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Place of Death in Canada: An Analysis of the Decedent Questionnaire of the Canadian Longitudinal Study on Aging

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ABSTRACT

Background: Understanding the factors associated with the place of death is important for planning individual care and health care services. **Objectives:** To determine the place of death of community living Canadians in a cohort study; and to investigate the factors associated with the location of death. **Design:** The CLSA is a prospective cohort study of aging which commenced in 2010, with a sample of 51,338 community-living participants aged 45 to 85. There were 1287 participants with completed proxy decedent questionnaires. **Setting:** The original sampling frame was from representative sampling frames across Canada. **Measurements:** Community was defined as the participant's home or other non-health care settings. Other locations were: Hospice/Palliative care, Hospital, and Nursing Home/Residential (long term care – LTC) setting. Age, sex, and income were from the CLSA survey. Cause of death, functional status prior to death and the functional trajectory to death were from the proxy report of the decedent questionnaire. **Results:** 25% died in the Community, 49% died in Hospital, 17% died in Hospice/Palliative Care, and 9% died in LTC. Older age was associated with death in LTC. In multinomial regression models, the cause of death and the trajectory of death were associated with the place of death. **Conclusions:** Hospitals are the most common place of death in Canada, and different diseases and disease trajectories are associated with the place of death. **These heterogeneous factors may complicate attempts to increase the proportion of people who die at home.**

BACKGROUND

The immediate symptoms of death have been well studied in palliative care, long term care and acute care settings. These studies show that the symptom burden is high^{1,2}, and that functional impairment is common immediately prior to death³. In some studies, the symptom burden is higher amongst those who die in hospital than those who die in the community^{4,5} and this may be due to family preferences⁶, different disease trajectories^{6,7}, hospitalization of those with the most symptoms, and treatments to extend life with more side effects. It is also not a universal finding^{8,9}. In most surveys of well people, most people want to die at home,^{10,11} albeit with considerable heterogeneity¹¹. Health policies often aim to reduce death in hospital¹², further impacting the number of deaths in community. However, quantitative surveys done in healthy populations prior to death may not fully capture preferences of those who are dying. Qualitative studies offer a more nuanced view of where people want to die, reflecting the complex and dynamic nature of these preferences^{13,14}. Further complicating policy is the lower availability of resources in community settings¹⁵, the underlying disease process¹⁶ and symptom trajectory leading to death, and the availability¹⁷ and preferences of family and caregivers. Finally, most prior research into location of death and preferred location of death are done in populations where death is expected – or at least foreseeable. Many people die without expecting or planning for it – and this will influence the place of death.

There is considerable variability in the place of death between countries¹⁸. Studies using administrative and demographic data have shown that the location of death in Canada has changed over time, with a decline in the proportion of deaths occurring in hospital. In 2016, 61% of deaths occurred in hospital, with a decline to 55% by 2020 – continuing previous and international trends^{19,20}. This has been accompanied by a rise in the proportion of deaths

occurring in nursing homes (NH),^{21,22} hospice and home⁵. While recent research has shed considerable light on the dying process, there are some unresolved issues. The data on place of death for most people comes from reports using administrative data, and many factors associated with the place of death are not clearly established, since administrative data does not include functional status data. It is not clear if different diseases and functional changes are associated with the place of death, or if there are demographic or medical factors associated with place of death.

Understanding the factors which are associated with the place of death is important for planning primary care, palliative, geriatric and home care services. The Canadian Longitudinal Study on Aging (CLSA) offers a unique opportunity to address some of these issues. **The CLSA is a cohort study which serves as a national research platform on health and aging allowing researchers to answer questions on the biological, medical, psychological, social, lifestyle and economic aspects of aging, disability and disease.** The CLSA follows 51,338 participants who were aged 45 to 85 at recruitment, for 20 years. The representative sampling frame of the CLSA allows for analysis which is as generalizable as possible into the circumstances of death in Canada, and the detailed questionnaires ensure that more social, demographic and functional data are available than are found in clinical or administrative data sets. The Decedent Questionnaire adds further detail into the place of death, symptoms around death, and the functional trajectory to death.

The specific **objectives** of these analyses are:

1. To determine the place of death of community living Canadians aged 45 to 85 on entry to the study; and
2. To investigate the factors associated with the location of death.

SAMPLE

The CLSA is a population-based cohort study of over 50 000 participants aged 45 to 85 at baseline, sampled from representative sampling frames across the country^{23,24}. The goal was to ensure that the sample was as representative of community living adults as possible. The sampling frames excluded adults living with cognitive impairment at recruitment, individuals unable to participate in English or French, individuals living in long term care (LTC) facilities, active **Royal Canadian Mounted Police (RCMP)** and military personnel, individuals living on First Nations reserves, those living in the three territories and those living in some rural and remote regions. There are two related cohorts – the “Tracking Cohort” of 21 241 participants randomly selected from within all 10 provinces who are interviewed by telephone; and the “Comprehensive Cohort” of 30 097 participants randomly selected from within 25–50 km of eleven data collection sites (DCSs) (in seven provinces) who are interviewed in person, take part in in-depth physical assessments at DCSs, and provide blood and urine samples^{23,24}.

A similar set of questions was asked on the first and second follow up wave of data collection (FUP1 and FUP2). We also used the decedent questionnaire. For these analyses, there were 3672 participants who died, and 1287 (35%) of the decedent questionnaires had been completed. This decedent questionnaire is answered by a close relative or friend of the participant²⁵. **The characteristics of those for whom a decedent questionnaire was available and those for whom it was not have been previously reported: CLSA participants who died with a completed decedent interview were more likely to be male, older, married, and identify a religious affiliation compared to those without a decedent interview²⁶.** The Baseline data were collected from September 2011 to July 2015. Death was measured up to FUP2 – the data collection for which spanned from June 2018 to Sept 2021.

MEASURES

We used data common to both the Tracking Cohort and the Comprehensive Cohort considering data from the [survey wave immediately prior to death](#) and from the decedent questionnaire²⁵.

There were 1287 completed decedent questionnaires. The study received ethics approval from the Health Research Ethics Board of the Bannatyne Campus of the University of Manitoba.

DATA FROM PARTICIPANT QUESTIONNAIRES

Sociodemographic Factors

The following factors were included: age at the time of death, sex was self-reported: “Are you male or female?”, and gender was self-reported at FUP1. Since sex and gender were extremely closely correlated, we used sex, which was measured at baseline. Education was considered in categories: “No post-secondary degree; some secondary education; secondary education; more than secondary education. Total personal income was self-reported (measured as <20 000; 20 000 – 50 000; 50 – 100 000; 100 – 150 000 and >150 000 Canadian dollars).

DATA FROM DECEDENT QUESTIONNAIRE

Cause of death

Questions about cause of death are asked of proxy respondents in a manner similar to the completion of death certificates. The primary cause of death is chosen from a list of common causes of death: Cancer, Heart Disease, Stroke, Heart failure, Respiratory, Dementia, Accident, Flu or pneumonia, Suicide, Kidney, Other, Don’t know and refused. For “other” a follow up

question was asked which was open ended. Conditions contributing to death are chosen from the same list (with no limits on the number of conditions that can be noted.)

Two authors (PStJ and RT) reviewed the cause of death and recoded some causes of death. In the rare cases where Medical Assistance in Dying (MAID) was noted as the primary cause of death, we considered the secondary cause of death as the primary cause of death. Covid deaths were coded as “Flu or pneumonia.” Note that the version of the decedent questionnaire we used was very early in the Covid pandemic and there were few Covid deaths; and Covid was not a choice on the questionnaire itself. We also added categories: “Chronic Neurologic,” which included Amyotrophic Lateral Sclerosis, and Parkinson Disease and syndromes. These were noted within the “Other” category, but were frequent. We also added “Gastro-intestinal” which included liver disease and non cancerous gastro-intestinal disease. Many of the “other” causes of death could be included in one of the existing categories (e.g. Heart Valve failure was recoded as cardiac). We left some in the “Other” category – this included very rare causes of death; and more often “Frailty,” “Old Age,” and “Multiple Organ Failure/Everything failed.”

Functional Status and Functional Trajectory to Death

A question related to the functional trajectory was asked in the decedent questionnaire, which is based upon previously reported trajectories²⁷. It went as follows: : “We are trying to understand how [decedent’s name] died. There are generally four ways to describe how people die. Once you’ve heard the categories, I will ask you which one best describes how [decedent’s name] died. Sudden death: To die suddenly with little or no warning. Function is normal up to the time

of death. Terminal illness: A distinct terminal phase of an illness. Function is reasonably good for a long time before the illness becomes overwhelming. Decline is rapid, often within a 1- 2 month period. Chronic illness: A serious illness or illnesses over a period of years. Gradual decline with times of worsening illness followed by partial or full recovery. Hard to predict length of illness and time of death. Slow, gradual decline: A slow, gradual decline usually over years with steadily increasing disability before dying.”

Functional status was measured by the proxy using items similar to the Older American Resource Survey (OARS)²⁸. This is a series of activities of daily living (ADL) and instrumental ADL (IADL) items that the participant was able to do one month prior to death. In CLSA, the responses are categorized as: “No ADL problems; mild ADL problems; moderate ADL problems; severe ADL problems and total ADL problems.” Since there were very few participants with severe and total problems, we collapsed moderate, severe and total ADL problems into one category **for regression models. We have left the original categories for graphs.**

Place of Death

The proxy is asked: “in which location did [decedent’s name] pass away?” This is chosen from a list of possible places: Their own home, another private home, residence for seniors, hospital, hospice, palliative care unit, NH or other LTC facility, other, and don’t know and refused. For “other,” the proxy is asked to clarify. Two authors (PStJ and RT) recoded the “Other” site of these deaths: nearly all of these occurred in community settings – hiking, driving, shopping, at work, etc. Those who died in transit between sites were coded where they were residing. We

collapsed those deaths occurring in the community and those who died in their own home or a private home as “Community.” “Hospice” and “Palliative Care” were also collapsed into one category. “Seniors residence” was considered with NH and LTC.

ANALYSIS

For all analyses, we used data from the last questionnaire completed prior to death and the decedent questionnaire. We did not use sample weights for these analyses. The issue of sample weighting is problematic when considering the decedent questionnaire, since the respondents represent a subset of those that died, which is in turn a subset of the overall sample. The sample weights, in contrast, consider the entire sample. Those who die are not similar to those who do not, and those who complete the decedent questionnaire are not similar to those who do not.

Thus, existing sample weights are inappropriate since they consider a reference population that represents the entire population and not the population of those who died. Therefore, applying the sample weights for the entire sample is problematic as it could introduce new selection bias while attempting to correct for it.

The outcome of interest was the location of death, considered as “Community, Hospital; Palliative Care/Hospice, and LTC.” We conducted bivariable analyses to determine the factors associated with the location of death. For continuous variables, we used Analysis of Variance (ANOVA); for categorical variables, we used chi-square tests (assuming unequal variance). Since there are several locations of death, we constructed multinomial logistic regression models. We constructed a series of regression models: Since the cause of death was correlated with the trajectory to death and the functional status prior to death, we constructed a model for each

factor, rather than a single full model. Models were adjusted for age, sex and education. Where there were fewer than six observations in a cell, we have suppressed the data for presentation. We also excluded some factors from multinomial models where there were small cell sizes. Missing variables were excluded from analyses. We constructed a model with an interaction for sex and the factor of interest with place of death as the outcome. This was not significant, so we have not presented results separately for males and for females. Of course, there were main effects for the association between sex and place of death. Analyses were performed with SAS version 9.4 and graphs were made with Excel.

RESULTS

There were 1287 proxy questionnaires in our analyses. The most common place of death was in hospital; where approximately one half of the sample died. The most common cause of death was cancer, followed by cardiac disease. Most of the participants did not have functional impairment in the time leading up to their death. The full characteristics of the sample are shown in Table 1. Age was strongly associated with place of death: Older age groups were much more likely to die in LTC (Figure 1; $p < 0.05$, F test ANOVA). Importantly, the original sampling frame was restricted to those who were living in the community, so this reflects people who moved to LTC care and subsequently died – and therefore likely underestimates the incidence of death in LTC in Canada. Income was associated with place of death as well (Table 1; $p < 0.05$ chi square test). Cause of death was also associated with the place of death (Figure 2; $p < 0.05$, chi square test): Those with cancer were markedly more likely to die in palliative care while those who died of heart disease were much more likely to die at home compared to those with other diseases. Those with dementia were more likely to die in LTC. It is also important to note that

this association is likely an underestimate – since the original sampling frame was those who were able to provide consent to participate and excluded many people living with dementia. Functional status prior to death was also related to the place of death – those with higher levels of impairment were more likely to die in LTC and less likely to die at home ($p < 0.05$, chi square test; Figure 3). The functional trajectory leading up to death was also associated with the place of death ($p < 0.05$, chi square test; Figure 4). Sudden death was much more likely to occur in the community, while those with terminal illness trajectories were more likely to die in Palliative Care settings.

Results of multinomial logistic regression produced similar findings. This shows the Odds Ratio (OR) and 95% confidence interval (CI) for each factor adjusted for age, sex and education. Table 2 shows the results for cause of death. The reference category is death in hospital (the most common location). Older age was very strongly associated with death in LTC; conversely younger age was more associated with death in the community. Cardiac causes of death were associated with death in the community; while non cancer causes of death were very strongly associated with death in a location other than Palliative Care. Death from chronic neurological conditions and dementia was strongly associated with death in LTC.

The functional trajectory prior to death was strongly associated with place of death (Table 3). Again, the reference category is death in hospital. Those with terminal, chronic illness, and gradual declines were all less likely to die in the community relative to those with sudden deaths. Conversely, a terminal decline was very strongly related to a death in palliative care. Gradual and chronic illness trajectories were associated with death in LTC. The cause of death was correlated with the trajectory to death, with cardiac deaths more likely to be sudden, and cancer

deaths more likely to be terminal decline, we **therefore** did not construct a model with all variables.

DISCUSSION

We have analyzed the decedent questionnaire of the CLSA and found that nearly one half of the participants died in hospital. This is consistent with the current estimates from administrative and vital statistics data for this time frame. We also found that the cause of death was strongly associated with the place of death: those dying of heart disease tended to die in the community or in hospital, while those dying of cancer tended to die in palliative care or hospital. Indeed, the majority of people who died in palliative care died of cancer. People living with dementia and chronic neurologic conditions were more likely to die in LTC compared to those who died from other causes. We also found that the trajectory leading to death was also associated with the place of death – those who died suddenly were more likely to die in the community or in hospital than those who died from other causes, while those who had a terminal decline over months were more likely to die in palliative care settings. Older age was associated with death in LTC. These associations may be underestimates of a true population effect. The initial sample included only those under the age of 85, so the true association between age and place of death may be even stronger. Also, the overall place of death for the sample may underestimate LTC as location of death. The sampling strategy excluded those living in LTC facilities and those with cognitive impairment that would preclude informed consent. This would likely further underestimate LTC as a place of death. In the unadjusted but not adjusted analyses, income was associated with the location of death; suggesting that perhaps the effect is mediated or confounded by the cause and trajectory to death. Further research is needed into disentangling these effects.

Our findings are broadly similar to the findings of other researchers. While there are large national differences in place of death, even amongst OECD countries¹⁸, in most places approximately one half of deaths occur in hospital. As well, other studies that consider cause of death also find that those who die of heart disease are more likely to die at home than those who die of other causes²⁹, and the percentage of cardiac deaths occurring in the community is increasing^{30,31}. Others have also found that deaths in palliative care settings are common in those who die of cancer¹⁶. While it is relatively unsurprising that those dying in the community are more likely to be functionally intact, there is much less literature on functional status prior to death or on the functional trajectories leading up to death.

Our findings are important for several reasons. First, both the cause of death and the related trajectory to death are strongly associated with the place of death. Of note, a substantial proportion of the sample died suddenly – often in the community. If efforts to prevent sudden cardiac death, such as bystander cardiopulmonary resuscitation and automated electric defibrillators, are successful and broadly adopted, then these sudden deaths will be less common. Those who survive out of hospital cardiac arrests will subsequently go on to a different trajectory with a higher likelihood of being hospitalized or admitted to LTC. This may be desirable, but this potential outcome needs to be considered in planning services and in the current policy of encouraging home deaths. Second, deaths occurring in palliative care are predominantly due to deaths from cancer. There have been efforts to broaden palliative care admission criteria to include other diseases and syndromes³², but these other diseases often have different symptom constellations, different functional trajectories, different treatments, and often different expectations of cure – so this may be difficult. Third, most of the participants were functionally intact in the months prior to death. This may make care planning difficult. Rapid

declines and rapid oscillations in symptoms and function may be difficult for both clinicians and for health care systems to plan and co-ordinate care. Clinical and social systems must be structured to anticipate changes in clinical status as functional impairment becomes apparent. Often, these systems are rigid and task oriented³³, and not able to adapt rapidly to symptom changes.

There are both strengths and limitations to our approach. The CLSA is a large cohort study which is as representative of the Canadian population as possible. However, the decedent questionnaire response rate, while initially low, is improving over time. The original sample from which the decedent questionnaire was drawn is representative, but the subsequent subsample may therefore not be fully representative of all Canadians who die. **The higher response rates of some social and demographic groups may also introduce selection bias into the findings, which is difficult to correct with statistical methods.** The CLSA has broad measures of health, and the measures are based upon reliable, valid measures. There are also some limitations. Our analysis time frame did not include important period effects. Notably, there were very few deaths from Covid in our sample, which may influence our findings³⁴. The pandemic may have also influenced the location of death for those who did not die of Covid³⁵. While our time frame included some of the time during which Medical Assistance in Dying (MAID) was available, it was early in the MAID adoption and there were few deaths involving MAID. Both of these period effects, together with the longer-term shift in deaths away from hospital, may alter future findings in this and in other cohorts. Another limitation is that the cause of death and the trajectory to death were reported by the proxy. We do not have medical records related to death, death certificates, or autopsy reports. On the other hand, there is evidence of inaccurate or incomplete data on cause of death, on death certificates, as well³⁶. A further limitation of this and

most other analyses is that the data are gathered after death. Looking retrospectively after death confers a certainty that rarely exists in the lead up to death. Functional decline is common prior to death, but not all functional declines result in death³⁷. Prospectively, it is difficult to prognosticate death³⁸. Even when death is fairly certain, the exact time to death may not be fully clear, or acknowledged by patients, their families or the health care team. The assertion that most people do not want to die in hospital presupposes that they expect to die. Prognostic uncertainty, together with an unwillingness to accept death may result in care decisions which favor hospitalization. Thus, death in hospital is not necessarily a failure of health care planning at an individual or at a population level. Rather, the place of death is strongly influenced by the cause of death and the functional trajectory leading up to death.

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