Economic Evaluation of Two Regional Palliative Care Programs for Terminally Ill Cancer Patients

March 31, 2003

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Funding Provided by:
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Alberta Heritage Foundation for Medical Research
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Reviewers
The investigators thank the CHSRF for their thoughtful review and editing of our initial draft. We also thank
numerous participants in conference presentations, medical rounds and workshops for their insight and
suggestions to help us better communicate study results and implications.

Financial Acknowledgements
Canadian Health Services Research Foundation (RC1-603-9)
Alberta Heritage Foundation for Medical Research
This study was conducted under the auspices of the Alberta Cancer Board Palliative Care Research Initiative.
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Key Implications for Decision Makers

- Access to palliative care services has increased from 45 percent to 81 percent for terminally ill cancer patients between 1993 and 2000 as a result of introducing comprehensive, regional palliative care programs in two large urban centers.

- Comprehensive, integrated palliative care programs can be implemented at no additional cost to the healthcare system in large urban settings. These findings support the introduction and expansion of palliative services where none currently exist. Where services already exist, these findings will help to maintain budgets in the face of increasing demands for shifting resources into other healthcare services.

- Acute care continues to account for the majority of costs at end-of-life. We identified health care services totaling $28,093 per person, two-thirds of which were provided by hospitals to terminally ill cancer patients in their last year of life. Physician services (10 percent), residential hospice care (8 percent), nursing home care (6 percent), homecare (6 percent) and prescription medications (3 percent) made up the rest. Age, gender, socioeconomic status, cancer diagnosis, disease burden, geographic, and healthcare system variables are significant predictors of these costs.

- Co-ordination of palliative care services meant that terminally ill cancer patients spent less time in hospital between 1993 and 2000, freeing up 74 beds per year between Edmonton and Calgary. A reduction in the demand for acute-care beds over this time period was achieved by providing additional palliative homecare and residential hospice care.

- Decision makers need to continue to develop communication initiatives that will inform the public regarding palliative care so that they can make informed decisions regarding quality end-of-life care for themselves and their families.

- Decision makers should continue to invest in management and collecting data in order to generate a strong evidence base upon which to improve decision-making in palliative care.
Executive Summary

Context

One in three Canadians is diagnosed with cancer at some point in his or her life, and about half of those people die of the disease. A review of the literature reveals there is a lack of large-scale, comparative studies of palliative care innovations — the net result of which is a small evidence base upon which decision makers can rely.

The objective of this study is to describe, explain and evaluate the economic consequences of introducing two comprehensive, co-ordinated and integrated palliative care programs in two large urban centres in Alberta, Canada.

This report brings out many implications for decision makers in all areas of healthcare. Those in clinical practice should continue education to maintain quality of existing palliative-care services, and expand knowledge of palliative-care management and services to other healthcare professionals, to improve practice, referral and overall access. In addition, clinicians need to recognize the value of palliative care, encourage participation in existing palliative-care services, and provide adequate clinical support for and education of family physicians in the care of terminally ill patients in the community and acute-care settings.

In the area of program management, it is important that new services and initiatives — including shared-care models with other healthcare teams — be implemented that further enhance access, co-ordination, quality of care, and appropriate use of resources. Furthermore, resources for residential hospice and homecare should be increased to allow patients to move out of acute care sooner, and decision makers should co-ordinate with the existing community and volunteer resources that already provide end-of-life care for palliative patients.

Policy makers can play an essential role by advocating for health-policy changes that ensure adequate public funding for palliative care, including continued investment in care provided to terminally ill patients in community settings. This is particularly important as palliative care supports more appropriate use of expensive acute-care facilities.
Public expectations around palliative care need to be shaped with communication initiatives that will provide information to allow people to make informed decisions. The significant contribution of families in sustaining a community-based model of care should also be recognized and supported.

Finally, data capture and management in palliative care needs to be better managed. For example, a “medical records culture” should be encouraged among providers who work in community settings. Decision makers must continue to invest in tracking data and management in all settings to create a strong evidence base which will improve decision-making. This can be accomplished in Alberta with partnerships between the Alberta Cancer Board, Alberta Health and Wellness, Regional Health Authorities and palliative care programs.

**Approach**

This study used a before and after analysis of linked administrative data for adults who died of cancer between April 1993 and March 2000 as residents of Edmonton or Calgary, Alberta. Individual, anonymized data from the cancer registry was linked to vital statistics, two palliative care program databases, and administrative databases managed by Alberta Health and Wellness. The latter databases contain information on use and cost of hospital and physician services, outpatient prescriptions, nursing homecare, and homecare.

**Results**

The results of the study show that access to palliative care increased from 45 percent to 81 percent between 1993 and 2000. As well, terminally ill cancer patients spent less time in hospital between 1993 and 2000, freeing up 74 beds per year in Edmonton and Calgary. Much of this time was spent in palliative home care (3.4 percent) and residential hospice care (2.4 percent or 61 beds). Despite this, acute care still accounts for most of the cost at the end of life. Two-thirds of $28,093 in services we identified were provided by hospitals to terminally ill cancer patients in their last year of life. Physician (10 percent), residential hospice care (eight percent), nursing home care (six percent), homecare (six percent) and prescription medications (three percent) comprised the remainder.
Many variables explain these results, including patient age, gender, socioeconomic status, cancer diagnosis, disease burden, and geographic location, as well as various healthcare system factors. The results clearly showed that comprehensive, integrated palliative care programs were implemented at no additional cost to the healthcare system.
According to the World Health Organization, one in three Canadians will be diagnosed with cancer at some point, and about half of those people will die of the disease. Cancer often means a lingering death for elderly patients, many of whom are deemed to have received inappropriate and costly care. In Canada, these findings were initially substantiated by the 1983 Canadian Medical Association (Watson) Task Force on Health Care Resource Allocation. (Watson 1983) The task force determined that a disproportionate number of elderly Canadians receive institutional care and excessive use of medical technologies driven by motives such as protection from litigation, and that not fully understanding all the care options leads to poor decisions by elderly individuals. As a result the task force recommended development of community services for elderly patients, with explicit goals of reducing institutionalization, improving quality of life and lowering costs. The task force’s findings established the hypothesis that de-institutionalization of healthcare services provided to elderly patients is a cost-effective strategy.

Palliative and/or hospice care services, intended to improve the quality of life for dying patients, (WHO) are delivered by 6,560 programs in 84 countries. (Hospice Information Service, 1999) In Canada, the Royal Victoria Hospital in Montreal and St. Boniface in Winnipeg opened the world’s first specialist palliative care units in 1974. Edmonton, Toronto, Vancouver, and Halifax followed their example. While this uniquely Canadian model helped integrate palliative care into the academic world and mainstream healthcare, it was acknowledged that a continued lack of community development meant too many people were dying in hospitals. To make matters worse, limited mechanisms for reimbursement of physician services in the community continued to restrict access.

Recommendations to co-ordinate, integrate and de-institutionalize palliative-care services were reinforced in the Expert Panel on Palliative Care’s report to the Cancer 2000 Task Force (which provides recommendations on priorities and co-ordination for cancer care to national cancer agencies). (Palliative Care 2000, 1992) In particular, the report included specific recommendations with respect to regional programs:
5.7 Interdisciplinary Palliative Care Program: Regional Cancer Centres should develop a full interdisciplinary team with clinical nurse specialist, and specially trained social workers and chaplain to be linked with the Division of Palliative Oncology. This Program’s objective would be service (direct management of complex, intense or intractable symptoms and establishing wider patterns of care and strategies of coordination with community and hospital resources), education and research. The Palliative Care Program would be accessible to all patients at any stage of cancer if they require the resources of the team. Prognosis should not act as a barrier to access.

The formation of numerous Senate committees shows that palliative care is a Canadian priority: the Special Senate Committee on Euthanasia and Assisted Suicide report *Of Life and Death*; (June 1995) the Subcommittee of the Standing Senate Committee on Social Affairs, Science and Technology report *Quality End-of-Life Care: The Right of Every Canadian*; (June 2000) and the Standing Senate Committee on Social Affairs, Science and Technology report *The Health of Canadians — The Federal Role: Interim Report: Volume Six: Recommendations for Reform*. (Oct 2002) In March 2001, Senator Sharon Carstairs was appointed as minister with special responsibility for palliative care with support from a Federal Secretariat on Palliative and End-of-Life Care, which was established within Health Canada in June 2001. As well, the recent Royal Commission on the Future of Health Care in Canada also discussed palliative care at the end of life.

Despite these recommendations and advocacy, review of the literature (Section 1.2, pages 2-3) reveals that there is a lack of large-scale, comparative studies of palliative care innovations — the net result of which is a small evidence base upon which decision makers can rely. Stated eloquently by another investigator, the case for this study can be summarized as follows: “there is some evidence — and there needs to be more.” (Higginson 1999)
Objective

The objective of this study is to describe, explain and evaluate the economic consequences of introducing two comprehensive, co-ordinated and integrated palliative care programs in Alberta. Specifically, the project will:

(1) Describe the public cost of care provided to terminally ill patients, including acute care, physician billing, prescription medications, hospice, long-term care (nursing homes) and homecare.

(2) Explain healthcare use by and cost of terminally ill patients. Demographic, geographic, healthcare system and clinical characteristics are examined.

(3) Evaluate whether use by and cost of terminally ill patients is influenced by implementation of regional palliative-care programs.

The study of the Edmonton and Calgary palliative care programs is for the period April 1993 to March 2000. Palliative care treatment and consequences are limited to terminally ill cancer patients in their last year of life.

The Case for Palliative-Care Evaluation

Evidence confirming that end-of-life care is expensive resulted in continued pressure to deinstitutionalize. In the United States for example, 10-12 percent of the overall health budget and 27 percent of the Medicare budget is spent on care associated with the end of life. (Lubitz and Riley, 1993) While policy makers continue to look for ways to control those costs, evidence suggested that cost savings weren’t always possible. The National Hospice Study (Mor et al, 1986) demonstrated cost savings that increased with nearness to death: 10 percent in last year and 17 percent in last six months. On the other hand, Kane et al (R Kane et al 1984 Lancet) conducted a randomized trial of hospice versus conventional care and found no effect on costs or outcomes, although patient and family satisfaction had increased. Raftery attributes cost savings through the delivery of palliative homecare to co-ordination and reduction of hospital inpatient days. (J Raftery et al, 1996) No effect on health outcomes was observed, although patient and family satisfaction were higher.
The implementation of community-based models of palliative care services in the mid-1990s in Canada is an example of successful attempts to de-institutionalize palliative care. These programs shifted their focus from acute settings to homes and hospices (located in continuing- or long-term care facilities). In Edmonton, this resulted in increased access for cancer patients from 21.0 percent in 1992 to 79.4 percent in 1999 (290 patients seen in two hospital-based palliative care programs compared to 1,147). (Edmonton Regional Palliative Care Program 2000 Annual Report) The number of people dying in acute-care facilities and the total amount of time they spend there have decreased significantly since the creation of the program (1,119 to 633 deaths; 22,608 days to 6,085 days, 1996/97 compared to 1992/93). (Bruera et al 1999 CMAJ) This reduction in patients’ final hospital stays translates to estimated annual savings of $1.65 million. (Bruera et al 2000) Dramatic reductions in the healthcare budget and hospital use were observed in Alberta between these two time periods, making it difficult to scientifically establish a causal relationship.

Despite considerable recent efforts to systematically review the literature, an evidence base proving the hypothesis is lacking. Divergent and innovative models of palliative care have been extensively reviewed. (Bosanquet and Salisbury, 1999) Of the 2,000 papers identified that were written between 1980 and 1998, 673 descriptive and comparative studies were analysed. Their review substantiated claims that the needs of palliative care patients were great and often not met. There is some evidence that home-based care is efficient when compared to institutional care in the U.S., but there is a dearth of evidence to characterize best practices as a function of nursing skill-mix. Specialist palliative care services do not substitute for typical in-patient services and hence are more expensive. However, it is generally accepted that in-patient pain and symptom management is better than conventional hospital or homecare. Patient and carer satisfaction are higher in all palliative care settings. The evidence generated by Bosanquet and Salisbury has since been further disseminated in a number of articles. (Bosanquet et al 1998, Salisbury 1997, Salisbury et al 1999, Wilkinson et al 1999) Further systematic reviews in the last five years did not alter these conclusions. (Critchley et al 1999, Wadhwa et al 1999, Hearn et al 1998, Francke et al 2000, Kite 1997, DIHTA, Raftery et al 1996, Jonen-Thielemann 1998)
Previous systematic reviews do not include an economic framework. The study investigators, using Canadian guidelines for economic evaluation, (CCOHTA 1997) systematically reviewed 38 articles describing costs of 47 programs. (Fassbender et al 2002) Concerns over methodological rigour remain and validated those of previous reviewers.

Not all evaluations of innovative practices have been disseminated in the academic literature. In Canada, the National Forum on Health recommended funding innovations that lead to a more integrated health system. (Health Canada) As a result, the federal government invested $150 million into the Health Transition Fund for 141 projects that will test and evaluate innovative ways to deliver healthcare services. Of these, 87 were integrated service delivery models, including three palliative care projects. (Health Canada) In Alberta, the Ministry of Health announced $32.2 million for the Health Innovation Fund, comprised of 48 projects, one of which is on palliative care. (Alberta Health and Wellness) Governments and organizations outside of Canada have funded similar innovative palliative care programs. Unfortunately, evaluations of these innovations have not contributed significantly to the evidence base.

**Technological Innovation in Palliative Care**

The Expert Panel on Palliative Care recommended co-ordination, integration and de-institutionalization of palliative-care services in interdisciplinary, community-based settings. The World Health Organization (WHO) defines palliative care as follows:

“Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
• offers a support system to help patients live as actively as possible until death;
• offers a support system to help the family cope during the patient's illness and in their own bereavement.

Radiotherapy, chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures are kept to a minimum.”

The ideal setting for palliative care is evidently complex. This observation is supported by the observation — reported in numerous literature reviews — that most articles do not provide a sufficient description of palliative care. In order to avoid similar criticism and to simplify the analysis, we specify an economic model of technological change that encompasses product, process and organizational innovation. (Zweifel and Breyer, 1997)

The Edmonton and Calgary regional palliative care programs were created in July 1995 and October 1996, respectively. The aim in both cities was to increase the access of patients with terminal illnesses to palliative care services and decrease the number of these patients dying in acute-care facilities. This is done through enhancing and developing community-based service options, such as home and hospice care, plus increasing the participation of family physicians and providing these physicians with adequate clinical support and education. The degree of co-ordination, integration, interdisciplinarity, and de-institutionalization reflects the visionary approach of local palliative care champions. In addition to core clinical services, the programs include activities in the administration, education and research domains.

We apply this model and describe the important elements of the two programs in Alberta, Canada in the next three sections. It should be noted, however, that some technological aspects of the program existed prior to program implementation while others were adopted at a later time. These and other aspects of the two programs are described below.
Product Innovation

According to the model, product innovation typically results in superior quality goods or services. As a result, expenditure increases can be expected (especially when old technology continues to be used alongside the new technology). Palliative care ‘product’ innovations are best exemplified by symptom control medications (goods) and palliative specialty consults (service). Palliative consults are further categorized according to whether they occur in an acute-care or community setting. Development and implementation of assessment tools is an important innovation but outside the scope of this study.

Significant innovations in symptom control medications have been observed during the last decade. In addition to new drugs, they include increased use of old drugs, new uses for old drugs, novel routes of administration and new settings (e.g., homecare). Innovative practices in Alberta include the use of methadone suppositories, metoclopramide for antiemesis, subcutaneous clodronate and terminal sedation in the home. (Bruera et al 1995, 1996; Walker et al 1997 and Slade et al 2002) In addition, during the study period, February 1999, Alberta Health and Wellness introduced a palliative care drug program in order to facilitate access to selected drugs in an outpatient setting.

Palliative care consultation teams were established in Edmonton and Calgary to provide twenty-four-hour support throughout the acute-care hospitals, ambulatory care settings, hospices, and at home. Palliative care consultant teams in acute-care facilities help patients manage symptoms related to physical, psychosocial, socioeconomic, spiritual, and cultural domains. They facilitate transition to home, hospice, tertiary care or other appropriate settings as required. In the community, these services are required for patients and families who no longer require the services of an acute-care setting, but who for a variety of reasons cannot manage by themselves.

Process Innovation

Process innovation permits the production of a good or service at lower cost. Although the distinction between product and process innovations may appear arbitrary, we nonetheless describe clinical services provided in tertiary palliative care, residential hospice care, and palliative homecare in terms of process innovations. The redeployment of personnel and capital
into these respective settings is an important component of palliative programs. Outpatient symptom control clinics are likewise important but, owing to the lack of data, remain outside of the scope of this study.

Tertiary or specialized palliative care units care for the five to 10 percent of patients with complex physical and psychosocial problems. These people require more intensive support from the palliative care physicians and interdisciplinary team members than they could receive elsewhere. In Edmonton, this service was set up in April 1993 at the Edmonton General Hospital as a 14-bed tertiary unit. It now occupies unit 43 at the Grey Nuns Community Hospital. Tertiary care was introduced in Calgary after the study end date.

Hospice palliative care units in free-standing or continuing care settings provide a “home like” environment. Here, a palliative-care interdisciplinary team provides enhanced nursing care and medications for patients who are unable to manage in their own home, yet do not need the services of acute care. The community clinical nurse and physician consultants provide ongoing support in this setting. In Edmonton, fifty-seven residential hospice beds are housed in four long-term care facilities and funded by contracts with the regional health authority. In Calgary, 42 hospice beds are managed by two local not-for-profit organizations.

Palliative homecare nurses provide care to patients and families in their own home with support from disciplines such as social work and rehabilitation. These individuals have specialized palliative care training, and they are distinct from homecare providers in the short-term or long-term programs and homecare provided in most other jurisdictions. Although this service was available in Edmonton and Calgary throughout the study period, a shift to 24/7 care occurred during the study time period.

Organizational Innovation

Organizational innovation entails reorganizing production processes. Like process innovations, organizational innovations are expected to decrease expenditures (and/or increase quality of service). Organizational innovation includes the role of central and program administration in
integration, interdisciplinary teams, continuity and co-ordination of care, and the degree to which silo mentalities are eliminated and management of disparate processes is amalgamated.

Integration refers to the creation of regional health authorities in April 1995. This made it easier to establish a program of care that covers all areas, from homecare to tertiary-level care, with central responsibility for clinical practice, education and research. A central office is responsible for co-ordinating continuity of care, standardizing assessment and practice, and streamlining care processes. Integration includes the voluntary sector through day hospitals, which offer social, spiritual and bereavement support by Pilgrim's Hospice in Edmonton and Hospice Calgary in Calgary.

Interdisciplinary teams are available at all sites of care to plan appropriate palliative care services. In each of these settings, core clinical services can be provided by physicians, nurses, social workers, pastoral care workers, rehabilitation therapists (occupational, physical and rehabilitation), pharmacists, and dieticians. Trained volunteers, family and friends provide complementary care.

Continuity and co-ordination of care recognizes that the family, palliative homecare and the family physician will provide the majority of palliative care. Acute and tertiary level services are available when needed, allowing persons to choose settings such as home and palliative hospice when stable. Criteria of admission for each area of the program assist staff in assessing appropriate care options. Palliative care consultants are available to support primary caregivers in any setting.

**Hypothesis**

Health reform is based on the hypothesis that it is cost-effective to provide services to elderly patients outside of an institutional setting. Our review of the literature provided limited support for this hypothesis. Palliative care does cost the healthcare system, however, as specialist consults and advances in the use of medications to control symptoms are expected to increase costs. Expansion of palliative homecare and introduction of residential hospice care will also increase costs. Therefore, the question is whether cost savings can be achieved by minimizing use of acute-care resources by palliative-care patients in exchange for increased resources for
tertiary palliative care units, hospice palliative care units, long-term care and homecare. Community-based palliative-care resources such as hospice and homecare services facilitate the appropriate use of acute-care beds. To answer this question we examine selected, individual sectors of the healthcare system: acute care, physician care and long-term care.

Hospital care is comprised of acute and tertiary care. Tertiary care represents increased quality of care for a small number of individuals and, as such, should replace days in a regular hospital unit; however, tertiary care comes at a higher cost per day. Better management of symptoms should result in fewer days in the hospital. Lastly, increased use of less-costly hospice and palliative homecare should mean fewer acute-care admissions. Higher cost per day for the remaining patients, whose illnesses are more severe, may not be observed because the proportion of averted patients will be relatively small.

The effect of palliative care on physician billings is ambiguous because of several conflicting forces. Palliative care consults represent a new service and therefore a cost increase. Out of total physician billings, the proportion will be small. Family practitioner behaviour may be influenced by their primary care role. New knowledge of symptom control techniques may result in increased services. Referrals to more expensive, non-palliative specialists should decrease as a result.

On the whole, cost neutrality best describes the net effects of these countervailing forces on cost. Because acute care is two-thirds of total cost, net cost will be largely dictated by what happens in that sector. A pure substitution effect should equate to cost savings as cost per day is lower for hospice and palliative homecare. Palliative care is also a small proportion of the total service received in the last year of life, increasing in importance closer to the end of life.

**Implications**

**Clinical Practice**
- Encourage the introduction of new or expansion of existing palliative care programs to provide services to more people, earlier and at a higher intensity.
• Continue education to maintain quality of existing palliative care services, and expand
knowledge of palliative care management and services to other healthcare professionals to
improve practice, referral and overall access.
• Recognize the value of palliative care, encourage participation in existing palliative care
services, and provide adequate clinical support for and education of family physicians in the
care of terminally ill patients in the community and acute-care settings.

Program Management
• Implement new services and initiatives in the continuum of care that further enhance access,
co-ordination, quality of care and appropriate resource use (e.g., respite and ambulatory
clinics).
• Increase resources in hospice and homecare to allow earlier care of more complex palliative
care patients who would otherwise remain in acute care.
• Integrate and co-ordinate with existing community and volunteer resources
providing end-of-life care for palliative patients.
• Develop, assess and implement shared-care models with other healthcare teams to provide
quality end-of-life care to those living and dying with other illnesses such as renal disease,
ALS, and chronic lung and heart disease.

Policy Making
• Advocate for health policy changes that ensure that public health funding for palliative care
services continues to grow to meet increasing demand and scope of palliative care services.
• Ensure sufficient reimbursement for care in community settings.
• Increase funding for palliative care to support appropriate use of expensive acute care beds to
prevent and minimize the time palliative-care patients spend in acute-care facilities.

Shaping Public Expectations
• Develop communication initiatives that will inform the public regarding palliative and
hospice care so that they can make informed decisions and advocate for quality end-of-life
care.
• Recognize and support the significant contribution of families to sustaining a community-
based model of care.
Palliative Care Databases

- Continue to invest in data capture and management in order to generate a strong evidence base upon which to improve decision-making.
- Encourage a ‘medical records culture’ among providers in community settings through education of clinicians and investment in health records management.
- Create a separate end-of-life care registry with partnerships between the Alberta Cancer Board, Alberta Health and Wellness, regional health authorities and palliative care programs.

Approach

Analytic Strategy

Study Design
In this section we describe methods employed to conduct before and after analysis of linked administrative data employed for adults who died of cancer between April 1993 and March 2000 as residents of Edmonton or Calgary, Alberta. Individual, anonymized data from the cancer registry is then linked to vital statistics, two palliative-care program databases, and administrative databases managed by Alberta Health and Wellness. The latter databases contain information on use and cost of hospital, physician, outpatient prescriptions, nursing homecare and homecare.

Actual costs, standard cost lists and relative value unit costing are used to assign dollars to observed use. These costs are described and disaggregated into period prevalence, intensity and duration (the multiplication of which equals total cost). A framework of technological innovation is used to define the primary independent or ‘treatment variables’ that characterize palliative care. A risk adjustment model, used to explain costs, is constructed with age, gender, socioeconomic status, cancer diagnosis, disease burden, geographic and healthcare system variables.

Regression techniques are used to evaluate the implications of palliative care services on end-of-life hospital and physician costs. Probability of referral to hospital or physician services is inferred from logistic regression. Multiple linear regressions are used to infer intensity (cost per day, visit and service) and duration (days, visits, and services).
Administrative Data Acquisition and Management

Eligibility of the study population is determined through application of the following inclusion and exclusion criteria to individuals identified in the Alberta Cancer Registry:

- Died between April 1993 and March 2000;
- Residents of the Edmonton and Calgary Regional Health Regions at time of death;
- Diagnosed with cancer;
- 18 years of age and older; and
- Valid personal health number (PHN).

Anonymity was established by virtue of the fact that the Alberta Cancer Board assigned a unique study identification number to each individual and provided the matched PHNs with study IDs to the Edmonton and Calgary Palliative Programs plus Alberta Health and Wellness. Each organization agreed to provide the investigators with data identified by study ID alone. The algorithm and study procedure was summarized in the document entitled “Analytic Plan, March 21, 2001” and was agreed to by all organizations through data-sharing agreements and administrative approval processes. Ethics approval had been granted by the Alberta Cancer Board and the universities of Alberta and Calgary ethics committees.

Deterministic record linkages were applied to the following databases using SPSS (v 10.5):

- Alberta Cancer Board Cancer Registry
- Vital Statistics (via Alberta Cancer Board)
- Edmonton Palliative Care Program
- Calgary Palliative Care Program
- Alberta Health and Wellness
  - Alberta Health Care Insurance Plan Registry
  - Acute care or hospital
  - Ambulatory care (emergency, day procedures, outpatient clinic)
  - Physician
  - Medications
  - Homecare
  - Nursing homecare
Variable Construction

Dependent Variables

Explanation and evaluation of absolute (total) cost for a specific healthcare sector requires decomposition into constituent elements in order to improve the precision of estimates and get more details about use and costs at the patient level. (M Feldstein 1969; N Duan et al. 1983, 1984) We employ a three-part model of period prevalence, intensity and duration:

Equation 1: Total Cost = $P \times I \times D$

where $P$ is the period prevalence rate (number of individuals who receive services within a given time frame), $I$ is the intensity of service provision ($$/service), and $D$ is duration (number of services).

As seen in Equation 2, service intensity for any individual can be generically described as a function of its constituent elements: wages, use and duration.

Equation 2: Service Intensity $(i) = \frac{\sum_{j=1}^{n} \sum_{k=1}^{m} w_{jk} \times u_{jk}}{LOS_{i}}$

where $i = 1…n$ patients; $j = services$; $k = providers$; $w_{jk} = a$ weighting factor; and $hr_{jk} = the amount of service. Intensity is expressed as $$/service where service is denominated in days for hospital care or services and visits for physician care. A cost list can be used to assign average (standard) costs for $w_{jk}, \forall j, k (each service-provider combination).

In this study we explain and evaluate hospital and physician costs, as they comprise the two largest constituents of overall costs at the end of life. As a result, the dependent variables are probability of referral to hospital care, number of days in hospital within the last 180 days, and cost per day. Likewise, we examine the probability of referral to physician services, number of services and visits, and costs per service and visit. A visit is defined as a single day. Actual costs were used.
Relative value unit costing was used to calculate the costs of a hospital encounter. First, resource intensity weights were calculated for all acute-care encounters after regrouping with the 2001/02 case mix group. (CIHI) Second, cost per weighted case was calculated using MIS (financial and statistical accounting system) data from 77 (roughly largest of the 100 total) reporting hospitals across Alberta. These costs include in-patient operating costs plus an allocation of fixed overhead, administration, education and research. The product of cost per weighted case and resource intensity weight equals the cost per encounter. The cost per encounter divided by the length of stay equals cost per day.

Description of total costs requires calculation of costs for hospice, nursing homecare, homecare, and outpatient medications. A rate of $230 per day for hospice care and $130 per day for nursing homecare was employed. In the case of nursing homecare, an average of $105 plus an average accommodation fee of $26.67 per day was rounded to $130 on the basis that many of these patients qualify for subsidization of co-payments. In the case of hospice care, a conservative estimate of $230 reflects an average reported cost during the study period but does not include the value of volunteer services. Actual costs are used for homecare and medications.

**Treatment Variables**

In this study, the treatment variables refer to the palliative care interventions received by terminally ill patients. Given the complexity of the Edmonton and Calgary programs, a “realistic” model cannot be fully operationalized. Rather, variables corresponding to the concepts outlined under technological innovation are constructed. In summary, referral to palliative care occurs when a patient receives any combination of specialized consults (acute or community), palliative homecare, residential hospice care, or tertiary palliative care. For each type of palliative care, a dummy variable (1 = yes) and date corresponding to admission or earliest service is recorded.

Three treatment dummy variables are computed for this study. Availability of palliative care takes the value of one when a patient dies more than six months after implementation of the regional programs (April 1995 in Edmonton and October 1996 in Calgary). Access takes the value of one if any of the constituent palliative services were used in the year prior to death.
Early referral takes the value of one if referral to palliative care occurred 90 days or more prior to death.

**Risk Adjustment Variables**

Age is calculated at time of death and denoted in years. Gender takes the value of one if female. Time takes the value of 1-7 for the fiscal years 1993/94 to 1999/00 (April to March). Geographic variation is denoted by a dummy variable where 0 = Edmonton and 1 = Calgary. Square terms are entered for both age and time. Cancer diagnosis is coded on the basis of underlying cause of death as recorded in vital statistics and modified in the cancer registry. Dummy variables are constructed according to the format recommended by the International Association of Cancer Registries (IACR). Dummy variables for disease burden are created using the Deyo modification of the Charlson index. (Romano et al 1993) Association with time trend is assessed with the chi-square test of linear-by-linear association.

**A Descriptive Model of Palliative Care Programs**

**Referral to Palliative Care Programs**

Referral to palliative care will be described using graphical methods to depict what percentage of patients receive five specific palliative services (treatment variables) as a function of time before death and as a summary measure for each of the seven study years.

**Use in Last 365 Days of Life**

Graphical methods are also used to depict use expressed as the number of days patients spend in different care settings. A patient is deemed to spend each day in their last year of life in one of several care settings. Double-counting is avoided by a hierarchical computer algorithm that assigns a care setting based on the following order: tertiary care, hospital care, hospice, nursing home, palliative homecare or home. For example, if a patient is deemed to be in tertiary care on day minus 365, then he cannot be in any other setting. If he is not in the first four settings, then he is deemed to be at home. ‘Home’ includes short- and long-term homecare, plus residence at lodges, assisted living and living with relatives. Palliative homecare is defined as the time interval from first to last palliative date of service while at home.
Costs in the Last 365 Days of Life

Calculation of costs is previously described (Section 3.1.3). Distribution of costs is graphically presented. Inflation is controlled by discounting all costs to the midpoint in the final study year (April 2000) using the Alberta Consumer Price Index (1996 healthcare basket).

Risk Adjustment and Explanation of Health Costs at End of Life

Regression techniques are used to explain end-of-life hospital and physician costs. Probability of referral to hospital or physician services is inferred from logistic regression. Multiple linear regressions are used to infer intensity (cost per day, visit and service) and duration (days, visits, and services). A table is constructed and regression estimates are included with notations of significance.

Evaluating the Impact of Palliative Care on Healthcare Costs

Multivariate regression methods are employed on observational data to reduce the effect of bias. Adjustment is made on the basis of variables identified in the literature and constrained by availability: age, gender, cancer diagnosis, disease burden (co-morbidity), time (exogenous technological innovation) and geographic practice variations. Use and unit costs for hospital costs and physician services are regressed on the three ‘treatment’ variables of availability, access, and early referral plus the risk adjustment variables. A table of treatment effects and notations for significance are provided. The units for the logistic regression are adjusted odds ratios, and natural units for the remaining variables (dollars, days, services or visits).

Knowledge Transfer

A strategy has been developed for dissemination to academics, policy makers, decision makers and the public. Study design and results have been vetted at numerous local, national and international palliative care conferences.

1. 13th Annual Palliative Care Conference Education and Research Days, Edmonton, 1 October, 2001 (Talk).
4. 2nd Congress of Research in Palliative Care, Lyon, May 23-25, 2002 (Poster).
5. Palliative Care Rounds, Edmonton, October 6, 2002 (Talk).
8. 8th Congress of the European Association for Palliative Care, The Hague, Netherlands, April 2-5, 2003 (1 Talk, 2 Posters).

This project has resulted in the creation of a substantive end-of-life care database. Project data have been made available for the training of numerous investigators. Titles and target journals for currently identified academic manuscripts (in various stages of preparation) are listed below:

2. Data Quality in Palliative Care Administrative Databases. *Journal of Palliative Care.*
3. Palliative Care in Alberta (Descriptive Results). *Journal of Pain and Symptom Management.*

Researchers and decision-making partners provided interpretation of the results at a meeting on February 7-9, 2003. Planning is currently underway to host a one-day workshop in May for representatives from regional health authorities in Alberta, Alberta Health and Wellness, Senator Carstairs, and the Secretariat on Palliative Care, Health Canada.
Dissemination to the public will be facilitated through the Alberta Cancer Board Palliative Care Research Initiative and the Canadian Health Services Research Foundation web sites.

**Limitations**

*Study Design*
Randomized clinical trials provide the highest level of evidence. However, it is unethical and impractical to withhold palliative care services. We therefore rely on observational data. Study design and analytical strategies have been devised to limit the role of bias in estimating the impact of palliative care on hospital and physician expenditures. It would have been impractical and costly to include rural and out-of-province patients as a control group. As a result, history bias during the study period is of greatest concern. Unit costs, quantities and quality of palliative care, non-palliative practice patterns, and funding levels have changed. In particular, overall funding for the Alberta healthcare system was curtailed and restored during this time period. A quadratic time function (cohort and cohort square) was introduced to partially control for this effect.

*Administrative Data*
Retrospective studies and their reliance on administrative data collected for purposes other than the project are subject to increased scrutiny. The resulting limitations are evaluated on the basis of coverage, detail, and quality.

The extensive coverage of the databases is shown by the ability to follow individuals throughout their illnesses, in both institutional and community settings. However, palliative care program data were not available for two outpatient clinics or consults at a local cancer center in Edmonton, and there were incomplete referral data during the first 18 months of the Calgary program. In terms of healthcare costs, comparable ambulatory care data were not available for the entire study period; diagnostic service data are not systematically collected and outpatient medications are only available for patients over 65 years of age. Insufficient out-of-pocket and no indirect costs were available to include a personal cost perspective.
The palliative-care programs data contained extensive details. A minor limitation is that the individual contribution of interdisciplinary team members cannot be identified. Furthermore, more detail (e.g., inpatient medications and diagnostic tests) through chart abstraction or linkage to hospital-specific databases is not feasible or cost-effective.

Compared to other palliative-care programs in Canada, Edmonton’s and Calgary’s are unique in their investment in dedicated database management. (P Critchley et al 2002) This resulted in a high degree of completeness and accuracy. The quality of the data elements (date of death, date of birth, gender, diagnosis — cancer vs. non-cancer — and region of residence) was tested by determining their accuracy and completeness against the Alberta Cancer Board registry for those patients identified in our population cohort. There was a significant trend towards fewer missing data for diagnosis (p<0.0001 Edmonton) and region (p<.0001 Edmonton and Calgary) over the years. Region of residence and date of death had the largest proportion of missing data. The data elements in both programs matched the corresponding element in the registry in more than 95 percent of records. Quality of Canadian health administrative databases is deemed sufficiently high for purposes of this study and is addressed elsewhere. (Roos et al 2002)

Quality of Life and Death

This study does not take into consideration the quality of life of patients, their families and their caregivers. Formal care providers’ and volunteers’ perspectives are likewise not included in the study. Review of the literature, however, did reveal that user satisfaction is highly correlated with the introduction of palliative care services at the end of life. Literature on quality of death was not reviewed for this study.

Results

Describing the Patient Population and Palliative-Care Programs

An Overview of Terminally Ill Cancer Patients
The course of illness for terminally ill cancer patients is illustrated in Figure 1. Pre-illness, diagnosis and therapy characterize the three phases. An average age corresponding to each of these phases is also depicted. Time to first cancer diagnosis is 65 years of age and time from last cancer diagnosis to death is two years. The discrepancy between the first and last dates of cancer
diagnosis reflects the fact that many of these patients are diagnosed with more than one primary cancer.

Figure 1: Illness Trajectory of Terminally Ill Cancer Patients

Terminally ill cancer patients in Edmonton and Calgary are on average 68.7 years of age (and increasing) and are equally distributed between genders and cities (Table 1). Half of the population is deemed low income, in that they qualify and have applied for subsidy of their healthcare insurance premiums. Cautious interpretation of socioeconomic status is recommended due to an assessment of compromised quality in 1994/95, and a policy shift that took place after 1995/96.

Half of the cancers are of the digestive and respiratory systems. There was an increase in breast cancers and lymphomas over the study period. Cancers of the male genital system decreased. This population also had significant non-cancer diseases with 19.5 percent diagnosed with chronic obstructive pulmonary disease, 14.5 percent with moderate or severe liver disease, and 10.4 percent with congestive heart failure in their last year of life. Disease burden however appears to be decreasing over time with five out of 12 categories significantly decreasing in prevalence over the study period.

Table 1: Demographic Characteristics of Study Population

Referral to Palliative Care

Figures 2-4 illustrate the probability of referral to palliative care as a function of time. Referral to the palliative-care program in 1999/00 is illustrated in Figure 2 as a function of time prior to death. As death approaches, the cumulative probability of referral for any of the five types of service increases. At the time of death, 81 percent of terminally ill cancer patients are referred to at least one mode of palliative care. Substantial percentages of these referrals occur in the last month: 31 percent of palliative homecare, 71 percent of hospice care, and 38 percent of total care.

Figure 2: Probability of Referral to Palliative Care by Type of Service as Function of Time before Death in 1999/00, n = 2,549.
In Figure 3, we see that total referrals increased from 45 percent to 81 percent over seven years. This growth came in a series of increases:

- 1993/94 to 1994/95 Homecare
- 1994/95 to 1996/97 Consults and hospice in Edmonton
- 1996/97 to 1997/98 Hospice
- 1997/98 to 1999/00 Acute consult in Calgary

Figure 3: Probability of Referral to Palliative Care by Type of Service at Any Time in Last Year of Life, 1993/94 to 1999/00, n = 16,282.

Referrals to palliative care cannot continue to increase at the same rate. Figure 4 illustrates diminishing returns to scale where referrals increase throughout the year prior to death in the first four study years. In the last three years, annual increases in referrals are observed in last month alone, and those occurred as a result of increased acute care consults in Calgary.

Figure 4: Probability of Referral to Palliative Care by Type of Service at Any Time in Last Year of Life, 1993/94 to 1999/00, n = 16,282.

Healthcare Use and Costs at End of Life

Tracking 16,282 patients for each of their last 365 days is computationally intensive but yields valuable insight into use of healthcare. Furthermore, where patients live is much more descriptive than where they die and yields more reliable data on location of death than census data obtained from vital statistics.

Over the course of 1999/00, 87 percent of patients’ time was spent at home, 12 percent while receiving palliative homecare near the end of life (Figure 5). Time spent at ‘home’ however does not distinguish between alternative living arrangements; with family, group homes, assisted living, or lodges for example. Institutional care over the year was provided as follows: 0.6 percent in tertiary palliative care, 7.5 percent in acute care, 2.4 percent in hospice, and 3.5 percent in nursing homes.
Location of death can be imputed from location on the day 0 (day of death). The numbers are as follows: 36.9 percent in acute care, 3.1 percent in tertiary care, 3.4 percent in nursing homes, 28.9 percent in hospice, and 27.8 percent at home (41 percent of whom received palliative homecare services on the day they died). Note that not all patients who die at home, in the hospital, or nursing homes were referred to palliative care in the previous year.

Figure 5: Probability of Receiving Care at Various Settings as a Function of the Last 365 Days Before Death, 1999/00, n = 2,549.

The vertical axis in Figure 6 illustrates time spent in a particular care setting. Over the seven-year study period, acute days decreased from 10.4 to 7.5 percent, representing a savings of 74 acute care beds. This was offset by care provided in less-costly settings: palliative homecare increased from 8.6 to 12 percent and hospice increased from 0 to 2.4 percent, equivalent to 61 beds in hospice. Tertiary care, nursing home and time at home remained constant.

Figure 6: Proportion of Time Spent in Various Care Settings in the Year Prior to Death, April 1993 to March 2000.

By translating the time spent in various care settings into costs and adding physician visits and outpatient medications results, a snapshot of the cost of care at the end of life emerges. In Figure 7, we see for example that acute care accounts for most of the cost at the end of life in 1999/00. Two-thirds of the $28,093 in services we identified were provided by hospitals. Physician (10 percent), hospice care (eight percent), nursing homecare (six percent), homecare (six percent) and prescription medications comprised the remainder.

Figure 7: Identifiable Public Costs of Terminally Ill Cancer Patients in Their Last 365 Days of Life, 1999/00, Total = Cdn $28,093.
In Figure 8, identifiable costs are compared across the seven study years. The decrease and increase of overall health financing is evident by following the total costs. Also evident is the fact that acute costs were not restored to historical levels, and they were primarily offset by the introduction of hospice care. Most importantly, we see that the total cost in 1999/00 is lower than of 1993/94, prior to the introduction of palliative care. Note that these figures are adjusted for inflation.

Figure 8: Identifiable Public Costs of Terminally Ill Cancer Patients in Their Last 365 Days of Life, 1993/94 to 99/00, Canadian 1999/00 Dollars.

Explaining Healthcare Costs at End of Life

Table 2 provides evidence that age, gender, socioeconomic status, cancer diagnosis, disease burden, and geographic and healthcare system variables can be used to explain hospital and physician costs. An example is chronic obstructive pulmonary disease. An individual with this diagnosis is more than four times as likely to be admitted to hospital in the last 180 days of life, cost $56 less per day and stay for an additional five days than the average. This same individual is nine times more likely to be referred to a physician, costing $0.50 less per service but requiring an additional 10 services during the last 180 days than the average. This model can be used to predict the cost of potential terminally ill cancer patients.

Table 2: Determinants of Use and Cost of Hospital and Physician Care in the Last 180 Days of Life.

Evaluating the Impact of Palliative Care on Healthcare Costs

Comprehensive, integrated palliative care programs have been implemented at no additional cost to the healthcare system. In Figure 8 we saw that the introduction of palliative care was associated with a slight decrease in costs to the healthcare system. In Table 3, estimates of adjusted impact on hospital and physician care are provided. Conservatively interpreted, they provide strong evidence supporting the hypothesis of cost neutrality. None of the co-efficients in the ‘availability’ column is significant. Availability is equivalent to the ‘intention to treat’ and is therefore a conservative estimate. Cost savings are observed if we adjust for ‘observed cohort’
(access), or if we divide the cohort into groups according to when they were referred to palliative care in relation to the date of death. For acute care, a modest increase in duration is more than offset by lower intensity of services.

Table 3: Evaluating the Impact of Palliative Programs on Use and Cost of Acute and Physician Care in the Last 180 Days of Life.

Additional Resources

Database Linkage and Quality Assessment
Research involving record linkage requires a substantial investment in paperwork, resources and specialized research staff. Administrative approvals, ethical approval, compliance with requirements outlined by data custodians and compliance with privacy legislation are the key elements in obtaining data. Familiarity with these steps is absolutely critical. Documentation can be easily obtained via the Internet or by request.

Assessment of quality and management of the data require specialized personnel. An ability to merge files, clean data and write/document syntax in programs such as SAS or SPSS is essential. Knowledge of data sources and epidemiological theory are a definite asset.

Guidelines for Costing and Economic Analysis
Numerous introductions to economic evaluation provide varying insights into the methods employed in this study.


Guides to reading and understanding the economic evaluation literature are also available:
• O'Brien BJ, Hayland D, Richardson WS, Levine M, Drummond MF. 1997. Users' guides to the medical literature: XIII. How to use an article on economic analysis of clinical practice: B. What are the results and will they help me in caring for my patients? JAMA 11 June 97, 277(22):1802-1806

And for the reader wishing to conduct an economic evaluation, referral to the following sources is advised:

Palliative Care Resources

The Canadian Hospice Palliative Care Association maintains a researcher registry, Canadian directory of services and a calendar of events listing upcoming conferences and meetings.

Further Research

Costing of Palliative Care Services
The costing methodology employed in this study is crude. Application of activity-based costing, microcosting, protocol costing, and/or workload measurement would provide refined estimates of cost. A better understanding of cost drivers would, however, emerge.

Implications for the private sector are not well understood. This includes indirect (patient and caregiver), out-of-pocket, and voluntary sector costs. Current activities in this domain include a pilot project entitled “Questionnaire and strategy to assess economic burden in palliative care patients and their families” in Edmonton. As well, a draft proposal for “Palliative care in Canada: Economic perspective” has been prepared by Serge Dumont (Laval University) and Konrad Fassbender.

Quality of Life
This study did not measure quality of life. In fact, there are no agreed upon preference-based measures for assessment of quality of life.

Assessment of Equity
In this study, we observe that 19 percent of study patients are not referred to palliative care. Furthermore, 15 percent of study patients die at home and 35 percent die in hospital, many without referral. As a result, the investigators have drafted a proposal entitled “Access to Palliative Care Services in Alberta” in an attempt to better understand the determinants of referral and the role of culture, religion, personal preferences and better socioeconomic variables.

End-of-Life Care Registry and Performance Indicators
Generating a strong evidence base upon which to improve decision-making could be realized with the creation of an end-of-life care registry. Application of consensual clinical and administrative performance indicators would then serve to help decision makers evaluate innovative palliative care models. The study investigators submitted a successful letter of intent to the Health Canada Primary Health Care Transition Fund entitled “Enhancing Palliative Care Performance.” Work on a final proposal is underway.
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