Identifying potential need for cancer palliation in Nova Scotia

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Abstract

Objective: To assess the degree to which Nova Scotia cancer patients who may need palliative care are being referred to the comprehensive Halifax-based Palliative Care Program (PCP).

Methods: The authors conducted a retrospective, population-based study using administrative health data for all adults in Nova Scotia who died of cancer from 1988 to 1994. Proportions and odds ratios (ORs) were used to determine whether there were differences in age, sex, place of residence, cancer cause of death, year of death and use of palliative radiotherapy between those who were referred to the PCP at the Halifax Infirmary and those who were not, and between those who were referred late (within 14 days of death) and those who were referred earlier.

Results: Of the 14,494 adults who died of cancer during the study period, 2,057 (14.2%) were registered in the PCP. Within Halifax County, 1,582 (36.4%) of the 4,340 patients with terminal cancer were seen in the PCP. Predictors of PCP registration were residence in Halifax County (OR 19.2, 95% confidence interval [CI] 15.4–23.9), younger age compared with those 85 years of age or older (for those 20–54 years of age, OR 4.9, 95% CI 3.2–7.6; 55–64 years, OR 3.4, 95% CI 2.2–5.1; 65–74 years, OR 3.1, 95% CI 2.1–4.5; 75–84 years, OR 2.1, 95% CI 1.4–3.1), and having received palliative radiation (OR 1.8, 95% CI 1.5–2.2). PCP referral was associated directly with head and neck cancer (OR 5.4, 95% CI 3.0–9.7) and inversely with hematopoietic (OR 0.2, 95% CI 0.4–0.9), lymph node (OR 0.3, 95% CI 0.1–0.4) and lung (OR 0.6, 95% CI 0.4–0.9) cancer. Predictors of late referral (being referred to the PCP within 14 days of death) were age 65–84 years (OR 1.4, 95% CI 1.1–1.8) and 85 years and over (OR 1.8, 95% CI 1.3–3.0), no palliative radiation (OR 2.0, 95% CI 1.4–3.1) and cancer cause of death. People dying within 6 months of diagnosis were somewhat less likely to have been referred to the PCP (OR 0.8, 95% CI 0.6–0.9), but those who were referred were more likely to have been referred late (OR 2.6, 95% CI 2.0–3.5).

Interpretation: Referral to the PCP and earlier rather than late referral were more likely for younger people with terminal cancer, those who received palliative radiation and those living closer to the PCP. Referral rates also varied by cancer cause of death and the time between diagnosis and death.

Résumé

Objectif : Évaluer dans quelle mesure les patients atteints du cancer qui vivent en Nouvelle-Écosse et peuvent avoir besoin de soins palliatifs sont référés au programme intégré de soins palliatifs (PSP) de Halifax.

Méthode : Les auteurs ont réalisé une étude stratifiée rétrospective en se servant de données administratives de l’état de santé de tous les adultes de la Nouvelle-Écosse qui sont morts du cancer de 1988 à 1994. Ils ont utilisé des proportions et des coefficients de probabilité (CP) pour déterminer s’il y avait des différences liées à l’âge, au sexe, au lieu de résidence, au type de cancer mortel, à l’année de la mort et à l’utilisation de la radiothérapie palliative entre ceux qui ont été référés au PSP du Halifax Infirmary et ceux qui ne l’ont pas été, et entre ceux...
A n increasing number of Canadians are living with progressive, life-threatening illnesses and are potentially in need of palliative care. The aging of the population and thereby a corresponding increase in the number of people being diagnosed with chronic diseases such as cancer will amplify this trend in the years to come. It is estimated that in 1998, 62,700 Canadians will die of cancer and by 2010 this number will have doubled (Dr. Ian McNeil, Department of Actuarial and Statistical Sciences, University of Western Ontario, London, Ont.: personal communication, 1997). There is little population-based information on the burden of care that will result and the challenges that will be placed on the health care system as a result.

High-profile and controversial cases have focused the attention of the Canadian public on end-of-life issues. The Special Senate Committee on Euthanasia and Assisted Suicide noted that the debate surrounding euthanasia could not be adequately addressed without examining the availability of accessible palliative care services across the country. Such services are fragmented, lack coordination and are under-resourced. Although the number of palliative care programs in Canada increased by 23% between 1990 and 1994, many of these are run by volunteers and have few professional resources.

Palliative care is defined by the Canadian Palliative Care Association as “the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from progressive life-threatening illness, or who are bereaved.” Historically, disease-oriented and palliative components of care were sequential elements in the continuum of care. The current working definition describes a potential role for palliative or supportive care at any point in the course of a patient’s illness, with palliation as the total focus of care in the final phase of the disease.

During the period covered by this study, 1988 to 1994, a comprehensive Palliative Care Program (PCP) was based in the Halifax Infirmary (now one component of a newly merged facility, the Queen Elizabeth II Health Sciences Centre). The Halifax Infirmary served the population of Halifax County (338,000 in 1991) as well as patients from other parts of the province, who were occasionally referred for specialized treatment. The PCP offered a 6-bed inpatient unit, in-hospital consultation services, clinic follow-up of ambulatory patients, home consultation services and bereavement support. Home
consultations were provided only to people living within a 25-km radius of the PCP. Referrals to the program came from hospital physicians, including those at the Nova Scotia Cancer Centre, and community physicians. Most of the patients had cancer. The PCP team included physicians, nurses, social workers, pastoral care workers, pharmacists and volunteers. In addition to its primary role as a regional clinic, the program served as an education and research resource for the entire province.

During the study period other palliative care services were scattered throughout Nova Scotia, but more than half of these were staffed solely by volunteers, and none had a dedicated full-time physician. Information from these programs is not part of the administrative database of the PCP.

Some of the patients not referred to the PCP probably would have benefited from additional palliative services; others may have been perfectly well served by the services to which they had access. The study data did not discriminate between these groups.

In this study of adults who died of cancer from 1988 to 1994, we compared those who had been referred to the PCP with those who had not been referred but for whom more comprehensive services might have been appropriate. The findings constitute baseline data that can now be used for program planning and policy development and to develop hypotheses for further investigation.

Methods

Data sources

There is no central database of information on all types of formal and informal palliative care provided to cancer patients in Nova Scotia, although the concept of such a database has been endorsed in the report describing the mandate of Cancer Care Nova Scotia. The 2 databases used for our research were the PCP database and the Nova Scotia Cancer Centre Oncology Patient Information System (OPIS).

The study included all adults who died of cancer from 1988 to 1994 in Nova Scotia, as identified from death-certificate data included in the Nova Scotia Cancer Registry, one component of OPIS. The PCP does not provide care for children with terminal cancer, so this study is limited to people 20 years of age and over.

For each patient, the OPIS database provided first and last names, provincial health card number, date of birth, sex, postal code, date of diagnosis, date of death and cause of death (International Classification of Diseases, 9th revision [ICD-9]) recorded on the death certificate. The PCP database provided first and last names, provincial health card number, date of birth, sex, postal code, ICD-9 diagnoses, date of referral to the PCP and, when available, date of death for all people registered from the time the program opened in 1987 to the end of 1994. Using probabilistic record-linkage methods, we linked OPIS and PCP databases by last and first names, health card number, date of birth, date of death and postal code.

OPIS also contains data on all courses of radiotherapy administered in the province since April 1992. Although there is no universally accepted definition of palliative, as opposed to radical or curative, radiotherapy, there is consensus that 3 markers can be used to characterize radiotherapy as palliative: a short course of treatment (sometimes as short as 1 day), an objective of symptom relief or prevention of disease advancement rather than cure and the expectation of imminent death. There is little agreement on the best course of treatment in specific situations, but that information was not required for this study. For this study, we classified radiotherapy as "certainly palliative" if the patient met all 3 of the following criteria: 5 or fewer fractions of radiation, assignment of palliative rather than curative intent code and receipt of radiation in the last 6 months of life. We classified radiotherapy as "possibly palliative" if the patient met only 1 or 2 of the criteria. Six months of retrospective palliative radiation data were available only for people who died of cancer in 1993 and 1994; such data were not available for those who died between 1988 and 1992, so these patients were excluded from analyses in which palliative radiation was considered.

Analysis

We used 2 measures of palliative care services: referral to the PCP and late referral to the PCP. Late referral was defined as initial registration in the PCP within 14 days of death. Cross-tabulations were used to identify predictors of PCP and time of referral among Halifax County and Nova Scotia residents.

Multiple logistic regression models were used to identify predictors of the need for palliative care among all adults who died of cancer during the study period. The independent variables investigated as predictors of need for palliative care were age, sex, cancer cause of death, the provision of palliative radiation, year of death, time between diagnosis and death, and place of residence (i.e., Halifax County or elsewhere in Nova Scotia). Associations between the predictive variables and the 2 measures of use of palliative care are reported in terms of proportions and odds ratios (ORs).

Results

A total of 2224 people registered in the PCP were resi-
dents of Nova Scotia and died between 1988 and 1994, and for 2057 (92.5%) of these, cancer was given as the cause of death on the death certificate. These people represented 14.2% of the 14,494 adults in Nova Scotia who died of cancer from 1988 to 1994. Of all adults in Nova Scotia who died of cancer, 4,340 (29.9%) were from Halifax County; 1,582 (36.4%) of these were registered in the PCP. These Halifax County residents represented 76.9% of the 2,057 Nova Scotians registered in the PCP (Table 1).

In 1988, the first full year the PCP was in operation, 21% of adults from Halifax County with terminal cancer were seen by the PCP; this proportion rose to just over 40% by 1991 and was still at that level in 1994. Approximately 20% of all those referred to the PCP were referred late; this proportion remained fairly constant from 1988 to 1994.

Of the 1,582 Halifax County residents who were PCP patients, 191 (12.1%) had their first contact with the program within 7 days of death and 137 (8.6%) within 8 to 14 days of death. However, 261 (16.5%) were first seen by the PCP more than 180 days (6 months) before death (Fig. 1). The median period of registration in the PCP was 54 days for both women and men, which indicates that more than half of the people were registered in the PCP for more than 2 months. The mean period of registration was 107 days for women and 124 for men; the mode was 4 days for both women and men.

Among people dying of cancer, rates of referral to the PCP varied by cancer cause of death. In Halifax County, the adults least likely to be referred to the PCP were those with hematopoietic (9 [7.1%]) and lymph node (42 [17.6%]) cancer, and those most likely to be referred had head and neck cancer (71 [61.7%]) (Table 2).

Of adults who were registered in the PCP and who died of cancer in 1993 or 1994 in Nova Scotia, those from Halifax County underwent radiotherapy that was possibly (110 [18.6%]) or certainly (120 [20.3%]) palliative at rates similar to those for people who lived elsewhere in the province (26 [19.3%] and 28 [20.7%] respectively). Of adults not registered in the PCP who died in 1993 or 1994, all rates of palliative radiation were lower; for those from Halifax County, radiotherapy was possibly palliative for 95 (12.7%) and certainly palliative for 91 (12.2%); for those who lived outside the county, the rates were 293 (10.5%) and 245 (8.7%) respectively.

Older people dying of cancer were less likely to be referred to the PCP at all and were more likely to be referred late than were younger people. In all, 499 (20.0%) adults under 65 years were referred to the PCP, but this percentage dropped steadily with age; 99 (5.6%) people 85 years and over were referred to the PCP. Of those 85 years and over referred to the PCP, 27 (27.3%) were referred late, but of those under 65 years of age, 132 (15.5%) were referred late.

By itself, sex was not a predictor of PCP referral. Among people who lived outside Halifax County, men and women 75 years of age or older were equally likely to be referred (OR 1.0) (Table 3); for those 20–74 years, men were more likely to be referred (OR 1.4). Among people who lived in Halifax County, men and women 75 years or older were about equally likely to be referred (for men, OR 1.2); for those 20–74 years old, men were less likely to be referred (OR 0.76). The association among age, sex and place of residence was statistically significant (χ² = 10.4, df = 3, p < 0.05).

The results of multivariate analyses to determine predictors of referral to PCP for adults who died of cancer in 1993 or 1994 in Nova Scotia are reported in Table 4. When other variables are controlled for, predictors of referral to the PCP were residence in Halifax County (OR

Table 1: Place of residence of adults in Nova Scotia who died of cancer from 1988 to 1994

<table>
<thead>
<tr>
<th>Place of residence</th>
<th>Registered in the PCP</th>
<th>Not registered in the PCP</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Halifax County</td>
<td>1,582 (76.9)</td>
<td>2,758 (22.2)</td>
<td>4,340 (29.9)</td>
</tr>
<tr>
<td>Elsewhere in Nova Scotia</td>
<td>475 (23.1)</td>
<td>9,679 (77.8)</td>
<td>10,154 (70.0)</td>
</tr>
<tr>
<td>Total</td>
<td>2,057 (100.0)</td>
<td>12,437 (100.0)</td>
<td>14,494 (100.0)</td>
</tr>
</tbody>
</table>

Note: PCP = Palliative Care Program.

Fig. 1: Number of days from registration in the Halifax Palliative Care Program (PCP) to death for all patients in the program who died of cancer in Halifax County from 1988 to 1994. The median period from registration to death was 54 days (solid line), and the proportion of people who registered in the PCP within 14 days of death was 20.9% (dashed line).
19.2), radiotherapy that was possibly or certainly palliative (OR 1.8), age (for those 20–54 years old, OR 4.9; 55–64 years, OR 3.4; 65–74 years, OR 3.1; 75–84 years, OR 2.1), head and neck cancer as the cause of death (OR 5.4) and survival for less than 6 months after diagnosis (OR 0.8).

Referral to the PCP was less likely for adults with hematopoietic (OR 0.2), lymph node (OR 0.3) and lung (OR 0.6) cancer relative to adults with cancer at all other sites combined. The lower PCP referral rates for people with lung cancer only became evident when referral patterns for palliative radiation, place of residence and age were taken into account.

In predictions of PCP use, we observed an association between residence in Halifax County and palliative radiation, but this association was not statistically significant. Interaction terms are not included in the multiple logistic regression models reported in Table 4. The models were run with and without interaction terms, and the differences in the ORs were negligible.

Predictors of late referral to the PCP (registration...
within 14 days of death) were older age (65–84 years, OR 1.4; 85 years or more, OR 1.8), survival for less than 6 months after diagnosis (OR 2.6), and residence in Halifax County (OR 1.3) (Table 5). Receiving radiotherapy that was certainly or possibly palliative was a predictor of earlier referral (OR 2.0, 95% CI 1.4–3.1) when the multivariate analysis was repeated with only 1993 and 1994 data. Cause of death listed on the death certificate was also a predictor of time of referral to the PCP in this multivariate analysis (χ² = 30, df = 19, p = 0.05). In a univariate analysis, the people most likely to have been referred late were those with cancer of the lymph nodes, the liver or

<table>
<thead>
<tr>
<th>Predictor</th>
<th>No. of late referrals*</th>
<th>Univariate odds ratio†</th>
<th>Multivariate odds ratio‡ (and 95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Place of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Halifax County</td>
<td>325</td>
<td>1.4</td>
<td>1.1 (1.0–1.8)</td>
</tr>
<tr>
<td>Elsewhere in Nova Scotia</td>
<td>73</td>
<td>1.0</td>
<td>1.0 (–)</td>
</tr>
<tr>
<td>Age group, yr</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20–64</td>
<td>132</td>
<td>1.0</td>
<td>1.0 (–)</td>
</tr>
<tr>
<td>65–84</td>
<td>239</td>
<td>1.5</td>
<td>1.4 (1.1–1.8)</td>
</tr>
<tr>
<td>≥ 85</td>
<td>27</td>
<td>2.0</td>
<td>1.8 (1.1–3.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>181</td>
<td>1.0</td>
<td>0.9 (0.8–1.1)</td>
</tr>
<tr>
<td>Male</td>
<td>217</td>
<td>1.0</td>
<td>1.0 (–)</td>
</tr>
<tr>
<td>Time from diagnosis to death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 6 months</td>
<td>213</td>
<td>2.5</td>
<td>2.6 (2.0–3.5)</td>
</tr>
<tr>
<td>6 to 12 months</td>
<td>56</td>
<td>1.2</td>
<td>1.1 (0.8–1.5)</td>
</tr>
<tr>
<td>≥ 12 months</td>
<td>129</td>
<td>1.0</td>
<td>1.0 (–)</td>
</tr>
</tbody>
</table>

*Not controlled for other predictors.
†Controlled for all other predictors.
gallbladder (or both), or the female genitals, or cancer of unknown or undefined origin. Those least likely to have been referred late had cancer of the bone, the stomach, the male genitals and the head and neck.

**Interpretation**

Over time there was an increase in the proportion of patients with terminal cancer using PCP services, but this proportion has leveled off at approximately 40% of adults with terminal cancer in Halifax County. It may be that this rate has not continued to climb because there is a limit to the number of people who need such comprehensive palliative care, the level of funding may have limited the capacity of the program, the value of palliative care may not be adequately recognized, and some patients may have chosen not to take advantage of the program. As well, those not registered in the PCP may have had their needs met by their primary caregivers and local services. The fact that people living in Halifax County were more likely to be registered in the PCP was expected, but if our analysis had been limited to residents of this county, information about people from elsewhere who had been referred to the program would have been lost.

The findings of this study are in line with those of a similar analysis conducted in South Australia, where 56% of people with terminal cancer received hospice services. Patients there were less likely to be referred if they were over 80 years old, lived in rural areas, died within 6 months of diagnosis or had a hematological malignancy.

Palliative care clinicians have known for many years about the variability in time of referral. As Allard and colleagues noted, “this estimation is a crucial step in determining the most appropriate clinical management strategy to alleviate suffering.” Although there is no consensus on the minimum period before death during which palliative care should be provided or on the factors that should be taken into account when considering a referral, 1 to 2 weeks before death is likely insufficient to provide optimal service. Delays in diagnosis, delays in referring a patient to a comprehensive palliative care program and delays on the part of the patient consenting to the referral may all contribute to a late referral.

The differences in opinion on the appropriate time for referral to palliative care are exemplified by the study data. It is clear that spending 4 days in the PCP (the mode) allows time for crisis intervention only. Half of those registered in the PCP received less than 55 days and half received 55 days or more of palliative care. The fact that the mean was more than 100 days reflects the number of people who were registered in the PCP for more than a year. This may mean that some people are being referred too early to the PCP, putting them at risk of having no committed care provider after their cancer has become unresponsive to curative therapies but before death is imminent.

The dividing line between treatment provided as curative therapy and that given for palliation may be difficult to draw. For example, is therapy palliative when a course of radiation for a person with lung cancer is extended to make breathing easier? The term “tertiary prevention” is used by epidemiologists to describe therapies that prevent the progression of disease and deterioration of a patient’s condition, such as radiation treatment given to improve a person’s quality of life by treating local disease that is producing symptoms. However, clinicians who provide active or palliative treatment do not use this term to describe care that is neither curative nor “end-of-life” but relieves symptoms and thus improves quality of life. Our study demonstrates the need for care after “curative” treatments have proven unsuccessful but before the patient’s disease becomes terminal.

The variability in referral rates by tumour site may indicate that people with certain types of cancer have greater palliative needs (e.g., those with cancers more likely to cause pain). The undertreatment of cancer pain is known to occur, and the treatment of pain is known to differ among patients and physicians. Institutional or clinical guidelines may influence referral patterns. For example, manuals containing clinical guidelines recommend nutritional support for patients with advanced head and neck cancer; if such care is viewed as the responsibility of a comprehensive palliative care program, higher-than-average referral rates of people with this form of cancer would be expected. However, Talmi and colleagues found that differences in referral patterns for people dying of head and neck cancer were the result of physician and patient preferences rather than a predetermined level of care. Before the Queen Elizabeth II Health Sciences Centre was established in 1995, the ear, nose and throat surgery unit was near the PCP unit; this may have led to higher referral rates for people with head and neck cancer.

There is evidence in the data that elderly patients may be underserved by the program, perhaps because their palliative needs are different from those of younger patients. For example, comorbidity increases with age and may influence which treatment options are recommended. Alternatively, elderly people may simply make different decisions about the care they wish to receive.

Among adults in Halifax County, the interaction between age and sex in determining referral rates indicates the need for further investigation of the hypothesis of Talmi and colleagues, that younger “wives were more supportive and better able to provide a home care environment for their disabled spouses than husbands . . . [and] due to the longer survival of women, fewer husbands were alive to provide care” in the older age groups.
Allard and colleagues13 provided more support for this hypothesis with their observation that married people were referred later. The fact that the data for Nova Scotians residing outside Halifax County do not support this hypothesis should be investigated further using information about local acute-care hospital and nursing home admissions and local palliative care services.

Receiving palliative radiation was a predictor of referral to the program, particularly for people living outside Halifax County. Such referrals may be influenced by the needs of these patients or may relate to subsequent referrals to either the PCP or for palliative radiation after an initial referral to the other service. Recently, Langley and colleagues12 studied the referral patterns of Nova Scotia family physicians and found that referrals were influenced by style of practice, geographic location and the relationships between the family physician and consultants.

Although the cost of providing comprehensive palliative care for all people with terminal cancer would be significant, the alternatives are probably at least as expensive, if not more so. In 1990 O’Brien20 reviewed deaths in Nova Scotia from colorectal cancer occurring 2 to 2.5 years after original diagnosis. He estimated that the per capita cost of keeping these patients in hospital for the last 6 months of their lives was about $13 500. For people who were still alive 3 years after diagnosis, the average hospital costs incurred for 6 months of care given between 24 and 36 months after diagnosis was approximately $1000. For all people in the province of the same age and sex, the average per capita cost of inpatient hospital care for a 6-month period was close to $650. The 6-month period before death has been used to denote the period when palliative care is needed.21,22 If the cost for the last 6 months of life for patients with colorectal cancer is typical of patients with other cancers, in 1998 Nova Scotia will pay at least $30 million ($13 500 – $1000) x 2450 cancer deaths23 for inpatient hospital care for people with terminal cancer. What needs to be determined is whether these dollars are distributed equitably and cost effectively among all people dying of cancer who require palliative care.

In this study we analysed data about patients who were referred to the PCP from 1988 to 1994, providing a baseline from which to study future trends in service delivery and identify areas that need further study. Linking existing administrative databases provides a way to evaluate the components of service delivery and enhance program planning and policy development.

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References


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