End-of-life care for nursing home residents dying from cancer in Nova Scotia, Canada, 2000–2003

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Abstract

Introduction—With our population aging, an increasing proportion of cancer deaths will occur in nursing homes, yet little is known about their end-of-life care. This paper identifies associations between residing in a nursing home and end-of-life palliative cancer care, controlling for demographic factors.

Methods—For this population-based study, a data file was created by linking individual-level data from the Nova Scotia Cancer Centre Oncology Patient Information System, Vital Statistics, and the Halifax and Cape Breton Palliative Care Programs for all persons 65 years and over dying of cancer from 2000 to 2003. Multivariate logistic regression was used to compare nursing home residents to nonresidents.

Results—Among the 7,587 subjects, 1,008 (13.3%) were nursing home residents. Nursing home residents were more likely to be female [adjusted odds ratio (OR) 1.4, 95% confidence interval (CI) 1.2–1.7], older (for 90 vs 65–69 years OR 5.4, CI 4.1–7.0), rural (OR 1.5, CI 1.2–1.8), have only a death certificate cancer diagnosis (OR 4.2, CI 2.8–6.3), and die out of hospital (OR 8.5, CI

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7.2–10.0). Nursing home residents were less likely to receive palliative radiation (OR 0.6, CI 0.4–0.7), medical oncology consultation (OR 0.2, CI 0.1–0.4), and palliative care program enrollment (Halifax OR 0.2, CI 0.2–0.3; Cape Breton OR 0.4, CI 0.3–0.7).

Conclusion—Demographic characteristics and end-of-life services differ between those residing and those not residing in nursing homes. These inequalities may or may not reflect inequities in access to quality end-of-life care.

Keywords

Nursing home; Cancer; Place of death; End-of-life; Palliative care

Introduction

With almost 50% of those diagnosed with cancer eventually dying from cancer [9] and with hospital and medical services being publicly funded, end-of-life and palliative care (PC) in Canada have developed through associations with oncology and hospital-based services. While there is some research on nursing home residents and the elderly with cancer, little is known about the availability of palliative cancer care for nursing home residents. If residence in a nursing home and demographic characteristics, such as age and sex, are playing a role in defining who receives palliative and oncology care, inequitable access may be occurring [1].

According to the 2001 Canadian census, 13% of the Canadian population is over the age of 65, and by 2026, this will rise to 20% [35, 36]. Among those over the age of 65 in the USA, close to half will, at some time, reside in a nursing home, and the majority of those admitted to nursing homes will die in nursing homes [21, 26, 27]. In some US states, the proportion of deaths occurring in nursing homes now exceeds 30% and, by 2040, is expected to exceed 40% [30]. Approximately 11% have a cancer diagnosis upon admission to a nursing home [7] and approximately 10% of the nursing home population has a cancer diagnosis that affects their function and/or treatment [23]. A significant proportion of nursing home residents with cancer have daily pain (24–38%), over a quarter of which goes entirely untreated [4, 7]. Between 6 and 24% of cancer patients die in nursing homes [2, 6, 17, 18, 22, 23, 28, 29, 34]. Nursing homes are not generally viewed as having well-developed expertise in care for dying people [33].

Almost 70% of cancer diagnoses and over 80% of cancer deaths occur in those over the age of 60 [9]. Elderly patients differ from younger cancer patients dying of cancer in that they are more likely to have untreated pain, suffer from depression, and commit suicide [27].

Nursing home residents tend to differ from the elderly who do not reside in nursing homes. Nursing home residents are more likely to be older, female, widowed, and have a disability [18, 25, 38]. They tend to have chronic diseases [32, 38] and more than half are diagnosed with progressive dementia [32]. They tend to require help with one or more activities of daily living and mobilizing, and they enter a nursing home if they have no family or their family cannot provide the level of care they require [7, 38]. Among those admitted to a

nursing home with a cancer diagnosis, the average age is 75.9 years, and over 70% of those admitted with cancer are over the age of 70 [7].

Relatively few nursing home residents with cancer receive active cancer treatment [7, 16, 23, 39, 41] despite the fact that research has shown that active treatment can be as effective and as well tolerated in the elderly as in younger patients [3, 31, 39]. Only 4.8% of nursing home residents with cancer were noted to be obtaining hospice services, with the percentage rising to 11% among those terminally ill [23].

This study of cancer decedents 65 years old and older identifies disparities between nursing home residents and nonresidents in end-of-life care received, controlling for demographic differences. This paper adds to the literature and enables dialogue on appropriate end-of-life care for nursing home residents by using linked administrative data for Nova Scotia (NS) adults who died of cancer from 2000–2003 to identify demographic, oncology, palliative, and place-of-death variables associated with being a nursing home resident.

In Canada, hospital and physician services are publicly funded. Thereby, the assumption is often made that there is equity in the provision of health care for all persons in Canada. However, palliative and end-of-life care is known to be in short supply, and continuing care at home and in long-term care settings is financed through a mix of public and private funding. Therefore, this paper presents methods and findings to begin to explore whether there are factors that may be markers of possible inequity in access to optimal end-of-life care for elderly persons dying of cancer that require further exploration.

Patients and methods

To carry out this retrospective population-based study, an end-of-life data set was created through the linkage of individual-level data from the NS Cancer Centre Oncology Patient Information System (OPIS), NS Vital Statistics, the Capital District Health Authority PC program (serving Halifax County), and the Cape Breton District Health Authority PC program (serving Cape Breton County). Using probabilistic record-linkage software, LinkageWiz (Payneham, Australia), and patients' names, dates of birth, OPIS chart numbers, and health card numbers, the various data sets were linked. Ethics approval was obtained from the research ethics committees of Capital and Cape Breton District Health Authorities.

Place of death was obtained from death certificate information in the NS Cancer Registry in OPIS. Also obtained from OPIS were sex, date of birth, date of death, cancer cause of death (2000 [11] and 2001–2003 [42]), postal code and county of residence, province of death, date of cancer diagnosis, and radiation and medical oncology consultation information. PC program databases were used to determine which subjects were registered in a PC program. Numerous data quality checks were carried out on the data prior to their use in the analysis (O'Brien, Johnston, and Gao, unpublished data).

Study subjects

Subjects were 7,587 NS residents who died of cancer (immediate or underlying cause of death) according to death certificates from 2000 to 2003, excluding 48 who died outside of the province. As only 6.5% of nursing home residents were under the age of 65, study subjects were limited to those 65 years of age or older at the time of death.

Definition of study variables

Subjects were grouped into one of three regions: Halifax County, Cape Breton County, or all other NS counties. Cancer causes of death were divided into five tumor groups: the four most prevalent cancers and a group representing all other invasive cancer types. Study subjects were divided into 5-year groups, with the exception of those 90 years old or older, who were grouped in one age group.

The systemic therapy-related variable used in this study was a medical oncology consultation in the last 12 months of life. Death out of hospital was defined as a death that occurred in a location other than an acute-care hospital bed, or a transitional- or continuing-care bed in an acute-care hospital. Description of the development of the palliative radiation variable [24] and length of survival after a cancer diagnosis [8] have been published. Death certificate only (DCO) is a diagnosis of cancer made only at death. These subjects have no pathological or other diagnostic confirmation, hospital admission diagnosis, or cancer treatment diagnosis recording a cancer diagnosis prior to their death. Thus, DCO subjects and their daily care providers may not have known that the subjects had cancer prior to the subjects' death.

As there is no province-wide electronic database identifying residents of nursing homes, nursing home residents were identified by comparing subjects' addresses on death certificates against a provincial list of nursing home addresses. Anyone who had a nursing home listed as his or her place of residence or place of death was deemed to be a nursing home resident. Anyone who had no indication on his or her death certificate of being from a nursing home was deemed a non-nursing home resident. Those with missing place-of-residence information ($n=115$) were not included in the analysis.

Analysis

Cross-tabulations and logistic regression analyses were used to compare nursing home and non-nursing home residents. Multivariate logistic regression analyses using backward elimination techniques were used to develop the most parsimonious model of residing in a nursing home. Univariate (crude) and multivariate (adjusted) logistic regression findings are presented as odds ratios (OR) with 95% confidence intervals (CI).

As enrollment data were only available for PC programs in Halifax and Cape Breton counties, this variable was only used in a subanalysis with subjects from these two counties.

Results

Of the 7,587 subjects, 13.3% (1,008) were nursing home residents at the time of death. Table 1 presents study characteristics by nursing home residency status. Because some of these

characteristics were correlated, multivariate analyses were carried out to control for correlations.

Multivariate regression (Table 2) showed that people who were residents of a nursing home were more likely to be female (OR 1.4, CI 1.2–1.7), be older (OR 5.4, CI 4.1–7.0 for 90+ years vs 65–74 years), only have a clinical diagnosis of cancer at death (DCO) (OR 4.2, CI 2.8–6.3 vs 0–60 days survival) or be more than 4 months from cancer diagnosis to death (OR 1.4, CI 1.1–1.8 vs 0–60 days survival), have lived in rural counties (OR 1.5, CI 1.2–1.8 vs Halifax County) and have died out of hospital (OR 8.5, CI 7.2–10.0).

Nursing home residents were less likely to receive palliative radiation in the last 9 months of life (OR 0.6, CI 0.4–0.7), a medical oncology consultation in the last 12 months of life (OR 0.2, CI 0.1–0.4), and PC program services (OR 0.2, CI 0.2–0.3, Halifax County; OR 0.4, CI 0.3–0.7, Cape Breton County).

Discussion

Universality in access to medically necessary health care is valued by Canadians. However, recent reports in Canada, as elsewhere, have identified inadequacies in palliative and end-of-life care. To date, end-of-life care studies have focused on access to palliative and home care and hospital and hospice use. There has been little focus on the role of the nursing home in terms of care for persons dying of cancer. Our methods and findings help overcome this problem.

Our findings, as has also been observed in other research [25, 40], showed that those who died in a nursing home are more likely to be female and older. Because females live longer than males [37] and because wives tend to be younger than husbands, a higher proportion of females than males outlive their spouses as age increases. Because females are more likely to be left without a spouse in older age, nursing home care may be more necessary for them as home care cannot as readily be provided for persons living alone at end of life. Palliative cancer patients were more likely to die at home if they were living with a spouse or family member [19].

Nursing home residents were more likely to live outside Halifax County. Per capita, there are a greater number of nursing homes beds available outside the Halifax regional municipality [12]. This may be allowing a greater proportion of the elderly population to be living in, and thus dying in, nursing home beds outside metro Halifax.

DCOs (cancer cases) were more common among nursing home than non-nursing home residents. Research has shown less access to cancer screening in nursing homes [5]. Less cancer screening and early detection among nursing home residents could be associated with a higher percentage of clinical cancer diagnosis at death rather than microscopic confirmation of cancer prior to death among nursing homes residents.

Nursing home residents were much more likely to die out of hospital than non-nursing home residents. Residence in a nursing home may be an enabler in allowing a person to die out of hospital because they provide more 24/7 long-term supportive care than normally can be

provided at home by family and friends, especially for the elderly living alone. For those living alone, full-time supportive care is important in allowing for an out-of-hospital death [20].

The proportion of persons dying out of hospital has been used as an indicator of access to community PC [10, 15]. Nursing home residency has not typically been considered as a covariate in research to date, even though a pattern of increased likelihood of dying out of hospital as age increases has been observed [6, 13, 14]. The findings reported herein show that nursing home residency is an important predictor of dying out of hospital and, along with age, should be taken into account in studies of quality end-of-life care.

Previous research also found that nursing home residents were less likely to have received palliative radiation and a medical oncology consultation in the last months of life [16, 23, 39, 41]. Reasons why nursing home residents are not receiving the same level of oncology services as those who do not reside in nursing homes need to be studied further. While the univariate analysis indicates that tumor type may be a factor, the multivariate findings confirm that this is not the situation when other variables such as age and sex are controlled (Table 2). Comorbidities that mitigate against the provision of these oncology services could be one factor. Another could be personal and family decisions and readiness for supportive care rather than hospital and cancer clinic interventions at the end of life. Other factors may be nursing home policies and practices of family physician care providers.

Nursing home residents were less likely to be registered in a PC program. This is consistent with a low referral rate of nursing home residents to hospice services [23]. Might nursing home care be a substitute for PC program enrollment? Assurance of quality PC services for nursing home residents should be further investigated, especially for those who do not have a clinical or microscopically confirmed cancer diagnosis on record prior to their date of death.

The apparent differences between the levels of oncology and palliative services received by nursing home residents compared to non-nursing home residents who died of cancer suggests that there may be inequity in care provided to nursing home residents. Alternatively, personal care goals and comorbidities may explain the differences observed. Studies should be undertaken to ascertain whether the inequalities observed in oncology and PC for nursing home residents are inequities that should be addressed so that all persons dying of cancer receive quality care, or whether the differences observed reflect appropriate care given personal decisions and clinical condition of the nursing home residents.

Due to the heavy cancer burden experienced by the older population and with our population aging, further research with nursing home residents on the adequacy and timing of cancer diagnostic processes, decision making and cancer survivorship experience, and the level of oncology and palliative service provision is critical.

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Table 1

Number of adults 65 and over who died of cancer from 2000–2003 in NS, by study characteristic and percentage of nursing home residents ($n=7,587$)

Predictor	Number ^a	% Nursing home residents
Sex		
Male	4,084	10.1
Female	3,503	17.0
Place of death ^b		
Out of hospital	2,171	34.2
In hospital	5,312	5.0
Time from cancer diagnosis to death, days ^c		
DCO	177	50.3
0–60	1,420	7.9
61–120	105	8.6
121	5,328	13.8
Age, years		
65–74	2,550	5.8
75–84	3,192	10.7
85–89	1,176	22.9
90+	669	37.7
Tumor group ^d		
Lung	1,545	10.0
Breast	666	22.1
Colorectal	1,080	12.7
Prostate	736	14.0
Other	3,483	12.7
Region ^e		
Halifax County	2,352	12.2
Cape Breton County	1,120	10.1
All other counties	4,105	14.8
Palliative radiation in last 9 months of life ^f		
No	5,816	15.2
Yes	1,708	7.0
Medical oncology consultation in last 12 months of life		
No	7,094	14.1
Yes	493	2.0
Enrollment in Capital Palliative Services ^g		
No	910	22.3
Yes	1,442	5.8
Enrollment in Cape Breton PC program ^h		
No	332	17.5

Predictor	Number ^a	% Nursing home residents
Yes	788	7.0

Proportions may not total 100 due to rounding

^aTotal population size varies slightly due to missing values. There were no missing values for sex, age, medical oncology visits, and palliative care enrollment in Capital Health and Cape Breton

^bThe 104 (1.4%) missing "place of death" typically relate to uncertainty regarding what to record when an elderly person with end-stage cancer is being cared for in a nursing home or in their own home by a family member or other lay care provider who opts to call an ambulance to have the dying person transported to an emergency department for possible hospital admission. The family or other physician on call who later completes the death certificate may rightly be unable to confidently record the actual place of death

^cThe 557 (7.3%) missing "time from cancer diagnosis to death in days" are normally deaths where the cancer diagnosis was clinically rather than pathologically confirmed by a physician with a note such as "symptoms indicate probable end stage cancer of xxx for 3 to 6 months prior to death." These persons are often frail with heart failure, dementia, or other comorbidities, indicating supportive care and symptom control as the optimal form of care

^dThe 77 (1.0%) missing "tumour group" include "cancer not otherwise specified"

^eThe 10 (0.1%) missing "region" are persons for whom there was no valid six-digit Nova Scotia postal code of residence available from the death certificate or cancer registry

^fThe 63 (0.8%) missing "palliative radiation in the last 9 months of life" are associated with the coding algorithm, which uses variables such as palliative or curative intent and number of treatment fractions. Details associated with the creation of this algorithm are in reference [24]

^gFor those residing in Halifax County only

^hFor those residing in Cape Breton County only

Table 2

Crude and adjusted ORs (and CIs) for predictors of residing in a nursing home

Predictor	Crude	Adjusted
Sex		
Male	1.0	1.0 (–)
Female	1.8 (1.6–2.1)	1.4 (1.2–1.7)
Place of death		
In hospital	1.0	1.0 (–)
Out of hospital	9.9 (8.5–11.5)	8.5 (7.2–10.0)
Time from cancer diagnosis to death, days		
DCO	11.8 (8.3–16.8)	4.2 (2.8–6.3)
0–60	1.0	1.0 (–)
61–120	1.1 (0.8–1.5)	0.9 (0.6–1.3)
121	1.9 (1.5–2.3)	1.4 (1.1–1.8)
Age, years		
65–74	1.0	1.0 (–)
75–84	1.9 (1.6–2.4)	1.6 (1.3–2.0)
85–89	4.9 (3.9–6.0)	3.5 (2.7–4.4)
90+	9.9 (7.9–12.4)	5.4 (4.1–7.0)
Tumor group		
Lung	1.0	1.0 (–)
Breast	2.6 (2.0–3.3)	1.1 (0.8–1.5)
Colorectal	1.3 (1.0–1.7)	0.7 (0.5–0.9)
Prostate	1.5 (1.1–1.9)	0.9 (0.6–1.2)
Other	1.3 (1.1–1.6)	0.8 (0.6–1.0)
Region of residence		
Halifax County	1.0	1.0 (–)
Cape Breton County	0.8 (0.6–1.0)	0.9 (0.7–1.2)
All other NS counties	1.3 (1.1–1.5)	1.5 (1.2–1.8)
Receipt of palliative radiation in last 9 months of life		
No	1.0	1.0 (–)
Yes	0.4 (0.3–0.5)	0.6 (0.4–0.7)
Medical oncology consultation in last 12 months of life		
No	1.0	1.0 (–)
Yes	0.1 (0.07–0.2)	0.2 (0.1–0.4)
Enrollment in Capital Palliative Service ^a		
No	1.0	1.0 (–)
Yes	0.2 (0.2–0.3)	0.2 (0.2–0.3)
Enrollment in Cape Breton PC Program ^b		
No	1.0	1.0 (–)
Yes	0.4 (0.2–0.5)	0.4 (0.3–0.7)

^aFor those residing in Halifax County only

^bFor those residing in Cape Breton County only