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# Palliative Care: Research and Treatment

# Death in Long-term Care: A Brief Report Examining Factors Associated with Death within 31 Days of Assessment

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#### ABSTRACT

**INTRODUCTION:** The ability to estimate prognosis using administrative data has already been established. Research indicates that residents newly admitted to long-term care are at a higher risk of mortality. Studies have also examined mortality within 90 days or a year. Focusing on 31 days from assessment was important because it appears to be clinically useful for care planning in end-of-life; whereby, greater utility may come from identifying residents who are at risk of death within a shorter time frame so that advance care planning can occur.

PURPOSE: To examine risk of mortality within 31 days of assessment among long-term care residents using administrative health data.

METHODS: Administrative data were used to examine risk of mortality within 31 days of assessment among all long-term care residents in Ontario over a 12-month period. Data were provided by the Canadian Institute for Health Information using the Continuing Care Reporting System (CCRS), Discharge Abstract Database (DAD), and the National Ambulatory Care Reporting System (NACRS).

**RESULTS:** A number of diagnoses and health conditions predict death within 31 days. Diagnoses that hold an increased risk of mortality include pulmonary disease, diagnosis of cancer, and heart disease. Health conditions that lead to an increased likelihood of death include weight loss, dehydration, and shortness of breath. The presence of a fall within the last 30 days was also related to a higher risk of mortality.

**DISCUSSION:** Long-term care residents who lose weight, have persistent problems with hydration, and suffer from shortness of breath are at particular risk of death. The presence of advanced directives also predicts death within 31 days of assessment.

KEYWORDS: aging, long-term care, death, mortality risk, survival

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#### Introduction

A greater number of residents are dying in long-term care homes instead of hospitals' or emergency departments' care. Approximately 24% of all deaths occur in long-term care, and the numbers of long-term care home deaths are expected to rise steadily by 2030. This has led to a growing interest in the development of end-of-life care programs in long-term care homes.

The need for long-term care homes to adopt standardized principles and practices in death and dying has never been

more apparent and is considered an essential component of health care in Canada.<sup>2</sup> Long-term care residents often have complex needs: many of them live with non-cancer comorbidities, heart disease, or dementia,<sup>3,4</sup> making care and end-of-life complicated.

Estimating prognosis is important for care planning. Porock et al<sup>5</sup> examined the ability to estimate mortality within six months using the Minimum Data Set (MDS) 2.0 assessment tool. They found that items strongly associated with death within six months include (1) admission to the care home within three



months, (2) unintentional weight loss over preceding three months, (3) renal failure, (4) chronic heart failure, (5) poor appetite, (6) being male, (7) dehydration, (8) shortness of breath, (9) active cancer diagnosis, (10) age, (11) deteriorated cognitive skills in the past three months, and (12) rate of physical decline.<sup>5</sup> Alternatively, Wallace and Prevost<sup>6</sup> found that 22 MDS items were strongly related to death within six months. These items indicated extremely low levels of functioning, limited activity and involvement, low fluid intake/dehydration, significant medical interventions intravenous (IV fluids and suctioning), and problematic skin ulcers, oral debris, and lung aspirations. Gambassia et al7 examined determinants of death but focused only on residents suffering from dementia. Predictors of death included advanced age, being male, limited physical function, conditions of malnutrition, and a diagnosis of diabetes or cardiovascular disease. Unfortunately, much of this research has been conducted in the United States. Very little research has examined death in long-term care in Canada because high-quality administrative data have not been available in Canada until recently.

The purpose of this paper is to examine the profile of long-term care residents who died within 31 days of assessment. Many deaths occur in long-term care; however, a significant number of deaths also take place in acute care settings (hospitals and emergency departments). As such, it is also important to examine where long-term care residents die. This is a necessary step in ensuring that appropriate care planning is taking place and strategies to improve end-of-life care in long-term care are being developed and/or improved.

#### Methods

**Sample.** The study sample included information on health from all long-term care residents in Ontario from April 1, 2011 to March 31, 2012. Information was collected using three databases: the Continuing Care Reporting System (CCRS), the Discharge Abstract Database (DAD), and the National Ambulatory Care Reporting System (NACRS).

The CCRS holds all information on the health and wellbeing from all long-term care homes in Ontario. This database gathers information using the MDS, Canadian version, a comprehensive standardized assessment tool made up of more than 400 items essential to care planning. A full assessment is required within 14 days of admission to any long-term care facility, annually, and after significant change in resident status. A shortened version is completed during each of the remaining three quarters while the resident is in long-term care. There is growing evidence in the literature of the reliability and validity of many of the items.<sup>8-14</sup> The domains include psychological, cognitive, physical, social, and spiritual well-being. 9,15 The MDS 2.0 is designed to assess level of cognition (Cognitive Performance Scale; CPS),11 activities of daily living (Activities of Daily Living (ADL) Hierarchy Scale), 16 depression (Minimum Data Set Depression Rating Scale),<sup>12</sup> and pain (Pain Scale).<sup>13</sup>

For the purposes of this study, four additional variables were created to examine the relationship of diagnosis with mortality

within 31 days: heart disease, pulmonary disease, psychiatric illness, and other comorbidities. Higher scores represent higher levels of comorbidity. The heart disease variable represents the additive summation of arterial heart disease, congestive heart failure, hypertension, a cerebrovascular accident, or any other cardiovascular disease (ranges from 0 to 5). The pulmonary disease variable is the summation of asthma, emphysema, pneumonia, and respiratory infection (ranges from 0 to 4). The variable to measure psychiatric disease includes the diagnosis of anxiety disorder, depression, or manic depression (ranges from 0 to 3). Other comorbidities include allergies, anemia, arthritis, diabetes, hypothyroidism, and urinary tract infection (ranges from 0 to 6).

The NACRS database contains admission and discharge information of patients admitted to an emergency department in Ontario. This database includes the date of admission, where patients are admitted from (home, long-term care, hospital), and basic information on diagnoses and treatment. It also records dates of death of patients who died while receiving care in an emergency department.

The DAD holds information on hospital admissions and discharges; it includes administrative, clinical, and demographic data. It also includes information detailing where patients were admitted from and discharged to, including dates of death.

All information on health (CCRS, NACRS, and DADs) was provided by the Canadian Institute of Health Information. All assessments were de-identified and anonymized; a unique identifier was provided so that the CCRS database could be linked to the DAD and NACRS databases. Ethics approval was provided by the Lakehead University Research Ethics Board.

Analyses. Data analyses were performed using SPSS v.22. A series of independent correlations, chi-squares, and tests of differences between means were used to examine factors associated with death within 31 days and place of death (long-term care vs. hospital care). Relationships were tested with a number of variables representing health conditions commonly found in long-term care. Multivariate analysis examined the relationships between the independent variables and the dependent variables using survival analysis and logistic regression, respectively. Multivariate models were derived using all statistically significant variables associated with the dependent variables found in univariate analyses. All variables were entered into the model in a single step. A probability level of P = 0.05 was used to determine whether the independent variables were statistically significant in the hypothesized model. A variable that was not significantly associated with the dependent variable was removed at each step, until no more non-significant variables remained.

#### Results

The most recent assessments from 96,760 residents were provided in the time frame of interest (April 1, 2011 to March 31, 2012). Assessments from 85,842 residents were available for examination. The majority of long-term care residents



were female (69%) and married (56%). Analyses showed that 19.4% (n = 18,778) of residents died over the course of the year, 14,668 died in long-term care, and 4,110 died while in hospital or emergency care. Of those residents who died, 42.2% (n = 7,924) died within one month (31 days) of assessment, 81.8% (n = 6,484) died in long-term care, and 18.2% (n = 1,440) died in hospital care.

Univariate analyses examined factors associated with death within 31 days. All factors associated with death within 31 days were entered into a Cox regression survival analysis model. Table 1 summarizes the independent predictors of mortality from all causes. Residents who were older, male, and experienced

**Table 1.** Results of Cox proportional hazards model of death within 31 days of assessment.

RISK FACTOR	RELATIVE RISK	(95 PERCENT CI)
Demographics		
New admission	1.491	(1.371–1.623)
Sex	1.357	(1.290-1.427)
Age at assessment	1.029	(1.027–1.032)
Scales		
Activities of daily living <sup>1</sup>	1.523	(1.488–1.558)
Pain <sup>2</sup>	1.254	(1.222–1.286)
Cognition <sup>3</sup>	1.049	(1.033–1.066)
Aggressive behaviour⁴	0.971	(0.961-0.981)
Diagnoses		
Pulmonary disease	1.127	(1.082–1.173)
Diagnosis of cancer	1.123	(1.050-1.201)
Heart disease	1.069	(1.045-1.093)
Psychiatric disease	0.892	(0.857-0.927)
Advanced directives		
Do not resuscitate	1.392	(1.289–1.502)
Do not hospitalize	1.316	(1.253-1.383)
Legal guardian	0.901	(0.818-0.991)
Health conditions		
End stage disease	5.029	(4.708-5.371)
Insufficient fluids	1.849	(1.746–1.958)
Weight loss	1.749	(1.657–1.846)
Shortness of breath	1.671	(1.573–1.776)
Fever	1.642	(1.515–1.779)
Dehydrated	1.434	(1.308–1.571)
Fell in past 30 days	1.358	(1.282–1.439)
Internal bleeding	1.344	(1.166–1.549)
Experiencing acute episode	1.327	(1.250-1.408)
Vomiting	1.210	(1.105–1.324)
Condition lead to instable	1.157	(1.102–1.215)
Delusions	0.762	(0.678-0.857)

Notes: <sup>1</sup>ADL Hierarchy Scale; <sup>2</sup>Pain Scale; <sup>3</sup>CPS; <sup>4</sup>Aggressive Behavioral Scale.

greater functional impairment, pain, and cognitive impairment were more likely to die within 31 days of assessment. Residents who suffered from heart disease (arterial heart disease, congestive heart failure, hypertension, cerebrovascular accident, or any other cardiovascular disease) or pulmonary disease (asthma, emphysema, pneumonia, or respiratory infection) were also more likely to die within 31 days of assessment. Psychiatric illness (anxiety disorder, depression, or manic depression) resulted in a decreased likelihood of death.

Advanced directives that include do-not-resuscitate and do-not-hospitalize orders were associated with a higher likelihood of death, while the presence of a legal guardian had an opposite effect. Health conditions that increased the likelihood of death include weight loss and dehydration or insufficient fluids. Residents who were assessed by physicians as having end-stage disease with six months or fewer to live were over five times more likely to die within 31 days of assessment than those who were not.

#### Discussion

There is little information on short-term survival of long-term care residents in Ontario prior to its mandated collection in April 1, 2010. Much of the existing published research focus on reports using data from outside Canada or are focused on subpopulations of long-term care (eg, focus on dementia only). As long-term care is increasingly becoming a place where residents choose to die, the need for best practices and guidelines will also increase. Studies like this one will help guide and inform these practices.

Demographic variables were first examined. Consistent with the existing research, increased age was associated with a greater likelihood of death, and being male led to a 35% increased risk of death. New admission also predicted death within 31 days of admission; this is consistent with Porock et al,<sup>5</sup> with the exception that Porock et al defined new admission as residents admitted within three months, whereas this study defined new admissions as residents admitted within 14 days. Nevertheless, the results are not surprising given that admission to long-term care may result from a health care emergency.

Activities of daily living were a strong predictor of death within 31 days. In fact, of the scales, reduced levels of activities of daily living were the strongest predictor, where each level of the ADL Hierarchy Scale leads to a 50% increased likelihood of death. Activities of daily living often follow a predictable decline; a closer examination of this decline may be warranted. Increased pain, as determined by the Pain Scale, and cognition, measured by the CPS, also predicted death, but aggressive behaviors appeared to have a small but significant protective effect. An examination of place of death showed that residents who were more functionally and cognitively impaired were also more likely to die in the long-term care facility. Aggressive behavior has a similar but smaller effect.



The fact that advanced directives predicted death was not surprising: residents who had a do-not-resuscitate order in place were 39% more likely to die and residents who had a do-not-hospitalize order in place were just over 30% more likely to die. When examining the place of death, residents who had completed a do-not-hospitalize order were far less likely to die in hospital (RR: 0.28, CI: 0.24–0.34). Residents who had completed a do-not-resuscitate order were also more likely to die in long-term care. Although death in long-term care is not always ideal, this suggests that long-term care staff are able to follow through with the wishes of residents.

Health conditions in relation to death within 31 days of assessment and how they relate to the place of death were also examined. Results show that residents who were assessed to be in the end-stage disease, or having six months or less to live, were five times as likely to die within 31 days of assessment. They were also far less likely to die in hospital care (RR: 0.22, CI: 0.17–0.28). This indicates not only that staff are able to identify residents who are nearing end-of-life but also that they are able to incorporate this into the care plan to prevent death in hospital.

Both insufficient fluids, which refer to an instance where the resident did not consume all or almost all liquids provided during the last three days, and weight loss, which refers to an instance where the resident lists 1.5 kg or more in the last seven days, increased the likelihood of death but had a protective effect against hospital admission (hospital or emergency department). Other health conditions that increased risk of death include shortness of breath, fever, dehydration, falling, internal bleeding, vomiting, and experiencing an acute episode or condition that is unstable.

To the author's knowledge, this is the first study to examine risk factors for death in 31 days among long-term care residents in Canada, although earlier studies have attempted to examine death in other health care settings (complex continuing care) and other locations (United States). One study by Hirdes et al<sup>17</sup> developed the MDS-CHESS (Changes in Health, End-Stage Disease, and Symptoms and Signs) Scale. This scale focused on complex continuing care patients but corroborated many of the findings reported by this study. One limitation outlined by Hirdes et al was that death was not recorded for patients discharged from complex continuing care; only patients who died while in care were included. This study included all long-term care residents; dates of death were recorded for not only residents who died in long-term care but also residents who were discharged to hospital care or emergency department care. Had hospital discharge data not been included, nearly 20% of long-term care home deaths would not be accounted for.

A total of 31 days from the assessment time frame was chosen because it appears to be clinically useful for care planning in end-of-life. Residents who are identified as being at risk of death within the next month can then ensure that their goals of care and final wishes are heard. This includes advance directives, where measures can be taken to prevent hospitalization

or resuscitation among residents who do not wish to receive these interventions.

The main limitation of this study was its inability to examine hospital use or emergency department use as a measure to predict mortality in long-term care. Further research to examine this relationship is likely warranted. Accuracy of data may also be a limitation. Earlier research suggests that functional status of residents may be overestimated and systematic inaccuracies may exist.<sup>18</sup>

A strength of this study is its use of the population-based administrative information on health from Ontario long-term care facilities, which included mortality data from residents who died in long-term care and were transferred to emergency care or admitted to hospital. Given that long-term care is most often the final place of residence, it is unlikely that many were transferred back home or to an alternate location.

#### Conclusion

The purpose of this paper was to examine the profile of long-term care residents in Ontario who died within 31 days of assessment. As stated previously, many deaths occur in long-term care; however, a significant number of deaths also occur in hospitals (including emergency departments). This study suggests that it is possible to predict short-term mortality among long-term care residents, and preparations and advance care planning for residents who are at risk are able to be finalized.

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#### **Author Contributions**

PB and MLK drafted the manuscript and participated in the design. PB performed the statistical analysis. PB and MLK conceived the study, and participated in its design and coordination. All authors read and approved the final manuscript.

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