $p < 0.001$ ). Overall, a higher proportion of residents were in the lowest area-level income quintile (28.9%) compared with those in the highest income quintile (14.0%), and income levels varied significantly across rurality groups ( $p < 0.001$ ). Furthermore, 35,909 residents (54.9%) had a history of cancer, 17,681 (27.0%) had congestive heart failure, and 30,010 (45.9%) had at least six comorbid conditions other than dementia. There was a significant difference in the prevalence of these conditions across rurality categories ( $p < 0.001$ ). Lastly, DNH and DNR orders significantly differed across rurality categories, with residents of the most urban LTC homes having the highest percentage with a DNH order (14.2%) and a DNR order (17.2%), compared with the residents of rural LTC homes (8.2% to 8.8% with a DNH order and 3.3% to 4.8% with a DNR order) ( $p < 0.001$ ).

### Location of death

In this population, 49,432 residents (75.6%) died in an LTC home, 14,054 (21.5%) died in an acute care hospital, 1,450 (2.2%) died in the community, and 439 (0.7%) died in a subacute care facility (Table 2). Residents of an LTC home in the urban 1 category had the lowest proportion of deaths in an LTC home (66.3%), whereas other rurality groups had a higher proportion of deaths in an LTC home (78.4% in the urban 3 category, 79.5% in the rural category, 80.6% in the urban 4 category, and 80.7% in the urban 2 category) ( $p < 0.001$ ).

After confounders were controlled for, residents of the most urban LTC homes were less likely to die in an LTC home than residents of rural LTC homes (relative risk [RR]: 0.84; 95% confidence interval [CI]: 0.83 to 0.85) (Table 3). Differences in RRs between other urban groups and rural residents were not statistically significant (urban 2 category [RR: 1.01; 95% CI: 1.00 to 1.02], urban 3 category [RR: 0.99; 95% CI: 0.98 to 1.00], urban 4 category [RR: 1.00; 95% CI: 0.99 to 1.02]). Unadjusted models had similar results to the adjusted model, suggesting that the confounding effects of the included covariates were small.

### Places of care

In this study population, 10,669 residents of LTC homes (16.3%) had at least one palliative hospitalization in the last 90 days of life (Table 4). As rurality increased, the proportion of these residents who had a palliative hospitalization in the last 90 days of life decreased, from a high of 23.7% for the residents of the most urban LTC homes to a low of 9.9% for the residents of rural LTC homes ( $p < 0.001$ ). The median palliative

**Table 3**  
Log-binomial regression model for location of death, modelling the risk of dying in or out of long-term care homes

	Unadjusted relative risk			Adjusted relative risk <sup>1</sup>		
	Relative risk	95% confidence interval		Relative risk	95% confidence interval	
from		to	from		to	
Urban 1 (population 1,500,000 or more) versus rural	0.82	0.83	0.85	0.84	0.83	0.85
Urban 2 (population 500,000 to 1,499,999) versus rural	1.02	1.00	1.03	1.01	1.00	1.02
Urban 3 (population 100,000 to 499,999) versus rural	0.99	0.97	1.00	0.99	0.98	1.00
Urban 4 (population 10,001 to 99,999) versus rural	1.01	1.00	1.03	1.00	0.99	1.02

1. Adjusted for age at death, sex, income quintile, and number of prevalent conditions.

Sources: Canadian Institute for Health Information Discharge Abstract Database, National Ambulatory Care Reporting System, National Rehabilitation Reporting System, Continuing Care Reporting System, Same Day Surgery Database, Ontario Mental Health Reporting System, and Home Care Database.

hospitalization LOS was 5 days (interquartile range [IQR]: 2 to 10 days). Individuals in the most urban LTC homes had the longest LOS (median 6 days [IQR: 3 to 12 days]) versus a median of 4 days (IQR: 2 to 8 days) for all other rurality groups ( $p < 0.001$ ).

Similarly, 12,795 residents of LTC homes (19.6%) had at least one non-palliative hospitalization during their last 90 days of life (Table 4). The residents of the most urban LTC homes had the highest proportion with at least one non-palliative hospitalization (28.3%), and other groups had lower proportions that were relatively similar, ranging from 14.9% in the urban 2 category and 15.9% in the rural category to 16.2% in the urban 3 and urban 4 categories ( $p < 0.001$ ). The median non-palliative care hospitalization LOS was 5 days (IQR: 3 to 10 days) (Table 3). The longest non-palliative LOS was in the urban 1 category (median 6 days [IQR: 3 to 11 days]), and it was lower in all the other rurality groups (urban 2 category: median 5 days [IQR: 3 to 9 days]; urban 3 category: median 5 days [IQR: 2 to 8 days]; urban 4 category: median 5 days [IQR: 2 to 8 days]; and rural category: median 5 days [IQR: 2 to 9 days] [ $p < 0.001$ ]) (Table 4).

The proportion of residents with at least one ED visit in the last 90 days of life was the highest for residents of the most urban LTC homes (20.2%) and lower for residents of all the other less urban LTC homes (urban 2 category: 16.7%; urban 3

category: 17.6%; urban 4 category: 18.3%; and rural category: 19.7%) ( $p < 0.001$ ) (Table 4).

## Discussion

In this population-based study of LTC home residents with dementia, residents of the most urban homes were 16% less likely to die in their LTC home, compared with those living in rural homes. The place of death did not differ between rural residents and residents of the other urban groups. Residents of the most urban LTC homes were also more likely to be admitted to the hospital, for either palliative or non-palliative purposes, in the last 90 days of life and had a longer LOS, compared with residents of the less urban LTC homes. The residents of the most urban LTC homes were also more likely to visit the ED than the residents of LTC homes in the less urban groups, although the differences were smaller than those observed for hospitalizations. These results suggest that residents of LTC homes in the most urban areas of Ontario are more likely to receive care in the hospital and die outside their LTC home, compared with residents of rural LTC homes.

These findings are contrary to previous studies that reported that individuals residing in rural areas were more likely to die in the hospital and have higher hospitalization rates and longer LOS, compared with individuals in urban areas.<sup>9-11</sup> However, those studies were not focused specifically on the population residing

**Table 4**  
Place of care in last 90 days of life for people living with dementia in Ontario long-term care homes

Variable	Total N=65,375	Urban 1	Urban 2	Urban 3	Urban 4	Rural
		(population 1,500,000 or more) N=19,754	(population 500,000 to 1,499,999) N=11,847	(population 100,000 to 499,999) N=16,736	(population 10,001 to 99,999) N=8,519	(population 10,000 or less) N=8,519
<b>At least one palliative care hospitalization in the last 90 days of life</b>						
Yes (number)	10,669	4,684	1,767	2,449	925	844
Yes (%)	16.3	23.7	14.9	14.6	10.9	9.9
<b>Total LOS (days) of palliative care hospitalizations in the last 90 days of life</b>						
Median	5	6	4	4	4	4
First quartile	2	3	2	2	2	2
Third quartile	10	12	8	8	8	8
<b>At least one non-palliative care hospitalization in the last 90 days of life</b>						
Yes (number)	12,795	5,588	1,764	2,713	1,378	1,352
Yes (%)	19.6	28.3	14.9	16.2	16.2	15.9
<b>Total LOS (days) of non-palliative care hospitalizations in the last 90 days of life</b>						
Median	5	6	5	5	5	5
First quartile	3	3	3	2	2	2
Third quartile	10	11	9	8	8	9
<b>ED visit in the last 90 days of life</b>						
Yes (number)	12,155	3,997	1,975	2,946	1,558	1,679
Yes (%)	18.6	20.2	16.7	17.6	18.3	19.7

Notes: LOS = length of stay and ED = emergency department.

Sources: Canadian Institute for Health Information Discharge Abstract Database and National Ambulatory Care Reporting System.

in LTC homes, nor on individuals with dementia. These findings suggest two potential implications: urban–rural differences in end-of-life care may vary between individuals in LTC homes and those in the community, and between those with dementia and those without. While further research is needed to fully understand these findings, they have potentially important implications for service delivery. Efforts aimed at reducing hospital use at the end of life may need to be uniquely tailored to the care setting (i.e., community or LTC homes), the presence of dementia, and the degree of rurality.

These findings may be explained by the observation that urban areas have a higher density of acute care hospitals and physicians, compared with rural areas.<sup>5,6</sup> The close geographic proximity of hospitals in many urban areas may increase the likelihood of transferring residents of urban LTC homes to the hospital, as transfers are perceived as potentially less burdensome. In contrast, providers may be less likely to send residents of rural LTC homes to the hospital, as hospitalization may take them far from their home community and support network. These differences in hospital access could explain the higher hospitalization admission rates and LOS in urban areas, compared with rural areas.

Planning for and delivering high-quality end-of-life care should be a key component of LTC. The COVID-19 pandemic, which disproportionately affected residents of LTC homes in Canada, highlighted the vulnerability of this population and the gaps in high-quality care delivery, including for residents who are nearing death. This study provides further evidence that there may be a need to improve end-of-life care in LTC homes. Overall, dying in the hospital and the use of acute care in the last 90 days of life were common among LTC home residents with dementia, with roughly one in five visiting the ED, being hospitalized, or dying in the hospital. One of the key challenges in end-of-life planning is related to both the prognostication of life expectancy and the identification of individuals who are nearing death. This is particularly true for individuals with dementia, for whom the course of the disease can be difficult to predict.<sup>21</sup> Incorporating a palliative approach to care in all aspects of care delivery may help meet the needs of residents of LTC homes and reduce any unnecessary and potentially harmful acute care use.

## Strengths and limitations

To the authors' knowledge, this is the first study to examine end-of-life health care use and the locations of death of Ontario LTC home residents with dementia. This research used health administrative databases that captured all residents of LTC homes in Ontario, minimizing the risk of selection bias in the results.<sup>30</sup> These findings are likely generalizable to other provinces in Canada and jurisdictions that have a similar LTC structure and organization. Additionally, the evaluation of multiple levels of urbanicity, rather than using a dichotomous rurality measure (urban versus rural), allowed the observation

that, while differences exist between the residents of the most urban LTC homes and those of rural LTC homes regarding places of care and the location of death, the residents of less urban LTC homes (urban 2, urban 3, and urban 4 categories) are relatively similar to those of rural LTC homes in these outcomes.

A limitation of this work is the use of secondary databases. The nature of secondary data is that the data were not collected to address the research question, and therefore, some variables were unavailable for analysis.<sup>31</sup> For example, the health administrative data exclude information on hospice use, making it impossible to report on end-of-life hospice use. However, with only 300 hospice beds in Ontario, hospice is an uncommon place of care, particularly for residents of LTC homes or people with dementia.<sup>32</sup> Further, important covariates were unavailable in the administrative data, including religion, ethnicity, family advocacy, social support, and caregiver support at the end of life. These factors may influence individuals' end-of-life care preferences and health care use and may differ between residents of urban and rural LTC homes. Moreover, this analysis does not provide information on LTC home residents' end-of-life care preferences, and some may have wanted to receive care in the hospital and die there. There may be uncontrolled confounding in the results because of the inability to measure and adjust for these characteristics. Additionally, this study used a decedent cohort, a common approach in end-of-life care studies. However, it has limitations, as it assumes death is foreseen. Some LTC home residents may have gone to the hospital without knowing they were near the end of life. While acute care use and the location of death may be different for LTC home residents who were clearly recognized as dying, such a cohort is difficult to identify using health administrative data.<sup>33,34</sup> This study was also restricted to LTC home residents with dementia, and these findings may not be generalizable to LTC home residents without dementia. Finally, the secondary outcome of the place of care was analyzed only using descriptive and bivariate analyses. Further research is needed to study these outcomes more comprehensively in relation to LTC home rurality.

In conclusion, this study found urban–rural differences in end-of-life care. Residents with dementia in LTC homes in the most urban areas are more likely to die outside their LTC home, be hospitalized, and visit the ED, compared with their rural counterparts. These findings will contribute to the enhancement of care for LTC home residents with dementia. They provide insights that can inform future end-of-life strategies and health policies, emphasizing the need for increased supports for end-of-life care that are tailored to the specific setting of LTC homes.

## Data availability

The dataset from this study is securely held in coded form at ICES. While legal data sharing agreements between ICES and data providers (e.g., health care organizations and government)

prohibit ICES from making the dataset publicly available, access may be granted to those who meet pre-specified criteria for confidential access, available at [www.ices.on.ca/DAS](http://www.ices.on.ca/DAS) (email: [das@ices.on.ca](mailto:das@ices.on.ca)). The full dataset creation plan and underlying analytic code are available from the authors upon request, with the understanding that the computer programs may rely on coding templates or macros that are unique to ICES and are therefore inaccessible or may require modification.

## Acknowledgments

This study was supported by ICES, which is funded by an annual grant from the Ontario Ministry of Health (MOH) and the Ministry of Long-Term Care. Parts of this material are based on data and information compiled and provided by the Ontario MOH and the Canadian Institute for Health Information. The analyses, conclusions, opinions, and statements expressed herein are solely those of the authors and do not reflect those of the funding or data sources; no endorsement is intended or should be inferred. Parts of this report are based on information on deaths from the Ontario Office of the Registrar General (ORG), the original source of which is ServiceOntario. The views expressed therein are those of the authors and do not necessarily reflect those of ORG or the Ministry of Public and Business Service Delivery. This document used data adapted

from Statistics Canada's Postal Code Conversion File, which is based on data licensed from the Canada Post Corporation, and data adapted from the Ontario MOH Postal Code Conversion File, which contains data copied under licence from the Canada Post Corporation and Statistics Canada. The authors would like to thank Jahanara Begum from ICES for accessing the ICES data for them.

## Funding

This study was funded by the Canadian Institutes of Health Research.

## Conflict of interest

The authors declare that they have no conflicts of interest with the contents of this article.

## Author contributions

All authors contributed to the study conception, design, and methods. All authors interpreted the findings. Hanbyoul Park drafted the manuscript and all authors revised it critically for important intellectual content. All authors approved the final version and agree to be accountable for all aspects of the work.

**Appendix A.1**

**Description of databases from ICES**

Health care sector	Database description and uses
<b>Health care use</b>	
Acute care hospitals	<p><b>Canadian Institute for Health Information's Discharge Abstract Database (DAD)</b>  <b>Description:</b> The DAD, which is prepared by trained abstractors, contains discharge records for all acute care hospitalizations in Ontario.  <b>Uses:</b> This data source was used to identify information on acute care deaths and palliative acute care hospitalizations during the last 90 days before death. It was also used to assign the presence of chronic conditions and comorbidities based on diagnosis codes within the records; these variables were used as potential confounders in the analysis.</p>
Emergency departments	<p><b>National Ambulatory Care Reporting System (NACRS)</b>  <b>Description:</b> The NACRS includes information on emergency department visits. Data include patient demographics, visit start and end dates and times, diagnoses, procedures and interventions delivered during visit, physician service providers, and visit disposition.  <b>Use:</b> This data source was used to identify information on emergency department visits during the last 90 days of life before death.</p>
Physician claims	<p><b>Ontario Health Insurance Plan (OHIP) Claims History Database</b>  <b>Description:</b> The OHIP Claims History Database contains claims data for all services provided by physicians in Ontario, including in inpatient and outpatient settings. Each billing claim represents a single service provided by the physician, identified by the fee code and a diagnosis code.  <b>Use:</b> This data source was used to measure deaths in subacute care.</p>
Long-term care (LTC)	<p><b>Continuing Care Reporting System (CCRS)</b>  <b>Description:</b> The CCRS contains resident information for over 600 publicly funded long-term care homes in Ontario and is updated every three months. Data include administrative data regarding deaths at LTC homes, LTC home stays (e.g., admission and discharge dates), and resident demographics.  <b>Use:</b> This data source was used to measure deaths in LTC homes and to identify the demographics of the population of study.</p>
Complex continuing care or chronic care	<p><b>Continuing Care Reporting System (CCRS)</b>  <b>Description:</b> The CCRS includes population-based information for all patients staying in a designated complex continuing care bed in Ontario. These individuals are typically deemed to be in a non-acute state, but still in need of treatment (e.g., rehabilitation) in an institution.  <b>Use:</b> This data source was used to measure deaths in subacute care.</p>
Rehabilitation	<p><b>National Rehabilitation Reporting System (NRS)</b>  Institute for Health Information and contains client data, including demographics, collected from participating adult inpatient rehabilitation facilities and programs.  <b>Use:</b> This data source was used to measure deaths in subacute care.</p>
Home care	<p><b>Home Care Database (HCD)</b>  <b>Description:</b> The HCD contains service information (e.g., service start and end dates, type of services, including end-of-life home care, and providers) for all publicly funded home care delivered in Ontario.  <b>Uses:</b> This data source was used to measure deaths in the community.</p>
Ambulatory care	<p><b>Same Day Surgery (SDS) Database</b>  <b>Description:</b> The SDS Database contains patient-level data for day surgery institutions in Ontario. Every record corresponds to one same-day surgery or procedure stay. Each individual dataset contains cases from one fiscal year.  <b>Use:</b> This data source was used to measure deaths in acute care.</p>
Mental health	<p><b>Ontario Mental Health Reporting System (OMHRS)</b>  <b>Description:</b> The OMHRS contains data on all patients in adult designated inpatient mental health hospital beds, including general and provincial psychiatric and specialty psychiatric facilities. The OMHRS also contains demographic and clinical information on all mental health admissions, including admission and discharge dates, reasons for admission, and diagnoses.  <b>Use:</b> This data source was used to measure deaths in subacute care.</p>
<b>Population and demographics</b>	
Demographics	<p><b>Registered Persons Database (RPDB)</b>  <b>Description:</b> The RPDB is an ICES-derived database that contains demographic information on all individuals who have ever held an Ontario health card, including their date of birth, date of death, sex, and OHIP eligibility start and end dates.  <b>Use:</b> This data source was used to determine study population eligibility through records of provincial health insurance coverage in the last year of life and to measure the decedent characteristics, including age at death, sex, and income quintile, used as confounders.</p>
Census	<p><b>Postal Code Conversion File (PCCF)</b>  <b>Description:</b> The PCCF macro converts any Canadian postal code to Statistics Canada's standard geographical areas. Given a dataset with postal codes, this macro links to the PCCF files to find other census geographic identifiers, such as dissemination area or enumeration area, census division, and latitude and longitude, as well as an urban or rural flag and neighbourhood income quintile.  <b>Use:</b> This data source was used to define the rurality groups.</p>

**Note:** ICES = formerly known as the Institute for Clinical Evaluative Sciences

**Source:** ICES Data Dictionary - Key to the knowledge produced at ICES is our ability to anonymously link population-based health information on an individual patient basis, using unique ICES identifiers that ensure the privacy and confidentiality of health information.

## References

- Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliative Care* 2013;12:1-13.
- Gozaló P, Teno JM, Mitchell SL, Skinner J, Bynum J, Tyler D, et al. End-of-life transitions among nursing home residents with cognitive issues. *New England Journal Med* 2011;365(13):1212–21.
- Monette EM. Cultural Considerations in Palliative Care Provision: A Scoping Review of Canadian Literature. *Palliative Med Rep* 2021 May 1;2(1):146–56.
- Canadian Institute for Health Information. Access to palliative care in Canada. Ottawa, ON: CIHI; 2023.
- Kornelsen J, Carthew C, Míguez K, Taylor M, Bodroghy C, Petrunia K, et al. Rural citizen-patient priorities for healthcare in British Columbia, Canada: findings from a mixed methods study. *BMC Health Serv Res* 2021;21(1):1–12.
- Wilson C, Rourke J, Oandasan IF, Bosco C. Progress made on access to rural health care in Canada. *Canadian Family Physician* 2020;66(1):31–6.
- Kaasalainen S, Brazil K, Williams A, Wilson D, Willison K, Marshall D, et al. Barriers and enablers to providing palliative care in rural communities: a nursing perspective. *Journal of Rural and Community Development* 2012;7(4):4–19.
- Temkin-Greener H, Zheng NT, Mukamel DB. Rural-urban differences in end-of-life nursing home care: Facility and environmental factors. *Gerontologist* 2012;52(3):335–44.
- Menece VH, Nowicki S, Kalischuk A. Transfers to acute care hospitals at the end of life: do rural/remote regions differ from urban regions? *Rural Remote Health* 2010;10(1):1281.
- Goodridge D, Lawson J, Rennie D, Marciniuk D. Rural/urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life. *Rural Remote Health* 2010;10(2):1349.
- Burge FI, Lawson B, Johnston G. Where a cancer patient dies: The effect of rural residency. *Journal of Rural Health* 2005;21(3):233–8.
- Tanuseputro P, Chalifoux M, Bennett C, Gruneir A, Bronskill SE, Walker P, et al. Hospitalization and Mortality Rates in Long-Term Care Facilities: Does For-Profit Status Matter? *Journal of American Medical Directors Association* 2015;16(10):874–83.
- Sachs GA, Shega JW. Barriers to Excellent End-of-life Care for Patients with Dementia: Is Dementia a Terminal Illness? *Journal of General Internal Medicine* 2004;1919(Mc 6098):1057–63.
- National Institute on Aging [Internet]. What is long-term care? Accessed November 7, 2022. Available from: <https://www.nia.nih.gov/health/what-long-term-care#:~:text=Long%2Dterm%20care%20involves%20a,everyday%20activities%20on%20their%20own.>
- Staykov E, Qureshi D, Scott M, Talarico R, Hsu AT, Howard M, et al. Do patients retain their family physicians after long-term care entry? A retrospective cohort study. *Journal of American Medical Directors Association* 2020;21:1951-1957.
- Huyer G, Brown CRL, Spruin S, Hsu AT, Fisher S, Manuel DG, et al. Five-year risk of admission to long-term care home and death for older adults given a new diagnosis of dementia: A population-based retrospective cohort study. *Cmaj* 2020;192(16):E422–30.
- Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330(7498):1007–11.
- Webber C, Chan R, Scott M, Brown C, Spruin S, Hsu AT, et al. Delivery of Palliative Care in Acute Care Hospitals: A Population-Based Retrospective Cohort Study Describing the Level of Involvement and Timing of Inpatient Palliative Care in the Last Year of Life. *Journal of Palliative Med* 2021;24(7):1000–10.
- Statistics Canada [Internet]. CMA and CA: detailed definition. Accessed November 7, 2022. Available from: <https://www150.statcan.gc.ca/n1/pub/92-195-x/2011001/geo/cma-rmr/def-eng.htm>
- Liisa Jaakkimainen R, Bronskill SE, Tierney MC, Herrmann N, Green D, Young J, et al. Identification of physician-diagnosed Alzheimer's disease and related dementias in population-based administrative data: A validation study using family physicians' electronic medical records. *Journal of Alzheimer's Disease* 2016;54(1):337–49.
- Gruneir A, Bronskill SE, Maxwell CJ, Bai YQ, Kone AJ, Thavorn K, et al. The association between multimorbidity and hospitalization is modified by individual demographics and physician continuity of care: A retrospective cohort study. *BMC Health Services Research* 2016;16(1).
- Koné Pefoyo AJ, Bronskill SE, Gruneir A, Calzavara A, Thavorn K, Petrosyan Y, et al. The increasing burden and complexity of multimorbidity disease epidemiology – Chronic. *BMC Public Health* 2015;15(1):1–11.
- Lane NE, Maxwell CJ, Gruneir A, Bronskill SE, Wodchis WP. Absence of a socioeconomic gradient in older adults' survival with multiple chronic conditions. *EBioMedicine* 2015;2:2094-2100.
- Mondor L, Maxwell CJ, Bronskill SE, Gruneir A, Wodchis WP. The relative impact of chronic conditions and multimorbidity on health-related quality of life in Ontario long-stay home care clients. *Quality of Life Research* 2016;25(10):2619–32.
- Mondor L, Cohen D, Khan AI, Wodchis WP. Income inequalities in multimorbidity prevalence in Ontario, Canada: A decomposition analysis of linked survey and health administrative data. *International Journal of Equity Health* 2018;17(1):1–13.
- Mondor L, Maxwell CJ, Hogan DB, Bronskill SE, Gruneir A, Lane NE, et al. Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population-based cohort. *PLoS Med* 2017;14(3):1–17.

27. Muggah E, Graves E, Bennett C, Manuel DG. The impact of multiple chronic diseases on ambulatory care use: A population-based study in Ontario, Canada. *BMC Health Serv Research* 2012;12:452
28. Petrosyan Y, Bai YQ, Koné Pefoyo AJ, Gruneir A, Thavorn K, Maxwell CJ, et al. The Relationship between Diabetes Care Quality and Diabetes-Related Hospitalizations and the Modifying Role of Comorbidity. *Canadian Journal of Diabetes* 2017;41(1):17–25.
29. Thavorn K, Maxwell CJ, Gruneir A, Bronskill SE, Bai Y, Koné Pefoyo AJ, et al. Effect of socio-demographic factors on the association between multimorbidity and healthcare costs: a population-based, retrospective cohort study. *BMJ Open* 2017;7(10):1-14.
30. Biau DJ, Kernéis S, Porcher R. Statistics in brief: The importance of sample size in the planning and interpretation of medical research. *Clinical Orthopaedics and Related Research* 2008;466(9):2282–8.
31. Cheng HG, Phillips MR. Secondary analysis of existing data: opportunities and implementation. *Shanghai Arch Psychiatry* 2014;26(6):371–5.
32. Health Quality Ontario. Palliative care at the end of life. Toronto: Queen’s Printer for Ontario; 2016.
33. Earle CC, Ayanian JZ. Looking back from death: The value of retrospective studies of end-of-life care. *Journal of Clinical Oncology* 2006;24(6):838–40.
34. Bach PB, Schrag D, Begg CB. A Study Design That Should Be Laid to Rest. *JAMA* 2004;292(22):2765–70.