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Inequalities in End-of-Life Care for Colorectal Cancer Patients in Nova Scotia, Canada

André R. Maddison,
Faculty of Medicine, Dalhousie University, 5849 University Avenue, Mailbox No. 257, Halifax, Nova Scotia, Canada B3H 4R2

Yukiko Asada,
Department of Community Health and Epidemiology, Dalhousie University, Halifax, Nova Scotia, Canada

Fred Burge,
Department of Family Medicine, Dalhousie University, Halifax, Nova Scotia, Canada

Grace W. Johnston, and
School of Health Administration, Dalhousie University, Halifax, Nova Scotia, Canada

Robin Urquhart
Cancer Outcomes Research Program, Cancer Care Nova Scotia, Halifax, Nova Scotia, Canada

Abstract

Access to high-quality end-of-life (EOL) care is critical for all those with incurable cancer. The objective of this study was to examine inequalities in access to, and quality of, EOL care by assessing registration in a palliative care program, emergency room visits in the last 30 days of life, and location of death among individuals who died of colorectal cancer in Nova Scotia, Canada, between 2001 and 2008. We used population-based linked administrative data and performed multivariate logistic regression models to assess the association between socio-economic, geographic, and demographic factors and outcomes related to access to, and quality of, EOL care (n=1,201). This study demonstrates that although access to, and quality of, EOL care appears to have improved, there remain significant inequalities throughout the population. Of primary concern is the variation in access to, and quality of, EOL care based on geographic location of residence and patient age.

INTRODUCTION

When a patient's cancer is no longer considered potentially curable, an important transition takes place from a curative to a palliative focus for both the patient and the health care team. At this transition point, the goal of care is to provide pain and symptom management, as well as psychological, spiritual, and social support. Although patient preferences vary, high-quality end-of-life (EOL) care should be accessible to all dying cancer patients.

Correspondence to: André R. Maddison.

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Accordingly, it is important that we understand inequalities in access to, and quality of, EOL care services.

Studies continue to report inequalities in the EOL care services received by cancer patients (1–6). Burge, Lawson, and Johnston (1) reported that in Nova Scotia, Canada, older patients, those who lived further from the palliative care unit, and those residing in long-term care (LTC) facilities had significantly less access to a palliative care program (PCP) than their counterparts. Studies have also reported that indicators of poor-quality EOL care, such as emergency room (ER) visits near death, chemotherapy during the last weeks of life, and dying in hospital vary according to socio-economic, demographic, and geographic factors (1, 4, 7). Even though inequalities in EOL care have been shown to exist, few studies have examined and compared inequalities in access to, and quality of, EOL care for dying cancer patients.

Having timely access to a PCP, dying out of hospital, and not visiting the ER close to death have been identified as meaningful and important indicators of accessible and high-quality EOL care (8, 9). It is generally agreed that patients who are registered in a PCP have access to appropriate EOL services, but if they are registered within the last two to three days of life, this indicates suboptimal access and poor-quality care (8, 9). Studies have found that ER visits within the last month of life are often preventable and cause unnecessary pain and emotional stress (4, 7). Most people nearing death prefer to die outside of hospital if adequate home care and support are available (1). However, due partly to inadequate access to care, the number of people who actually die outside of hospital is much lower than one would expect based on reports of patient preferences (1,10).

The objective of this study was to examine inequalities in access to, and quality of, EOL care for individuals who died of colorectal cancer (CRC) in Nova Scotia, Canada, between 2001 and 2008. CRC is the second leading cause of cancer death; the number of deaths from this disease has steadily risen since 2000 (11). It affects individuals of all ages, and both men and women roughly equally, which permits examination of inequalities by age and sex (11). Specifically, this study examined inequality of access to a PCP, timing of PCP registration, ER visits in the last 30 days of life, and location of death by socio-economic, demographic, and geographic factors.

METHODS

Data and Study Population

The Nova Scotia Cancer Registry identified all individuals diagnosed with CRC between January 1,2001 and December 31,2005. It then undertook a comprehensive chart review to stage these individuals, which yielded a five-year population-based cohort (the Access to Colorectal Cancer Services in Nova Scotia [ACCESS] cohort) (n=3,501), which became the focus of this study. This cohort was anonymously linked at the patient level to 14 administrative health databases, including hospital discharge abstracts, physician billings, the Capital District Health Authority (CDHA) Integrated Palliative Care Service, the PCP of the Cape Breton District Health Authority (CBDHA), and 2001 Canadian census data (12). These databases have been identified as highly reliable and accurate for analyses of health

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services utilization (3,13). Exclusions from the cohort included: individuals who had non-invasive/collaborative stage 0 CRC, and those who were diagnosed by death certificate or autopsy only (see Urquhart and Grunfeld [12] for a complete description of the cohort). For this study, we included all adults (20 years of age or older) in the ACCESS cohort who died of CRC between January 1, 2001 and March 31, 2008, the latest date of death clearance data (n=1,201) (12). A CRC death was determined based on the cause of death reported on the death certificate and identified through the Nova Scotia Cancer Registry. From the registry, we also determined the date of death. We determined location of death (in or out of hospital) from the Discharge Abstract Database, following the method used by Grunfeld and colleagues (13).

Outcomes of Interest

We were primarily interested in four outcome variables. The two dependent variables related to access were registration in a PCP (yes or no) and timing of a PCP registration (over 60 days prior to death, or 60 days or less prior to death). For analyses using the PCP dependent variables, we only included patients residing in the CDHA or CBDHA regions, as PCP data were only available in these regions (n=602). Together, these regions contain more than 50 percent of the Nova Scotia population. For analyses using the other two dependent variables, we included all CRC deaths as specified earlier (n=1,201). Additionally, in our examination of the timing of a PCP registration (n=385), we excluded all individuals who died less than 60 days after CRC diagnosis.

The other two dependent variables were related to quality: number of ER visits in the last 30 days of life (0 versus ≥1) (n=1,084); and location of death (out of hospital versus in hospital) (n=1,201). In our examination of ER visits, we excluded all individuals who died less than 30 days after diagnosis to avoid potential bias.

Independent Variables

We included these independent variables based on previous studies: age at death, sex, income, number of comorbidities, location of residence (distance to a palliative care centre, rural or urban), tumour stage at diagnosis, and residency in an LTC facility near death (2–4, 14, 15). For analyses of PCP registration and timing, we also included location of death and ER visits in the last 30 days of life as independent variables, since previous studies have shown these to be important indicators (2, 4).

We created patient income, an ecological variable, using 2001 Canadian census data. Patient postal codes at the time of diagnosis, retrieved from the Nova Scotia Cancer Registry, were linked to a specific dissemination area using the Statistics Canada postal code conversion file and assigned the median household income for that area (15). We measured comorbidities using the Elixhauser Index, which includes 31 possible conditions (16). For this study, we computed an Elixhauser score (0 to 28) representing the sum of all recorded comorbid conditions, excluding cancer, in the two years prior to the date of diagnosis, which we retrieved from the hospital discharge abstracts.

For location of residence, we measured driving distance to the nearest palliative care unit for the access outcomes, and rural-versus-urban residency for the quality outcomes. Using

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Google Maps (17), we measured distance as the driving distance from the patient's area of residence (based on postal code) to the nearest palliative care unit (in the CDHA or CBDHA). The rural/urban variable was derived from Statistical Area Classification and metropolitan influence zones and dichotomized from seven categories (categories 1 to 3, urban; categories 4 to 7, rural) (18). This classification system categorizes census subdivisions based on population size and urban influence.

For the LTC facility variable, if an individual had at least one physician visit at a Nova Scotia-based LTC facility within the last six months of life, we considered that person to be a resident of that facility. Physician-visit location was obtained from the physician billings database. The length-of-survival variable was measured by subtracting the date of death from the date of diagnosis.

Analysis

We ran separate logistic regression models for each of the four dependent variables. All analyses were two-sided, and no multiple-comparison corrections were made. We considered $p < 0.05$ as statistically significant. All analyses were conducted using Stata 11 (StataCorp LP, 2010). The data included all Nova Scotian CRC patients in the specified study period and thus did not require sample weights. Data access was approved by the research ethics boards of the CDHA and Dal-housie University.

RESULTS

Descriptive statistics indicate that almost three-quarters of individuals in the CDHA or CBDHA had access to a PCP. Throughout the province, almost three-quarters had no ER visits in the previous 30 days, and nearly 40 percent died outside of hospital (Table 1). Also notable was the fact that 48 percent of those who died of CRC in Nova Scotia were initially diagnosed with stage IV cancer, 50 percent were 75 years of age or older, and 53 percent were men.

We identified inequalities in access to, and quality of, EOL care for CRC patients in Nova Scotia (Table 2). Although the majority of individuals in the CDHA or CBDHA who died of CRC had access to a PCP, we observed statistically significant inequalities within those health regions. Individuals who were diagnosed with stage II or III tumours, were 85 or older, resided in an LTC facility, lived over 20 kilometres away, and had a shorter survival time had statistically significantly lower odds of accessing a PCP than their counterparts. Among those 85 and older, the odds of accessing a PCP were 68 percent less than they were for those under 65; and among those who resided in an LTC facility, the odds of accessing a PCP were 82 percent less than they were for those who did not reside in such a facility. However, we found that fewer variables (age, LTC facility residency, and location of death) were statistically significantly associated with inequalities in the timing of PCP registration. Interestingly, the odds of registering more than 60 days prior to death among those who resided in LTC facilities were 7.23 (95 percent CI: 1.5–34.8) times greater than they were for those who did not live in such facilities.

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The indicators of poor-quality EOL care for individuals who died of CRC appeared to be most influenced by geographic location of residence. Those living in urban areas of Nova Scotia had 3.18 (95 percent CI: 2.0–5.1) times greater odds of having at least one ER visit during the last 30 days of life, but odds of 0.48 (95 percent CI: 0.3–0.7) for dying in hospital. Additionally, individuals with a median household income of over $45,000 had less chance of dying in hospital, as did those residing in LTC facilities. Patient age and sex were not significantly associated with either indicator of poor-quality EOL care; however, certain trends were noteworthy. As age increased, the odds of have one or more ER visits decreased steadily. Moreover, although not statistically significant, women had odds of 0.70 (95 percent CI: 0.6–1.0) for having one or more ER visits.

Individuals diagnosed with stage II and III CRC were significantly less likely to register in a PCP compared to those diagnosed with stage IV. This finding prompted a stratified analysis (stage I, II, III, and unknown versus stage IV) (Table 3). Notably, among those diagnosed with stages I through III CRC, individuals with an annual income of more than $45,000 had 2.74 times greater odds (95 percent CI: 1.1–6.9) of registering in a PCP than individuals with incomes of under $30,000. Income was not statistically significant among those diagnosed with stage IV CRC, yet older individuals were found to have significantly lower odds of registering in a PCP.

DISCUSSION

Using population-based linked administrative data, this study described access to PCP registration and quality of EOL care for individuals who died of CRC in Nova Scotia. Though others have measured similar access and quality outcomes in their research (13), to our knowledge, this is the first study to explicitly discuss and compare inequality in access to care and quality of EOL care. Our rich data have enabled us to contrast the factors that contribute to inequality in access versus quality of care, as well as identify factors that consistently influence inequality in both access and quality.

This study identified several factors that significantly influenced individual EOL care outcomes, but only geographic location of residence and LTC residency significantly affected both access to PCPs and indicators of EOL care quality. Individuals who resided in an LTC facility were statistically significantly less likely to be registered in a PCP, yet those who did register were more likely to do so early than were individuals who did not reside in an LTC facility. However, we should note that less than 10 percent of the study population resided in LTC facilities, and this may have influenced interpretation.

The impact of geographic location on variations in EOL care is complex. Though the different indicators of geography (distance versus rural/urban) prevent a direct comparison, it is clear that geographic location has an important influence on EOL care. This study reinforces the need for further investigation into variations in EOL care services by geography, particularly investigation into whether variations are acceptable or of social concern. We applied distance as an indicator of geographic location for PCP access because palliative care is a specialized service centred on a palliative care unit; we assessed this

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indicator only for individuals in the CDHA or CBDHA. In contrast, ER visits and location of death are community-based indicators that are distributed throughout the province.

Results of inequality in quality of care based on rural/urban residency are notable and deserve further study. Our analysis suggests that individuals who live in urban areas have statistically significantly greater odds of having at least one ER visit during the last 30 days of life, which is often considered an indicator of poor-quality care due to insufficient community-based EOL care services (9). However, our analysis also indicates that individuals in urban areas have statistically significantly better odds of dying out of hospital, which can be associated with well-planned EOL home care (9). This gives rise to the question of whether the number of ER visits near death and the location of death are depicting quality of care or describing fundamental differences in rural versus urban provision of health care. For example, accessing ER services near death and dying in hospital do not indicate poor care in every circumstance. A patient may prefer to die in hospital, deriving a sense of security from the ongoing medical attention. Or a patient may choose to visit the ER within 30 days of death, as it is often the quickest route to access nurse or physician services. In addition, in certain instances, an increased number of ER visits by urban individuals may not be an indication of poor EOL care but rather an indication of better access to emergency services in urban areas. It is possible that individuals are more likely to access health services if or when such services are available in their area. An example includes the use of ER services to manage acute problems and community- and home-based services to permit a home death (when desired). The findings of higher ER use and higher proportion of out-of-hospital deaths in urban areas clearly require more study to explain how care is currently organized in urban versus rural locations.

Consistent with previous literature (3, 14), we determined that older individuals (85 and over) who died of CRC had a 68 percent lower chance of registering with a PCP than those under 65, even after controlling for all other factors, including survival time after diagnosis, comorbidities, and LTC facility residency. It is unrealistic to expect all individuals who died of cancer to have registered in a PCP, yet it is disconcerting that the proportion that did register decreased considerably with age. Further research should explore the reasons, including whether older individuals are less aware of, or less comfortable with, palliative care, or whether they face increased systemic barriers in accessing these services.

All individuals who died of CRC eventually developed advanced-stage disease (regardless of disease stage at diagnosis), yet those who were initially diagnosed with stage IV had twice the chance of being registered in a PCP compared to those diagnosed with stages I, II, or III disease. It is encouraging that 79.9 percent of CDHA and CBDHA residents diagnosed with stage IV CRC were registered in a PCP, yet there appear to be barriers to accessing a PCP for those diagnosed with stages I, II, or III disease who eventually died of their cancer. The stratified analysis (stages I through III versus stage IV) sheds light on a potential influence of patient income on PCP registration among those diagnosed with stages I through III. Individuals with low incomes who are diagnosed with stages I through III but eventually die of CRC are at higher risk of not registering in a PCP, while income appears to be less influential among those diagnosed with stage IV CRC. A further explanation may be that individuals diagnosed with primary stage IV CRC are more likely to be referred directly for

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a palliative care consultation, whereas those diagnosed with primary stages I through III are typically referred for curative treatment. Therefore, if a stage I through III diagnosis becomes incurable, the health care team and patient must switch from a curative to a palliative focus, which may delay or even prevent PCP registration.

This study is not without limitations. It would have benefitted from data on palliative care services throughout the province and more in-depth data on location of death. We were only able to examine PCP outcomes for individuals residing in the CDHA or CBDHA. While palliative care services are available in other areas of Nova Scotia, data are limited to the two specialized PCPs in these health regions. Additionally, location of death (dying in versus out of hospital) is a crude indicator of the quality of EOL care. While it is widely used as such in the literature, it does not account for variations in patient wishes, differences in hospital characteristics, or availability of services. Nevertheless, at the population level, if a high number of patients are dying in hospital, or if large variations exist across subpopulations, this indicator can serve as a flag to prompt further investigation (8).

Other limitations relate to data availability. The proxy for individual income was the median household income in each patient's neighbourhood. Although using an ecological measure as a proxy for the individual-level measure can create an ecological fallacy (19), this was the best income measure available from the databases. The comorbidities among our study population are likely to have been under-reported. Data on comorbidities came from hospital discharge abstracts in the two years prior to the date of diagnosis. Hospital discharge abstracts capture information on comorbidities that require hospitalization and thus miss information on less severe comorbidities. Such data limitations are likely not unique to Nova Scotia and may contribute to the challenge of measuring and comparing EOL care on a national level (11).

This study demonstrates that there remain significant inequalities in access to, and quality of, EOL care in Nova Scotia. Of primary concern is the variation in access to, and quality of, EOL care by survival time and geographic location, as well as lower rates of PCP access among older individuals (as compared to those under age 65). It may be unrealistic to expect EOL care to be equally distributed throughout the population, as there may be considerable differences in patients' need and preferences for care. However, when variations in access to, and quality of, EOL care exist and are systematically associated with factors that should not guide health care or health service utilization decisions — such as patient age, location of residence, or income — our health system should take note and work to minimize these variations.

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Table 1

Study Population: All Individuals Who Died of Colon or Rectal Cancer

	n	%
Sex		
Men	643	53.5
Women	558	46.5
Age at death		
<65	294	24.5
65–74	299	24.9
75–84	381	31.7
85+	227	18.9
Mean (standard deviation): 72.2 (12.68)		
Year of death		
2001–2002	230	19.3
2003	227	18.9
2004	231	19.2
2005	244	20.3
2006	164	13.7
2007-March 31,2008	164	8.7
Number of comorbidities		
0	654	54.5
1	255	21.2
2+	292	24.3
Stage at diagnosis		
I	49	4.1
II	190	15.8
III	287	23.9
IV	579	48.2
Unknown	96	8.0
Rural/urban		
Rural	485	40.4
Urban	716	59.6
Income ($)		
<30,000	301	25.1
30,000–44,999	552	46.0
45,000+	309	25.7
Missing	39	3.2
Length of survival after diagnosis (days)		

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	n	%
0–99	304	25.3
100–299	262	21.8
300–749	347	28.9
750+	288	24.0
Location of death		
In hospital	753	62.7
Elsewhere	448	37.3
Number of ER visits in the last 30 days of life		
0	922	76.8
1+	279	23.2
Residing in a long-term care facility		
Yes	112	9.3
No	1,089	90.7
Registered in a PCP[a] in CDHA[b] or CBDHA[c,d]		
Yes	443	73.6
No	159	26.4
Registered in a PCP in CDHA or CBDHA >60 days before death[e]		
Yes	214	48.3
No	229	51.7
Distance to the nearest PCP (km)		
0–9.99	317	52.7
10–19.99	156	25.9
20+	129	21.4

[a]Palliative care program.

[b]Capital District Health Authority.

[c]Cape Breton District Health Authority.

[d]Individuals who received care in the CDHA or the CBDHA (n=602).

[e]Individuals who received care in the CDHA and the CBDHA and who registered in a PCP (n=385).

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Table 2

Adjusted Odds Ratios

	Access		Quality	
	Registered with palliative care program OR (95% CI)[a]	**Registered 60 or more days prior to death OR (95% CI)[a]**	**1 + visits OR (95% CI)[a]**	**Died in hospital OR (95% CI)[a]**
Comorbidities				
0	1.00	1.00	1.00	1.00
1	1.01 (0.6–1.8)	1.32 (0.8–2.3)	0.71 (0.5–1.1)	1.12 (0.8–1.6)
2+	0.95 (0.6–1.6)	0.94 (0.5–1.7)	0.94 (0.6–1.4)	1.26 (0.9–1.8)
Stage				
IV	1.00	1.00	1.00	1.00
III	**0.48 (0.3–0.9)[b]**	1.26 (0.7–2.2)	1.15 (0.8–1.7)	1.15 (0.8–1.6)
II	**0.47 (0.3–0.9)**	0.94 (0.5–1.7)	0.71 (0.4–1.2)	1.30 (0.9–1.9)
I	0.47 (0.1–1.5)	1.67 (0.5–6.1)	1.11 (0.8–1.6)	0.54 (0.3–1.1)
Unknown	0.82 (0.4–2.0)	0.95 (0.3–2.7)	0.54 (0.2–1.2)	1.54 (0.9–2.7)
Income				
<30 k	1.00	1.00	1.00	1.00
30,000–44,999	0.68 (0.4–1.2)	1.28 (0.7–2.3)	0.79 (0.6–1.2)	0.90 (0.6–1.3)
>45 k	1.43 (0.8–2.7)	0.86 (0.5–1.6)	0.90 (0.6–1.4)	**0.64 (0.4–0.9)**
Missing	0.50 (0.2–1.7)	1.54 (0.3–7.6)	1.24 (0.5–3.2)	**0.37 (0.2–0.8)**
Age				
<65	1.00	1.00	1.00	1.00
65–74	0.79 (0.4–1.5)	0.88 (0.5–1.5)	0.89 (0.6–1.3)	1.15 (0.8–1.8)
75–84	0.69 (0.4–1.3)	**0.51 (0.3–0.9)**	0.70 (0.5–1.1)	0.85 (0.6–1.2)
85+	**0.32 (0.2–0.7)**	0.51 (0.2–1.2)	0.60 (0.3–1.0)	0.94 (0.6–1.5)
Sex				
Male	1.00	1.00	1.00	1.00
Female	0.85 (0.5–1.3)	1.52 (1.0–2.4)	0.70 (0.6–1.0)	1.19 (0.9–1.6)
Long-term care residency				
No	1.00	1.00	1.00	1.00
Yes	**0.18 (0.1–0.4)**	**7.23 (1.5–34.8)**	0.44 (0.2–1.2)	**0.15 (0.09–0.2)**
Rural/urban				
Rural	–	–	1.00	1.00
Urban	–	–	**3.18 (2.0–5.1)**	**0.48 (0.3–0.7)**
Distance				
0–10 km	1.00	1.00	–	–
10–20 km	0.96 (0.5–1.8)	1.09 (0.6–1.9)	–	–

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	Access		Quality	
	Registered with palliative care program OR (95% CI)[a]	**Registered 60 or more days prior to death OR (95% CI)[a]**	**1 + visits OR (95% CI)[a]**	**Died in hospital OR (95% CI)[a]**
20+ km	**0.26 (0.1–0.4)**	0.86 (0.4–1.7	–	–
ER visits during the last 30 days of life				
0	1.00	1.00	–	1.00
1+	0.68 (0.4–1.2)	0.65 (0.4–1.1)	–	**0.24 (0.2–0.3)**
Location of death				
Out of hospital	1.00	1.00	1.00	–
In hospital	0.62 (0.4–1.1)	**0.57 (0.4–0.9)**	**3.88 (2.7–5.7)**	–
Year of death				
2001–2002	1.00	1.00	1.00	1.00
2003	1.59 (0.8–3.0)	1.42 (0.6–3.0)	0.60 (0.4–1.0)	1.49 (1.0–2.3)
2004	**2.75 (1.4–5.4)**	0.86 (0.4–1.8)	0.58 (0.4–1.0)	1.02 (0.7–1.6)
2005	**2.57 (1.3–5.2)**	0.94 (0.4–2.0)	**0.46 (0.3–0.8)**	1.08 (0.7–1.7)
2006	1.92 (0.9–4.2)	1.18 (0.5–2.7)	**0.46 (0.3–0.8)**	1.20 (0.7–2.0)
2007–2008	2.81 (0.8–9.3)	1.12 (0.4–2.8)	0.64 (0.4–1.2)	0.97 (0.5–1.8)
N	602	385	1084	1201
Pseudo R-squared	0.2180	0.0650	0.1247	0.1415
Log likelihood	−271.791	−247.265	−501.60915	−681.062

[a]OR=odds ratio; CI=confidence interval.

[b]Bold figures indicate statistical significance at p<0.05.

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Table 3

Adjusted Odds Ratios, Stratified by Stage

	Registered in a palliative care program Stage I, II, III	Stage IV
Comorbidities		
0	1.00	1.00
1	0.77 (0.4–1.7)	1.48 (0.6–3.6)
2+	0.90 (0.4–2.0)	1.45 (0.6–3.6)
Stage		
I	1.00	–
II	1.21 (0.4–4.3)	–
III	1.15 (0.3–4.1)	–
Unknown	2.04 (0.5–8.2)	–
Income		
<30 k	1.00	1.00
30,000–44,999	0.89 (0.4–2.0)	0.56 (0.2–1.3)
>45 k	**2.74 (1.1–6.9)**[a]	0.68 (0.3–1.8)
Missing	0.33 (0.6–1.9)	2.45 (0.2–31.3)
Age		
<65	1.00	1.00
65–74	0.72 (0.3–1.9)	0.89 (0.3–2.3)
75–84	1.12 (0.4–2.9)	**0.36 (0.2–0.9)**
85+	0.36 (0.1–1.0)	**0.13 (0.04–0.4)**
Sex		
Male	1.00	1.00
Female	1.01 (0.5–1.9)	0.62 (0.3–1.2)
Long-term care residency		
No	1.00	1.00
Yes	**0.11 (0.04–0.3)**	0.34 (0.08–1.6)
Distance		
0–10 km	1.00	1.00
10–20 km	0.93 (0.4–2.3)	0.92 (0.4–2.3)
20+ km	**0.23 (0.1–0.5)**	**0.21 (0.1–0.5)**
ER visits during the last 30 days of life		
0	1.00	1.00
1+	0.62 (0.3–1.4)	0.75 (0.3–1.7)
Location of death		
Out of hospital	1.00	1.00
In hospital	0.74 (0.4–1.5)	**0.36 (0.2–8)**

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	Registered in a palliative care program Stage I, II, III	Stage IV
N	2.99	2,303
Pseudo R-squared	0.2753	0.1796
Log likelihood	104.16	54.66

[a]Bold figures indicate statistical significance at $p<0.05$.