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*This article has been peer reviewed.*

CMAJ 1999;161:290-3

# Edmonton Regional Palliative Care Program: impact on patterns of terminal cancer care

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## Abstract

THE EDMONTON REGIONAL PALLIATIVE CARE PROGRAM was established in July 1995 to measure the access of patients with terminal cancer to palliative care services, decrease the number of cancer-related deaths in acute care facilities and increase the participation of family physicians in the care of terminally ill patients. In this retrospective study the authors compared the pattern of care and site of deaths before establishment of the program (1992/93) and during its second year of operation (1996/97). Significantly more cancer-related deaths occurred in acute care facilities in 1992/93 than in 1996/97 (86% [1119/1304] v. 49% [633/1279]) ( $p \leq 0.001$ ). The number of inpatient days decreased, from 24 566 in 1992/93 to 6960 in 1996/97. More cancer patients saw a palliative care consult team in 1996/97 than in 1992/93 (82% v. 22%). The shift from deaths in acute care facilities to palliative hospices suggests that the establishment of an integrated palliative care program has increased access of patients with terminal cancer to palliative care.

In Edmonton and other Canadian cities the limited integration of community-based physicians and nurses, continuing care facilities, acute care hospitals, cancer centres and palliative care specialists has become a major obstacle to patients seeking access to palliative care in the most suitable setting. Most cancer patients die in acute care facilities after medium to long-term stays.<sup>1-3</sup> The resulting increased cost and inappropriate care occurs because staff in these institutions are not trained in the management of the physical and psychosocial complications of terminal cancer.<sup>4-11</sup> One of the perceived reasons why patients die in acute care facilities in Edmonton is the limited involvement of family physicians in their care. In the Edmonton region in 1992/93, only 25% of family physicians had hospital admitting privileges, whereas more than 80% of cancer-related deaths occurred in these institutions after an average stay of about 1 month. Therefore, most of these admissions took place under the care of a specialist.

The Edmonton Regional Palliative Care Program was established in July 1995 to increase the access of patients with terminal cancer to palliative care services, decrease the number of cancer-related deaths in acute care facilities, increase the participation of family physicians in the care of terminally ill patients, and provide these physicians with adequate support.<sup>12</sup>

We compared the patterns of utilization of health care services and access to palliative care by patients before the establishment of the program (1992/93) and during its second year of operation (1996/97).

## The Edmonton Regional Palliative Care Program

The program consists of previously existing and newly established or upgraded elements (Fig. 1). Previously existing elements include a 14-bed tertiary palliative care unit and a weekly tertiary multidisciplinary palliative care clinic in the local cancer centre. These 2 components were maintained at the same level of funding.

Five new elements were added to the program. A palliative hospice (palliative



continuing care unit) was set up in 3 continuing care hospitals, providing a total of 56 beds. Four full-time salaried teams, consisting of a consultant palliative care physician and nurse, provide consultations for palliative care patients at home, in the 3 hospices, in the region's 3 community hospitals and in the continuing care facilities. Funding to the Regional Home Care Program was increased for the delivery of 24-hour palliative care at home. Another team (consultant palliative care physician and nurse) was added to the existing team to serve patients in the region's 2 tertiary care hospitals. Finally, a registry of family physicians willing to deliver palliative care to new patients was begun and widely publicized among the city's family physicians. In addition, an increased fee for the delivery of palliative care at home or in hospice was established for family physicians.

Symptom assessment tools were developed, including the Edmonton Symptom Assessment System,<sup>13</sup> the Mini Mental State Questionnaire,<sup>14</sup> the CAGE questionnaire,<sup>15</sup> the Edmonton Functional Assessment Test<sup>16</sup> and the Edmonton Staging System for cancer pain.<sup>17,18</sup> These tools, as

well as a unified system for recording medical history and medication, were used to ensure simple transfer of patients among the various care settings. In addition, a common protocol was used in all settings for the management of various physical and psychosocial symptoms.<sup>19</sup>

All physicians licensed in the region were notified by mail about the program and the procedure for consultations, a monthly update on the management of specific symptoms was mailed with a reminder about the consultation procedure, and a description of the program was presented during medical rounds at the cancer centre and all family medicine programs and was posted on the University of Alberta's family medicine home page ([www.palliative.org](http://www.palliative.org)).

### Impact on cancer care and mortality patterns

A total of 1304 patients died of cancer in the Edmonton region in 1992/93 and 1279 in 1996/97 (Table 1). The number and location of cancer-related deaths in acute care facilities (tertiary care hospitals, community hospitals and

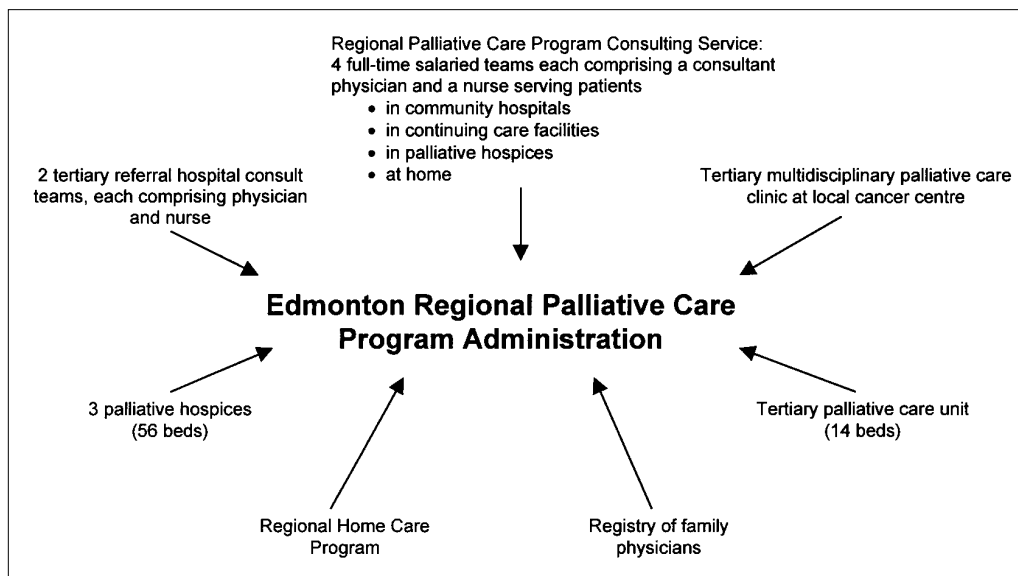


Fig. 1: Model for the Edmonton Regional Palliative Care Program, established in July 1995.

Table 1: Distribution of cancer-related deaths by location in the Edmonton region from 1992/93 (before establishment of the Edmonton Regional Palliative Care Program in 1995) to 1996/97 (the program's second year of operation)\*

Location	Year; no. (and %) of cancer-related deaths					p value†
	1992/93 n = 1304	1993/94 n = 1281	1994/95 n = 1240	1995/96 n = 1342	1996/97 n = 1279	
Acute care facility‡	1119 (86)	1062 (83)	877 (71)	671 (50)	633 (49)	< 0.001
Palliative hospice	0	0	0	244 (18)	378 (30)	< 0.001
Continuing care centre§	53 (4)	63 (5)	96 (8)	143 (11)	38 (3)	0.10
Home	126 (10)	152 (12)	259 (21)	279 (21)	227 (18)	< 0.001
Other	6 (0.5)	4 (0.3)	8 (1)	5 (0.4)	3 (0.2)	0.48

\*Data are from the Alberta Cancer Registry, except for palliative hospice data, which come from the Edmonton Regional Palliative Care Program Registry. The Alberta Cancer Registry data are provisional because some deaths may have been registered in subsequent years.

†From  $\chi^2$  analysis.

‡Includes acute care hospitals, the local cancer centre and the tertiary palliative care unit.

§Includes continuing care facilities, nursing homes and auxiliary hospitals.



the cancer centre), palliative hospices, continuing facilities (including regular continuing care facilities, auxiliary hospitals and nursing homes) and at home are summarized in Table 1. There was a significant shift in location from acute care facilities to continuing care facilities and home over that period. Post hoc comparisons showed that, between 1992/93 and 1994/95, there was a small decrease in the number of deaths in acute care hospitals accompanied by an increase in deaths at home ( $p < 0.001$ ,  $\chi^2$  analysis).

The number of deaths and lengths of stay in acute care hospitals and the cancer centre decreased significantly between 1992/93 and 1996/97 (Table 2). They did not change over time in the tertiary palliative care unit.

In 1992/93, 22% of cancer patients (290/1341) had consulted a palliative care team, as compared with 84% (1110/1326) in 1996/97 ( $p < 0.001$ ). In 1996/97, 372 physicians consulted the program for joint care of specific patients. Of these, 287 (77%) were family physicians, representing 35% of the 816 family physicians registered in the Edmonton region.

A subset of 268 consecutive patients with terminal cancer who were discharged from the cancer centre were asked whether they wanted to remain under the care of their family physician or wished to change, or whether they had no designated family physician. Most (240 [89%]) wanted to remain under the care of their family physician. The remaining 28 expressed a need for a new family physician; in all cases, an alternative physician was identified within 24 hours from the list of 150 family physicians who were willing to take charge of new patients.

## Interpretation

We found a significant shift in deaths from hospital to palliative hospice and home care settings since the introduction of the Edmonton Regional Palliative Care Program as well as a significant decrease in average length of stay in both acute care facilities and the cancer centre. Although we reported only patients' last stay in these facilities before death, it is unlikely that a decrease in this time (in our experience, the longest stay) after the inception of the

program would be offset by an increase in the duration of earlier stays. It is our impression that increased access to palliative care and improved planning of care have resulted in a decrease in total inpatient bed use. However, our patient data systems were not able to test this hypothesis, and further studies are required to measure the overall utilization of acute care beds.

There was a significant discrepancy in the number of cancer-related deaths reported by the Alberta Cancer Registry and the Capital Health Authority for both 1992/93 and 1996/97. According to the latter, the total number of deaths in acute care hospitals was 955 in 1992/93 and 498 in 1996/97 (Table 2), as compared with 1119 and 633, respectively, reported by the Alberta Cancer Registry (Table 1). This discrepancy is probably due in large part to different definitions of cause of death. However, data from both sources confirm a large and significant shift in the number of deaths from acute care facilities to palliative hospices and home.

The main uncertainty regarding this program was the level of interest on the part of family physicians and their willingness to cooperate with the program's consultants. We found that 287 (35%) of the family physicians in the Edmonton region consulted the program regarding their own patients during 1996/97, and more than 550 have consulted the program since July 1995. Family physician involvement in palliative care is likely higher than reported here because some physicians may be delivering care to their patients without consulting the program. These findings suggest that palliative care programs in which primary care is delivered by palliative care specialists may not be necessary as long as adequate reimbursement, education, consultant support and access to beds are available to family physicians.

The main disadvantage of programs in which primary care is delivered by full-time palliative care specialists is that they do not promote education on palliative care delivery among family physicians, thereby fostering dependency and reducing the likelihood that family physicians will apply this knowledge earlier in the course of illness or to patients with diseases other than cancer. In addition, these programs make it necessary for patients and their families to establish a new relationship with a different treating physician, and they may delay and decrease the rate of referrals by primary practitioners or specialists who want to remain the treating physician.<sup>20</sup>

On the other hand, the main limitation of a palliative care program in which primary care is delivered by family physicians is the limited exposure of family physicians to palliative care patients: during 1996/97, 1279 cancer-related deaths occurred in the Edmonton region, where there are 816 registered family physicians. However, our program deals with this potential problem by providing physician-nurse consult teams to assist family physicians throughout the patient's illness.

For the current analysis, we were unable to compare data on symptom control in 1996/97 and 1992/93 because most of the deaths in 1992/93 occurred in acute care facili-

**Table 2: Number of cancer-related deaths and length of last hospital stay before death in 1992/93 and 1996/97**

Variable	1992/93	1996/97	p value
<b>Acute care hospitals*</b>			
No. (and %) of deaths	825 (63)	403 (32)	< 0.001
Mean length of stay (and SD), d	27 (16)	15 (7)	< 0.001
No. of patient-days	22 608	6 085	NA
<b>Cancer centre†</b>			
No. (and %) of deaths	130 (10)	95 (7)	0.02
Mean length of stay (and SD), d	15 (21)	9 (10)	< 0.005
Total number of patient-days	1 958	875	NA

Note: SD = standard deviation, NA = not applicable.

\*Source: Evaluation, Information and Research, Capital Health Authority, Edmonton.

†Source: Health Records, Cross Cancer Institute, Edmonton.



ties, where physical and psychosocial distress are not routinely measured. However, there is strong evidence that the delivery of palliative care to patients in hospital by oncologists and specialists is frequently inappropriate.<sup>4,5,11,21-24</sup> The shift of patients from acute care facilities to palliative hospices and home under the program most likely improved comfort for patients and their families.

Further studies should assess symptom control as well as patient and family satisfaction. Future research should also address cost of care. Because inpatient services are the most expensive mode of care for terminally ill patients,<sup>25</sup> it is likely that programs such as ours will result in cost savings.

Competing interests: None declared.

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