Identifying potential need for cancer palliation in Nova Scotia

Grace M. Johnston,*† MHSA, PhD; Laurie Gibbons,‡ MSc; Frederick I. Burge,§ MD, MSc; Ron A. Dewar,† MSc; Ina Cummings,|| MD; Isra G. Levy,‡ MB, BCh, MSc

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, 2057 (14.2%) were registered in the PCP. Within Halifax County, 1582 (36.4%) of the 4340 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% Cl 2.2–5.1; 65–74 years, OR 3.1, 95% Cl 2.1–4.5; 75–84 years, OR 2.1, 95% Cl 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 1.1–3.0), 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 sur 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



Evidence

Études

From *the School of Health Services Administration, Dalhousie University, Halifax, NS; †the Nova Scotia Cancer Registry, Queen Elizabeth II Health Sciences Centre, Halifax, NS; ‡the Cancer Bureau, Laboratory Centre for Disease Control, Ottawa, Ont.; §the Department of Family Medicine, Dalhousie University, Halifax, NS; and ||the Palliative Care Program, Queen Elizabeth II Health Sciences Centre, Halifax, NS

This article has been peer reviewed.

CMAJ 1998;158:1691-8



qui ont été référés tard (dans les 14 jours précédant le décès) et ceux qui l'ont été plus tôt.

Résultats : Sur les 14 494 adultes qui sont morts du cancer pendant la période à l'étude, 2057 (14,2 %) étaient inscrits au PSP. Dans le comté de Halifax, le PSP a accueilli 1582 (36,4 %) des 4340 patients qui avaient un cancer en phase terminale. Les prédicteurs de l'inscription au PSP étaient la résidence dans le comté de Halifax (CP de 19,2; intervalle de confiance [IC] à 95 %, de 15,4 à 23,9), chez les 84 ans ou moins, l'âge moins avancé (chez les 20 à 54 ans, CP de 4,9; IC à 95 %, de 3,2 à 7,6; chez les 55 à 64 ans, CP de 3,4; IC à 95 %, de 2,2 à 5,1; chez les 65 à 74 ans, CP de 3,1; IC à 95 %, de 2,1 à 4,5; chez les 75 à 84 ans, CP de 2,1; IC à 95 %, de 1,4 à 3,1) et la radiothérapie palliative reçue (CP de 1,8; IC à 95 %, de 1,5 à 2,2). On a établi un lien direct entre la présentation au PSP et un cancer à la tête ou au cou (CP de 5,4; IC à 95 %, de 3,0 à 9,7) et un lien inverse avec les cancers liés à l'hématopoïèse (CP de 0,2; IC à 95 %, de 0,4 à 0,9), des ganglions lymphatiques (CP de 0,3; IC à 95 %, de 0,1 à 0,4) et du poumon (CP de 0,6; IC à 95 % de 0,4 à 0,9). Les prédicteurs d'une présentation tardive (patients qui ont été référés au PSP dans les 14 jours précédant le décès) étaient l'âge de 65 à 84 ans (CP de 1,4; IC à 95 %, de 1,1 à 1,8) et l'âge qui dépassait 85 ans (CP de 1,8; IC à 95 %, de 1,1 à 3,0), l'absence de radiothérapie palliative (CP de 2,0; IC à 95 %, de 1,4 à 3,1) et le type de cancer mortel. Il y avait un peu moins de chances que les personnes qui sont mortes dans les 6 mois suivant le diagnostic aient été référées au PSP (CP de 0,8; IC à 95 %, de 0,6 à 0,9), mais celles qui l'ont été étaient plus susceptibles de l'avoir été tardivement (CP de 2,6; IC à 95 %, de 2,0 à 3,5).

Interprétation : Les personnes plus jeunes qui avaient un cancer en phase terminale, celles qui ont reçu de la radiothérapie palliative et celles qui vivaient plus près du PSP avaient plus de chances d'être référées au PSP et de l'être plus tôt que tard. Les taux de présentation ont aussi varié selon le type de cancer mortel et la période écoulée entre le diagnostic et la mort.

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 cancer¹ and that 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 result² 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 often 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.⁵

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.⁸ 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 revision⁹ [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,10 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, 4340 (29.9%) were from Halifax County; 1582 (36.4%) of these were registered in the PCP. These Halifax County residents represented 76.9% of the 2057 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 1582 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, 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

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

	No. (and %) of patients		
Place of residence	Registered in the PCP	Not registered in the PCP	Total
Halifax County	1 582 (76.9)	2 758 (22.2)	4 340 (29.9)
Elsewhere in Nova Scotia	475 (23.1)	9 679 (77.8)	10 154 (70.0)
Total	2 057 (100.0)	12 437 (100.0)	14 494 (100.0)

Note: PCP = Palliative Care Program.

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 ($\chi^2 = 10.4$, 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

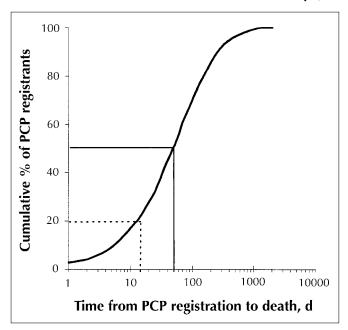


Fig. 1: Number of days from registration in the Halifax Palliative Care Program (PCP) to death for all patients in the program who died of cancer in Halifax County from 1988 to 1994. The median period from registration to death was 54 days (solid line), and the proportion of people who registered in 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 pat-

terns 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

Table 2: Site of cancer causing death* for the adults from Halifax County who died from 1988 to 1994

Cancer cause of death	ICD-9 codet	No. of patients (and %)	No. registered in PCP (and %)
Bone marrow (hematopoietic)‡	203-208	127 (2.9)	9 (7.1)
Lymph node§	200-202	238 (5.5)	42 (17.6)
Esophagus	150	74 (1.7)	20 (27.0)
Brain, spinal cord	191-192	102 (2.4)	33 (32.4)
Female genitalia	179-184	167 (3.8)	54 (32.3)
Thyroid, endocrine glands	193-194	9 (0.2)	3 (33.3)
Bladder	188	101 (2.3)	35 (34.6)
Peritoneum	158-159	158 (3.6)	55 (34.8)
Unknown or undefined	195, 199	367 (8.4)	128 (34.9)
Breast	174, 175	412 (9.5)	149 (36.2)
Male genitalia	185-187	260 (6.0)	95 (36.5)
Stomach	151	166 (3.8)	62 (37.3)
Liver, gallbladder	155, 156	89 (2.0)	34 (38.2)
Lung, mediastinum	162-165	1172 (27.0)	462 (39.4)
Colon, rectum, bowel	152-154	418 (9.6)	168 (40.2)
Melanoma of skin	172	52 (1.2)	21 (40.4)
Pancreas	157	179 (4.1)	76 (42.4)
Bone	170-171	29 (0.7)	13 (44.8)
Kidney	189	105 (2.4)	52 (49.5)
Head and neck	140-149, 160- 161, 190	115 (2.6)	71 (61.7)

^{*}As reported on death certificate.

||Lip, tongue, mouth, pharynx, tonsil, larynx, sinus, eye.

Table 3: Multivariate analysis of effects of place of residence, age and sex on referral to PCP of patients with terminal cancer who died in Nova Scotia in 1993 and 1994

			No. o		
Place of residence	Age group, yr	Sex	Registered in PCP	Not registered in PCP	Odds ratio (and 95% CI)
Halifax County	20–74	М	215	242	0.76 (0.6–1.0)
		F	194	166	1.00 (–)
	≥ 75	M	93	159	1.2 (0.8–1.7)
		F	89	179	1.00 (–)
Elsewhere in Nova Scotia	20–74	M	70	850	1.4 (0.9–2.0)
		F	38	659	1.00 (–)
	≥75	M	15	717	1.00 (0.5–1.8)
		F	12	579	1.00 (–)

Note: CI = confidence interval

[†]International Classification of Diseases, 9th revision.9

[‡]Multiple myeloma, leukemia.

[§]Hodgkin's disease, non-Hodgkin's lymphoma.



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 ($\chi^2 = 30$, 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

Predictor	No. registered in PCP	Univariate odds ratio*	Multivariate odds ratio† (and 95% CI)		
Place of residence					
Halifax County	591	16.5	19.2	(15.4–23.9)	
Elsewhere in Nova Scotia	135	1.0	1.0	(–)	
Received palliative radiation					
Certain or possible	284	2.5	1.8	(1.5-2.2)	
No	442	1.0	1.0	(–)	
Age group, yr					
20–54	129	4.5	4.9	(3.2-7.6)	
55-64	146	3.4	3.4	(2.2-5.1)	
65–74	242	2.7	3.1	(2.1-4.5)	
75–84	165	1.8	2.1	(1.4-3.1)	
≥ 85	44	1.0	1.0	(-)	
Sex					
Female	333	1.1	1.0	(0.8-1.2)	
Male	393	1.0	1.0	(-)	
Time from diagnosis to death					
< 6 months	272	0.7	0.8	(0.6-0.9)	
6 to 12 months	130	1.1	1.1	(0.8-1.5)	
> 12 months	324	1.0	1.0	(-)	
Cancer cause of death					
Head and neck	44	3.3	5.4	(3.0-9.7)	
Bone marrow (hematopoietic)	6	0.2	0.2	(0.4-0.9)	
Lymph nodes	27	0.6	0.3	(0.1-0.4)	
Lung	205	1.1	0.6	(0.4-0.9)	
Other	444	1.0	1.0	(–)	

^{*}Not controlled for other predictors. +Controlled for all other predictors.

Table 5: Multivariate analysis of predictors of late referral to PCP, 1988–1994				
Predictor	No. of late referrals*	Univariate odds ratio†	Multivariate odds ratio‡ (and 95% CI)	
Place of residence				
Halifax County	325	1.4	1.3 (1.0–1.8)	
Elsewhere in Nova Scotia	73	1.0	1.0 (-)	
Age group, yr				
20–64	132	1.0	1.0 (-)	
65–84	239	1.5	1.4 (1.1–1.8)	
≥ 85	27	2.0	1.8 (1.1–3.0)	
Sex				
Female	181	1.0	0.9 (0.7-1.2)	
Male	217	1.0	1.0 (-)	
Time from diagnosis to death				
< 6 months	213	2.5	2.6 (2.0-3.5)	
6 to 12 months	56	1.2	1.1 (0.8–1.5)	
> 12 months	129	1.0	1.0 (–)	

^{*}Referred to PCP within 14 days of death. †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,11 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 colleagues¹³ 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 com-

mitted 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,¹⁴ 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,15 and the treatment of pain is known to differ among patients and physicians.¹⁶ 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;¹⁷ if such care is viewed as the responsibility of a comprehensive palliative care program, higher-thanaverage referral rates of people with this form of cancer would be expected. However, Talmi and colleagues¹⁸ 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, ¹⁸ that younger "wives were more supportive and better able to provide a home care environment for their disabled spouses than husbands were . . . [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 colleagues¹⁹ 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 $[(\$13500 - \$1000) \times 2450 \text{ cancer deaths}^{1}]$ 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.

Support for this work was provided by the Laboratory Centre for Disease Control of Health Canada, Ottawa, the Queen Elizabeth II Health Sciences Centre, Halifax, and Dalhousie University, Halifax.

References

- National Cancer Institute of Canada. Canadian cancer statistics 1998. Toronto: The Institute; 1998.
- Burge F. The epidemiology of palliative care in cancer. J Palliat Care 1992; 8(1):18-23.
- Special Senate Committee on Euthanasia and Assisted Suicide. Of life and death. Ottawa: Minister of Supply and Services; 1995.
- 4. Lynn J. Caring at the end of life. N Engl J Med 1996;335(3):201-2.
- Canadian Palliative Care Association. Canadian directory of services palliative care and HIV/AIDS. Ottawa: The Association; 1996.
- Canadian Palliative Care Association. Palliative care: towards a consensus in standardized principles of practice. Ottawa: The Association; 1995.
- Saunders CM, editor. The management of terminal disease. London (UK): Edward Arnold; 1978.
- 8. Response to Cancer Care Nova Scotia: a plan for action. Halifax: Nova Scotia Department of Health; 1996.
- World Health Organization. Manual of the international statistical classification of diseases, injuries and causes of death, 9th rev, vol. 1. Geneva: The Organization; 1977.
- Kirkbride P. The role of radiation therapy in palliative care. J Palliat Care 1995;11(1):19-26.
- 11. "We die badly in Canada," Montreal expert says. CMAJ 1997;156(1):72.
- Hunt R, McCaul K. A population-based study of the coverage of cancer patients by hospice services. *Palliat Med* 1996;10:5-12.
- Allard P, Donne A, Potvin D. Factors associated with length of survival among 1801 terminally ill cancer patients. J Palliat Care 1995;11(3):20-4.
- Mausner JS, Kramer S. Epidemiology an introductory text. Philadelphia: WB Saunders; 1985. p. 12.
- Jacox A, Carr DB, Payne R, et al. Management of cancer pain: adults quick reference guide, no 9. AHCPR publ no 94-0593. Rockville (MD): Agency for Health Care Policy and Research, US Department of Health and Human Services; 1994.
- Cleeland CS, Gonin R, Hatfield AK, Edmonson JH, Blum RH, Stewart JA, et al. Pain and its treatment in outpatients with metastatic cancer. N Engl J Med 1994;330(9):592-6.
- Canadian Committee on Cancer Staging, Sub-Committee of the Advisory Committee on Cancer Control. Report and recommendations of the leadership consultation on cancer staging in Canada. Toronto: National Cancer Institute of Canada; 1997. p. 10.
- Talmi YP, Bercovici M, Waller A, Horowitz Z, Adunski Z, Kronenberg J. Home and inpatient hospice care of terminal head and neck cancer patients. 7 Palliat Care 1997;13(1):9-14.
- Langley GR, Minkin S, Till JE. Regional variation in nonmedical factors affecting family physicians' decisions about referral for consultation. CMAJ 1997;157(3):265-72.
- O'Brien B. Estimation of the first three years of hospital costs for colorectal cancer cases diagnosed in Nova Scotia in 1990 [dissertation]. Halifax: Dalhousie University; 1996.
- Reilly GF, Potosky AL, Lubitz JD, Kessler LG. Medicare payments from diagnosis to death for elderly cancer patients by stage at diagnosis. *Med Care* 1995;33(8):828-41.
- Christakis NA, Escarce JJ. Survival of Medicare patients after enrollment in hospice programs. N Engl J Med 1996;335(3):172-8.

Reprint requests to: Dr. Grace M. Johnston, School of Health Services Administration, Dalhousie University, 5599 Fenwick St., Halifax NS B3H 1R2; fax 902 494-6849; grace.johnston@dal.ca