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Does access to end-of-life homecare nursing differ by province and community size?: A population-based cohort study of cancer decedents across Canada

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ABSTRACT

Background: Studies have demonstrated the strong association between increased end-of-life homecare nursing use and reduced acute care utilization. However, little research has described the utilization patterns of end-of-life homecare nursing and how this differs by region and community size.

Methods: A retrospective population-based cohort study of cancer decedents from Ontario, British Columbia, and Nova Scotia was conducted between 2004 and 2009. Provinces linked administrative databases which provide data about homecare nursing use for the last 6 months of life for each cancer decedent. Among weekly users of homecare nursing in their last six months of life, we describe the proportion of patients receiving end-of-life homecare nursing by province and community size.

Results: Our cohort included 83,746 cancer decedents across 3 provinces. Patients receiving end-of-life nursing among homecare nursing users increased from weeks -26 to -1 before death by: 78% to 93% in British Columbia, 40% to 81% in Ontario, and 52% to 91% in Nova Scotia. In all 3 provinces, the smallest community size had the lowest proportion of patients using end-of-life nursing compared to the second largest community size, which had the highest proportion.

Conclusions: Differences in end-of-life homecare nursing use are much larger between provinces than between community sizes.

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1. Introduction

Cancer patients comprise the majority users of end-of-life homecare services [1-3]. Homecare nursing, in particular, has become an important service because the majority of end-of-life cancer patients state they prefer to die at home [4-6]. End-of-life homecare nursing focuses on managing complex symptoms, such as pain, dyspnea, and delirium, which if left untreated can cause patients to go to the ED and hospital [7]. Policymakers also support end-of-life homecare because of its potential to avoid high acute care costs at end of life. For instance, the last year of life costs 25% of the Medicare budget (over age 65) in the US [8]. For cancer

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patients, hospitalizations represent an estimated 70% of costs in the last year of life [9]. Indeed in most countries most cancer patients die in hospitals [10-13]. This trend is especially true in rural communities, where access to homecare may be more difficult [14–18]. Additionally, hospitalizations and Emergency Department (ED) visits near death and hospital deaths are well accepted indicators of poor quality end-of-life care [19,20]. As a result, policymakers are focusing on improving access to end-of-life homecare nursing.

International research, including systematic reviews, have shown that end-of-life homecare nursing services is strongly associated with patients dying at home, fewer hospitalizations at the end of life, and fewer hospital deaths [21-25]. Canadian research in cancer patients has corroborated these findings using standard definitions across multiple jurisdictions: they demonstrated an association between using more end-of-life homecare nursing with fewer hospital deaths, fewer hospitalizations and emergency

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Fig. 1. Proportion of cancer patients receiving palliative homecare nursing of those receiving.

department (ED) visits at end of life, and including lower health system costs. [22,26–29]. However, this research neither described utilization patterns of end-of-life homecare nursing to determine the proportion of end-of-life cancer patients accessing the efficacious service nor compared variation by province or rurality and community size. Community size is especially important to examine because research has identified challenges for rural patients to access to end-of-life care including distant geography, limited workforce, educational deficits, and higher out-of-pocket costs [14–18]. One US study estimated that 62% to 92% of rural counties did not have access to community hospice providers [17].

Our study specifically examines the utilization patterns of endof-life homecare nursing among cancer decedents in the three Canadian provinces of Ontario (ON), British Columbia (BC) and Nova Scotia (NS), which collectively represent 55% of cancer deaths nationally. We examine utilization patterns by province and by community size. We also compare differences in provincial endof-life homecare health policy. This study complements the robust body of knowledge about the effectiveness of end-of-life homecare nursing to reduce hospital use by describing how many cancer patients are actually using end-of-life homecare nursing services prior to death.

2. Methods

We conducted a retrospective cohort study of cancer patients who received homecare nursing in the Canadian provinces of Ontario (ON), Nova Scotia (NS) and British Columbia (BC). Our inclusion criteria were adult decedents (19 years or older) who had at least one record of homecare nursing following their cancer diagnosis and within six months of their date of death during the study period between April 1, 2004 and March 31, 2009. Due to a time lag in capturing cancer-confirmed cause of death in cancer registries, this was the most recent data available at the time of study inception. To derive our cohort, we used a unique encrypted patient identifier within each province to link with multiple administrative databases: cancer registry for cancer type, cancer diagnosis, and confirmed cause of death from cancer; provincial homecare database for homecare nursing use with standard or end-of-life intent; Canadian Institute for Health Information's Discharge Abstract Database for comorbidity; and the provincial health insurance databases for demographics of age at death, sex, and postal code for both income quintile and community size [30-33]. The community sizes represented in each province are defined by the Canadian Census Metropolitan Area (CMA), from smallest to largest, as a community with a population of: <10 K; 10 K to <100 K; 100 K to <500 K; 500 K to <1.5 M; and >1.5 M.

Homecare nursing intent is recorded in each provincial homecare database. Standard intent nursing is provided to patients with service goals ranging from providing "short-term care" with a predictable recovery (e.g., wound care) to "preserving the client's level of function and autonomy" with a prognosis of very gradual decline (e.g., early onset of frailty) [34]. Whereas end-of-life intent is provided to patients classified as "not responsive to curative treatment and are dying, with service goals being "to alleviate distressing symptoms to achieve the best quality of life by providing complex support in the last stages of their illness, and a typical prognosis of an "expected death within 6 months."34 At each week, the number of patients receiving standard or end-of-life homecare nursing was identified. Nursing visits were measured as time (hours/day) in ON and as nursing visits received in BC and authorized in NS over a month. For each province, we calculated the proportion of patients specifically receiving end-of-life homecare nursing among those who were receiving any homecare nursing at each week. We then described the proportion of patients in each week receiving end-of-life homecare nursing between the different community sizes in each province. We examined the statistical difference at three time points: 26, 13, and 1 week prior to death across all three provinces and across the different community sizes within each province respectively. Statistical significance was defined as a p-value of <0.05 using the Cochrane-Armitage test of significance.

Last, to support interpreting and contextualizing findings, we compared relevant homecare and end-of-life care health policies in the three provinces by conducting a document review of publicly available documents. The study was approved by research ethics boards at McMaster University (ON), Capital Health (NS), and BC Cancer Agency (BC).

3. Results

3.1. Cohort demographics

83,746 cancer decedents met the inclusion criteria in our multiprovince cohort study from 2004 to 2009: 58,787 were from ON, 19,706 from BC, and 5253 from NS (Table 1). Greater than half (56%) of decedents were older than 70. The most common site of diagnosis was lung cancer (26%), with colorectal cancer being the second most prevalent (14%). 17% of patients had one or more comorbidities beyond cancer. ON was the only province with patients residing in all five community sizes, BC had four, and NS had three. All patients included in this study had at least one homecare visit in the last 6 months of life, and among those, end-of-life homecare nursing was ever delivered to 68% of decedents in ON, 89% in BC, and 86% in NS.

3.2. End-of-life homecare provision by week across provinces

Among those patients receiving any homecare nursing at any given week, the proportion using end-of-life homecare nursing increased from weeks -26 to -1 by: 78% to 93% in BC, 40% to 81% in

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