

Topics in Pallative Care, Volume 5

Eduardo Bruera, M.D.
Russell K. Portenoy, M.D.,
Editors

OXFORD UNIVERSITY PRESS

Topics in Palliative Care

Volume 5

Series Editors

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TOPICS IN PALLATIVE CARE

Volume 5

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OXFORD
UNIVERSITY PRESS

2001

OXFORD
UNIVERSITY PRESS

Oxford New York

Athens Auckland Bangkok Bogotá Buenos Aires Calcutta

Cape Town Chennai Dar es Salaam Delhi Florence Hong Kong Istanbul

Karachi Kuala Lumpur Madrid Melbourne Mexico City Mumbai

Nairobi Paris São Paulo Shanghai Singapore Taipei Tokyo Toronto Warsaw

and associated companies in

Berlin Ibadan

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Published by Oxford University Press Inc.,

198 Madison Avenue, New York, New York, 10016

<http://www.oup-usa.org>

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Library of Congress Cataloging-in-Publication Data

Topics in palliative care / edited by Eduardo Bruera, Russell K. Portenoy

p. cm.—(Topics in palliative care: v. 5)

Includes bibliographical references and index.

ISBN 0-19-513220-3

I. Cancer—Palliative treatment.

II. Bruera, Eduardo.

III. Portenoy, Russell K.

III. Series.

[DNLM: 1. Palliative Care. 2. Neoplasms—drug therapy.

3. Pain—drug therapy.

WB 310 T674 1997] RC271.P33T664 1997

616.99'406—dc20 DNLM/DLC for Library of Congress 96-22250

9 8 7 6 5 4 3 2 1

Printed in the United States of America
on acid-free paper

*To our wives,
Susan and Maria,
whose love and support
make our work possible.*

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Preface to the Series

Palliative Care, a series devoted to research and practice in palliative care, was created to address the growing need to disseminate new information about this rapidly evolving field.

Palliative care is an interdisciplinary therapeutic model for the management of patients with incurable, progressive illness. In this model, the family is considered the unit of care. The clinical purview includes those factors—physical, psychological, social, and spiritual—that contribute to suffering, undermine quality of life, and prevent a death with comfort and dignity. The definition promulgated by the World Health Organization exemplifies this perspective.^o

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 the achievement of the best possible quality of life for patients and their families.

Palliative care is a fundamental part of clinical practice, the “parallel universe” to therapies directed at cure or prolongation of life. All clinicians who treat patients with chronic life-threatening diseases are engaged in palliative care, continually attempting to manage complex symptomatology and functional disturbances.

The need for specialized palliative care services may arise at any point during the illness. Symptom control and psychological adaptation are the usual concerns during the period of active disease-oriented therapies. Toward the end of life, however, needs intensify and broaden. Psychosocial distress or family distress, spiritual or existential concerns, advance care planning, and ethical concerns, among many other issues, may be considered by the various disciplines that coalesce in the delivery of optimal care. Clinicians who specialize in palliative care perceive their role as similar to those of specialists in other disciplines of medicine: referring patients to other primary caregivers when appropriate, acting as primary caregivers (as members of the team) when the challenges of the case warrant this involvement, and teaching and conducting research in the field of palliative care.

^oWorld Health Organization. Technical Report Series 804, Cancer Pain and Palliative Care. Geneva: World Health Organization, 1990:11.

With recognition of palliative care as an essential element in medical care and as an area of specialization, there is a need for information about the approaches used by specialists from many disciplines in managing the varied problems that fall under the purview of this model. The scientific foundation of palliative care is also advancing, and similarly, methods are needed to highlight for practitioners at the bedside the findings of empirical research. *Topics in Palliative Care* has been designed to meet the need for enhanced communication in this changing field.

To highlight the diversity of concerns in palliative care, each volume of *Topics in Palliative Care* is divided into sections that address a range of issues. Various sections address aspects of symptom control, psychosocial functioning, spiritual or existential concerns, ethics, and other topics. The chapters in each section review the area and focus on a small number of salient issues for analysis. The authors present and evaluate existing data, provide a context drawn from both the clinic and research, and integrate knowledge in a manner that is both practical and readable.

We are grateful to the many contributors for their excellent work and their timeliness. We also thank our publisher, who has expressed great faith in the project. Such strong support has buttressed our desire to create an educational forum that may enhance palliative care in the clinical setting and drive its growth as a discipline.

New York, N.Y.
Houston, TX

R.K.P.
E.B.

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I

**CULTURAL ISSUES IN
PALLIATIVE CARE**

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1

Models for the Delivery of Palliative Care: The Canadian Model

CARLEEN BRENNEIS AND EDUARDO BRUERA

The notion of palliative care, providing comfort to the dying, is not new to Canada or other countries. However, the context of the delivery of care has changed considerably since the mid-1970s. In the second half of the twentieth century in North America, care of the terminally ill moved from the home into the hospitals. The success of medical technology shifted the focus in hospitals to prolonging life and avoiding death. This change moved the medical care of the patient from the family physician and home nurse into a field of specialties, where until recently, palliative care was not recognized.¹⁻³ Beginning with the pioneering work of Dame Cicely Saunders at St. Christopher's Hospice in England in 1967, a focus on quality of life and symptom management has occurred throughout the hospice movement.

The first palliative care programs in Canada were established in Montreal and Winnipeg in 1975 (The Royal Victoria and St. Boniface Hospitals). The initial growth focused on hospital-based programs with some of the world's earliest specialty units within tertiary teaching hospitals. Canada is known internationally for the development of palliative care units and consultation teams within hospitals.⁴⁻⁵ Since the palliative care units were under the auspices of host institutions, minimal standards of care were ensured.⁶ Programs generally grew out of existing hospital-based programs and spread into the community through outpatient clinics and some home-based care.^{2,6} In Canada, the connection to teaching hospitals and funding from the public health care system provided for a stronger academic base than most British and American programs, which maintained a strong hospice focus.⁵ This chapter describes the growth of palliative care services delivery in Canada and uses the Edmonton Regional Palliative Care Program as an example.

Definition of Palliative Care

Palliative care was defined by the Palliative Care Foundation in 1981 along with the first guidelines on palliative care developed by National Health and Welfare.⁷ The 1989 definition and guidelines by Health and Welfare Canada reflected more of a continuum of care with curative treatment and strengthened the notion of the interdisciplinary team. These updated guidelines reflected the increase of palliative care in the home.^{2,8,9} The World Health Organization (WHO)'s definition of palliative care developed in 1990 again underscored the value of psychosocial, spiritual as well as physical care, yet continued to suggest palliative care be provided to patients not receiving active anti-disease therapy.^{6,10} The Canadian Palliative Care Association (CPCA)'s, the national representative for hospice and palliative care in Canada, definition from the Standards Committee (1995) suggests palliative care is provided as primary, secondary, and tertiary roles throughout the trajectory of illness. In September 1998, the CPCA Board of Directors approved a short definition: "Hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or are bereaved."¹¹

Palliative Care Development

In part because of the Report to Cancer 2000 Task Force by Expert Panel on Palliative Care (1991), there has been an ongoing debate about the types of palliative care services that should be created over the last several years. Impetus for these discussions have been:

1. Increasing burden of suffering based on the aging population and increasing cancer prevalence. This expands the population for palliative care. The number of people over 75 years of age is expected to increase by 158% from 1981 to 2021 (2.4% annually).¹² Across Canada, there is a projected increase in mortality with as many as 70,000 Canadians dying of cancer per year by 2000. Cancer has become more chronic yet 50% of patients will die of this disease following months or years of treatments. Cancer is characterized by aspects of physical, emotional, and spiritual suffering.⁵ The Report to Cancer 2000 Task Force (1991) recommended reallocation of cancer resources to palliative care services, increased education and research, and a major shift of resources to home care. To a large extent, this reallocation of resources has not occurred.

2. Regionalization of health care service as a response to diminishing resources. The result of regionalization in most areas is an amalgamation and decrease in the number of acute care beds. As care shifts to the community, increased resources must move with the care to provide enhanced home care, respite, and other care options.^{5,13,14} Part of the move to the community is to save the "hotel" and other costs associated with acute care beds. However, as yet there are no Canadian studies showing the cost of community care to be cheaper. And,

if the cost to the caregivers is included (cost shifted), costs savings are much less.¹⁵⁻¹⁷

3. Emphasis on community-based care as a response to individual choices. The literature is replete with an increased focus for community-based care. Palliative care is seen to be a model of care that works well for community care. Providing options of care for seniors, and informing and including patients in decision making has also enhanced focus on the option of maintaining quality of life and choosing end-of-life care at home. The proportion of patients who chose a home death, and have maintained their choice over time, is not well-documented.^(15,18-20) Canada has had a long history of high use of acute care beds for palliative patients. The move toward more people dying at home requires a substantial shift in our socialization and learned expectation.

4. Increased medical provision of palliative care sometimes referred to as high tech. Increased options for care fuels the controversy between the potential for futile or depersonalized care, and patients' rights to access active symptomatic treatment.^{2,21} There has been significant knowledge gained in symptom management and the use of this knowledge is not widespread beyond palliative care specialists, underscoring the need for more broadly targeted education.^{4,21-23}

5. Public concern over care of the dying, as seen in the euthanasia debate and increasing discussion of advanced directive legislation. During the 1990s, there was strong public demand for more information and control related to health care issues, requiring improved communication between health care professionals and the public.³

6. The ongoing call for sensitive and standardized data collection to assess if palliative care services are making a difference for patients and families.²⁴⁻³⁰ The lack of common definitions, measurement, and outcomes does not assist people who work in palliative care to clearly describe palliative care to other health professionals or to the public. The definition of palliative care, that which is offered when all else fails, is still prevalent with the public and with health care workers. Canada has begun to address this issue through a process of national consensus of definitions and identification of outcomes.^{6,31}

Jurisdiction for Health Care

Canada has a publicly funded health care system. The Canada Health Act,³² is federal legislation that facilitates reasonable access to health services without financial or other barriers through public administration, comprehensiveness, universality, portability, and accessibility. However, *comprehensiveness* describes health services provided by hospitals and medical practitioners, and it is up to the law of each province to define similar or additional services. Therefore, home care coverage varies from province to province and within regions of most provinces. Costs for medications and other services are provided through private insurance or provincial programs. Consequently, community-based palliative

care can vary in the access to services and in the range of services. Patients may incur variable costs in medications, supplies, availability of home care and medical services, and family assistance such as respite.⁹

The Constitution of Canada defines health care as a provincial jurisdiction in Canada. In practice, responsibility for health care is shared between the federal and provincial governments. The federal government impacts health care through legislation, regulations, and activities of its various departments, and control of financial resources for funding of health care. The provinces have the authority over health care but do not have significant resources to fund it. Therefore the creation of standards is often the interplay between national bodies, such as the CPCA, the federal government Department of Health, and the provinces.¹⁴ Consequently, a primary focus for the CPCA, founded in 1991, is the development of standardized principals of practice. In 1995, a working document including proposed definitions, statements of philosophy, principles of practice and model guidelines of practice was published as part of the process for consensus.⁶ A second document outlining the status of consensus was completed in 1999.³¹ Using the Delphi technique, the workgroup reached consensus on over 70 of the 101 items. Further national consensus building will continue, with completion anticipated by 2001. The process and result of gaining consensus on 13 principle functions will assist Canada in utilizing a common terminology, and ensuring that palliative care programs are aware of and choose to include these areas in model development.

Health Canada has provided some financial support of the CPCA. The CPCA promotes palliative care awareness, education, and research, advocating at a national level for policy, resource allocation, and support for caregivers. It organizes a national conference every second year and publishes a directory. There are provincial palliative care associations in each province. The *Journal of Palliative Care*, published by the Centre for Bioethics Clinical Research Institute of Montreal, a legacy of the Palliative Care Foundation from the 1980s, is a peer reviewed journal available internationally.

Programs of Care

Accurate statistical data about the number and type of programs, facilities, number of patients, and costs of palliative care in the literature for Canada are scarce.¹⁴ The Canadian Palliative Care Foundation completed surveys in 1981 and 1986 and the McGill Palliative Care Service completed surveys in 1990. Further surveys have been completed by the CPCA in 1994 and 1997 in the Canadian Directory of Services Palliative Care. The information from these surveys must be viewed with caution since they are based on self-reporting. Not all programs may have provided information and the definitions are not standardized.^{14,28} In 1997, for the first time, descriptor codes for common terminology were used in the directory.

Palliative care programs increased by over 300% between 1981 and 1986 (116 verses 359). The number of programs then decreased to 345 by 1990, and increased to 432 in 1994. The shift to community-based programs, rather than hospital-based programs, was noted during these time periods.³³ Programs that were based in hospitals increasingly had assigned palliative care beds (266 in 1981 to 767 in 1990). An increase was noted in long-term care facilities and the presence of a broader variety of professionals on the team.²⁸ Although there are over 600 palliative care services listed in the 1997 directory, the impact of regionalization, with the consolidation of acute care beds and the networking of services within an area, makes it difficult to determine if there is increased growth or an increase in reporting.

The number of programs and surveys does not assist us in knowing the access Canadians have to palliative care, particularly in rural settings. It is generally believed that a small minority of patients, 5%, has access to palliative care services.¹³⁻¹⁴ The majority of terminally ill patients die in acute care facilities.^{3,19,34}

There is currently a highly variable range of palliative care services development. Four provinces provide guidelines outlining components, or principles of palliative care services. Saskatchewan's guidelines outline a planning procedure and 12 core components for provision of services.³⁵ Some provinces, such as Manitoba, have specifically identified palliative care as a core health care service that every region must offer. In general, the literature discusses the need for a range of options depending on the needs of the person and his or her family at a particular point in time.^{3,33,35} The Report of the Special Senate Committee on Euthanasia and Assisted Suicide (1995) recommended that palliative care programs become a top priority in restructuring the health care system and that there be an integrated approach to palliative care: "The delivery of care, whether in the home, in hospices or institutions, with the support of volunteers, must be coordinated to maximize effectiveness."¹⁴ The Invitational Symposium reinforced the need to be flexible in allowing for episodes of heavy care, with lighter care in between. No one setting is the answer, and there are limits to what can be provided in the home. At the same time, a person may be able to stay home comfortably without the aid of any formal services. An interdisciplinary practice model including volunteers is promoted.⁹

A subcommittee update to the 1995 Special Senate Committee on Euthanasia and Assisted Suicide, released in June 2000, states that in the 5 years since the tabling of the report, little progress has been made in the area of quality end of life care. The new report recommends the federal government, in collaboration with provinces, develop a national strategy for end-of-life care.³⁶

Provinces in Canada are in different stages of regionalization of health care services. Palliative care services, which require collaboration for continuity of care, can serve as a model of program of care across sectors. In her report to *Health Canada*, Kristianson (1997) recommends a mixed model, structured as a continuum of care weighted toward home care: "... Development of this model would require vigorous home supports, home substitutes for family caregivers

respite, day hospices, trained family physicians who are affiliated with home care services. Long term hospice setting in extended care settings, and intensive specialized palliative care units in tertiary care teaching hospitals. Tertiary units would treat patients with complex symptoms and transfer to less intensive settings if stable. The model would include two consultative services: (a) a centralized, consultative service accessible by telephone or written consultation, and (b) a mobile palliative team to provide consultation to rural and remote communities.⁷² Some individuals would continue to be cared for in settings where they have received the majority of their care (for example, pediatric settings, renal dialysis units, pediatric, medical units).

Communities with large specialized populations (e.g., persons with acquired immunodeficiency syndrome [AIDS]) may create specialized units. Canada's large rural geography underlines the need for programs to have outreach components. Kristianson and others emphasized that this continuum of care requires infrastructure.

At the Invitational Symposium on Palliative Care: Provincial and Territorial Trends and Issues in Community-Based Programming (1997), provinces generally reported that models were emerging utilizing generic services complemented by specialized services. Model development includes essential components of palliative care such as pain and symptom management, interdisciplinary team, medical consultation, psychosocial/counselling care, spiritual care, volunteer, and bereavement programs.

Four underpinnings in model development are: accessibility, continuity of care, education mandate, and research-based practice. An example of a program utilizing a mixed model in Edmonton, Alberta is presented.

Edmonton Regional Palliative Care Program

The Regional Palliative Care Program for the Capital Health Region in the Edmonton area began in July 1995 following 18 months of planning. Prior to 1995, palliative care consultation was available at two sites, the Misericordia Hospital and the Edmonton General Hospital. Both programs extended into the community through either a home program (distinct from home care) or an outpatient clinic. Palliative home care services have existed in Edmonton since 1985.

The World Health Organization, in its description of planning for services, recommended four types of information to be gathered for service development: (1) number of local deaths to estimate the need, (2) information about the area to define what is changing, (3) information about resources in the area, and (4) data about the adequacy of the resources to meet the need.¹⁰ In Edmonton, the need for a coordinated, integrated palliative care program was based upon 78% of oncology patients dying in acute care hospitals, with an average of more than 20,000 patient days per year. Access to palliative care services was inconsistent and inequitable. In 1992, 290/1341 (22%) of the cancer patients who died that

year accessed one of the two available services. The need to develop accessible, cost effective, quality palliative care services within the Edmonton region was identified.

The program was designed in the midst of health care reform in the province of Alberta. Alberta was one of the earliest provinces to restructure health care into regional health authorities and significantly decrease resources for health care. Acute care beds were decreased by 30% (2731 beds in December 1992 verses 1910 beds in January 1999). A community-based program that would decrease the need for acute care beds was a timely and supported proposal for the region. In addition, in 1993, the Alberta government produced guidelines titled *Palliative Care: A Policy Framework*. The document assigned responsibility for palliative care services to the regions, and emphasized a community-based approach within a continuum of care.³⁷ The region had a clear mandate to provide palliative care services.

The model chosen for the program fit well with the provincial guidelines and is similar to the mixed model described by Kristianson.² A community-based model based on a continuum of care shifts the focus of care from acute care to the home and hospice settings. Patients and their families should have access to palliative care services regardless of their care setting. The primary site of care is the home with palliative home care and family physician support. Clearly, a goal of the program is to increase the participation of the family physicians in palliative care and to provide these physicians with adequate support.

An essential component to the acceptance of a regionalized integrated palliative care service was to involve key stakeholders in the planning and implementation of the program. Stakeholders, with the authority to approve changes, were involved in the planning of the program, and formed the basis of the ongoing Regional Palliative Care Advisory Committee (Fig. 1.1). Overall administrative support for the stakeholders to be involved and implement change within their own areas proved essential to the process.

Agreed upon definitions of palliative care and its philosophies were supported (Tables 1.1, 1.2). The goal of the program was to (1) increase access to palliative care services, (2) decrease the number of deaths in acute care facilities and (3) increase participation of the family physician in the care of the terminally ill, and provide the physicians with adequate support. The structure of the program should support patients moving freely within the various components of the regional program.

Program structure

A centralized coordinating office was established with responsibilities to: (1) coordinate the delivery of care, (2) develop standards and common assessment tools (3) identify and advocate for funding, (4) provide education for professionals and the public, (5) coordinate research, (6) educate and support volunteers, (7) identify, coordinate, and encourage the development of bereavement

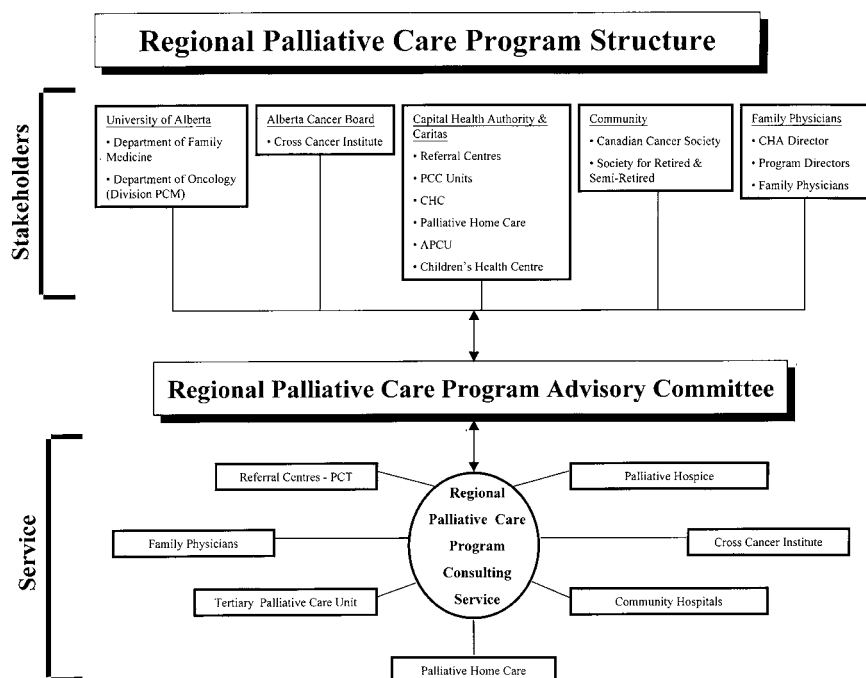


Figure 1.1. Regional palliative care program structure.

Table 1.1. Philosophy guiding the regional palliative care program

- Palliative care specialists (physicians and nurses), by offering support to primary caregivers (family doctors and interdisciplinary caregivers in the community and continuing care) and specialists when appropriate, will assist these people to provide quality palliative care through adherence to sound standards of practice.
- Every individual has the right to participate in informed discussions about the health care resource options that may help to optimize the quality of his or her life during the course of living with a life-threatening illness, especially when dying, and to choose the best possible options based on that information.
- Palliative care strives to meet the physical, psychological, social, and spiritual needs of patients and families, with sensitivity to their personal, cultural, and religious values, beliefs and practices, through patient-directed supportive interventions by an interdisciplinary team of appropriately trained professionals and volunteers.
- Care should be delivered in a patient-focused, family-centered environment.
- A patient or family-driven program contributes to successful achievement of health care outcomes.
- The program will promote interdependence, with each participating organization having both autonomy and accountability for delivering quality, cost-effective palliative care within a coordinated network of services.

Data from Ref. 47.

Table 1.2. Regional palliative care program: criteria for admission

Palliative Care Is:

Active total care offered to a patient with progressive disease and his or her family when it is recognized that the illness is no longer curable, in order to concentrate on the quality of life and the alleviation of distressing symptoms in the framework of a co-ordinated service. Palliative care neither hastens nor postpones death. It provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of care. In addition, it offers a support system to help relatives and friends cope during the patient's illness and bereavement.

(Medical/Nursing/Midwifery Advisory Committee—United Kingdom)

Based upon this definition, all people admitted to the program will:

- be experiencing progressive disease where the focus of care is on comfort, not cure, and improving his or her quality of life
- require active care to alleviate distressing symptoms related to physical, psychosocial, and spiritual needs

Approximately 85%–90% of these people will have a cancer diagnosis.

Admission Criteria to Specific Areas:

Home

- above criteria
- expected length of stay on the program of approximately 3–4 months
- do not require acute or tertiary care
- the ability to provide services within financial resources
- desire for the person or family to be cared for at home

Continuing Care (Hospice)

- above criteria
- cannot be managed at home
- do not require acute or tertiary care
- expected length of stay of approximately 2 months
- over 18 years
- accepting of no code status

Acute Care

- for management of acute medical problems (that is, pathological fracture, bleed, acute respiratory distress)
- anticipated short stay

Tertiary Palliative Care Unit

- severe symptom problems for which management has not been successful in any of the other settings, and requiring intensive management
- expected length of stay of approximately 2 weeks
- over 18 years
- accepting of no code status

Data from Ref. 47.

services, (8) manage the data and identify outcomes, and (9) provide consult teams (nurse or physician) to assist primary caregivers in providing care in the home, the hospice, and continuing care and community hospitals. The regional office liaises with the various levels of palliative care services to coordinate the delivery of services.

To increase access and provide quality palliative care services, multiple points of entry into palliative care were needed in order to address needs along a continuum of care. Four levels of care were identified to provide a continuum of care for patients and families in the region. Criteria of admission for palliative care overall and for each level of care were identified. The criteria have proved invaluable in describing the patient population, and the need for various levels of care given the complex needs of palliative care patients (Table 1.2). In all levels of care, access to consultants is available. However, to provide the shift of care from acute care to the community, increased resources were required in home care and palliative hospice.

Components of care

The following are the major components of the Edmonton Regional Palliative Care Program:

1. Palliative home care services: Palliative care services in the home were already available in the region. Increased funding was allocated to home care for increased delivery of palliative care at home, including 24-hour care. Some respite is provided in the home. Family physicians provide primary medical care for palliative patients in the community. Referrals can be made to a volunteer community day hospice program (Pilgrim's Hospice), or other day and respite programs in the region. Accessible transportation and level of acuity are barriers to patients' using these services.

2. A total of 57 palliative hospice beds in 3 continuing care centers were allocated from existing continuing care level services. The hospices received increase resources for nursing, interdisciplinary teams, and medications. Each of the three hospices has a dedicated nurse manager and 24-hour registered nurse coverage. Enhanced interdisciplinary teams include social work, pastoral care, pharmacy and rehabilitation. Respite care is available in the hospice if a bed is available.

3. Four full-time salaried teams of a consultant nurse and physician were established in order to provide community consultation. An automatic consultation occurs upon admission to a hospice bed. The consultants also serve as the access for palliative hospice beds, triaging, and coordinating admissions.

4. Each referral centers for acute care have nurse and physician teams available for consultation throughout the hospitals. Increased funding was provided to ensure equitable services to both referral centers. Community consultants provide coverage at the community hospitals.

5. The tertiary palliative care unit (14 beds), which existed previous to the regional program, could now focus on admitting patients with the most severe symptoms for which management has not been successful in any other setting.

6. Palliative care codes for physician reimbursement were added in 1994 in Alberta, allowing family physicians to be compensated for longer visits (including the home) required for palliative care assessment, and for family and interdisciplinary formal discussion.

7. A centralized training and support program for volunteers was designed in the first year of operation. Volunteers are members of their own site's volunteer program, with a centralized support and training base. Volunteers in this region do not provide physical care, but provide a multitude of services for patients, families, and staff.

8. A bereavement model was designed utilizing focus groups and staff input. The model outlines the need to identify persons at high risk for complicated bereavement, to provide equitable access to bereavement follow-up through information and telephone, and to identify community resources for bereavement.

9. To provide seamless care for palliative patients, strong links are required with the cancer agency to ensure that discharged patients, or patients no longer receiving curative therapy, are linked to regional palliative resources. A community liaison nurse based at the cancer agency is responsible for assessing all patients discharged who are receiving no further curative treatment. The nurse provides a palliative assessment, utilizing symptom assessment tools used throughout the region, and ensures the patient has a family physician caring for them. The nurse encourages patients to discuss with her or his family physician the physician's ability to provide home visits and on-call coverage 24 hours per day. The nurse maintains and distributes a list of family physicians able to care for palliative patients if the patient is not already linked to a physician. In addition, an interdisciplinary outpatient clinic for consultation of pain and symptom control is available for outpatients at the cancer agency.

10. To provide common language, decrease duplication, and ensure a complete assessment, common patient assessment tools are used by all sites. The following common tools are utilized; the Edmonton Symptom Assessment System,³⁸ the Mini Mental State Examination,^{39,40} the CAGE Questionnaire^{41,42} and the Edmonton Staging System for cancer pain.⁴³ All data from the above assessments are entered into a palliative care database.

The program is designed to be evidenced-based and outcome-driven. Guidelines are set on best available research findings. Handbooks of palliative care guidelines are written for family physicians,^{44,45} nurses⁴⁶ and family caregivers.⁴⁷ Outcomes of criteria of admission, availability of consultants, numbers of deaths per setting, and average length of stay were set out at the beginning of the program. The outcomes of the program for each year are compared to the data available during program planning (1992/1993) every year in the annual report of the program.

11. Education: A primary role of the program is to educate both health professionals and the public about palliative care. A model of care based on primary caregivers providing palliative care, with consultant support as necessary, requires initial and ongoing education for nursing, interdisciplinary staff, and family physicians. The average family physician will see 1–2 cancer deaths per

year. In the Edmonton region, there are approximately 840 family physicians registered, with approximately 1300 cancer deaths per year. If one supports the continuum of care for patients, allowing physicians to follow their patients during the terminally ill phase, these physicians will require education and support in palliative care.^{48,49} Attending physicians are encouraged to provide primary medical care for their patients in the hospice setting.

Consultants provide initial orientation to new staff working directly in any of the palliative care sites. Ongoing inservices, palliative care rounds and city wide rounds, community bus rounds (biweekly),⁵⁰ workshops, annual retreat for palliative care staff, and an annual palliative care conference (350 registrants in 1998) are provided. Standardization of teaching material is occurring, with the availability of audiovisual teaching aids and handouts about common palliative care topics.

12. Research: All physicians work within the Division of Palliative Medicine and therefore have clear expectations for education and research. The tertiary palliative care unit is designed as both an intense clinical, educational, and research unit for all disciplines. Family medicine residents rotate to the unit for 2 weeks, also going out into the community with the community consultants. There is an accredited conjoint Postgraduate Program in Palliative Medicine (College of Family Physicians and Royal College of Physicians and Surgeons of Canada), based on the tertiary unit. This unit frequently trains physicians from many settings for varying lengths of time. Because of common standards and ethics reviews, research studies are now easier to expand beyond the tertiary unit into other palliative care settings.

13. A palliative care database, created prior to the start of the program for the tertiary unit, was adapted to allow data entry from all levels of care. A dedicated database was considered essential for program planning and quality control. Patient demographics, clinical data (diagnosis, symptom assessment, Edmonton Staging Symptom (ESS), CAGE Questionnaire Mini Mental State Examination (MMSE), comfort assessment, and data describing the movement of patients through the program (referred from, discharged to, hospice preference site) are recorded. The referring physician is listed to gather information on the number and type of physicians referring patients. A data manager is responsible for quality control and reporting. All areas of the program, except home care, are presently entering data (acute care collects patients referred for palliative care consultation only). Home care began data entry in 1999.

Outcomes

An increase in access to palliative care services as measured by palliative care consultation was significant. During 1992, 290/1341 (21%) patients accessed a palliative care consult team compared to 1110/1326 (84%) in 1996 and 1070/1229 (87%) during 1997 ($p < 0.0001$ overall). The numbers of cancer patients access-

Table 1.3. Number of cancer deaths by site of death in the Edmonton Region (Capital Health Authority)

<i>Place of death^b</i>	<i>1992/1993^a (%)</i>	<i>1994/1995^a (%)</i>	<i>1996/1997^a (%)</i>	<i>p</i>
Acute care facilities ^c	1119 (86)	877 (71)	633 (49)	<0.0001
Palliative hospices	0	0	378 (30)	<0.0001
Continuing care centers ^d	53 (4)	96 (8)	38 (3)	<0.0001
Home	126 (10)	259 (21)	227 (18)	<0.0001
Other	6 (—)	8 (1)	3 (—)	=0.299
Total	1304 (100)	1240 (100)	1279 (100)	

^aBased on fiscal year of April 1–March 31.

^bData from Alberta Cancer Registry except for Palliative Hospices data from Edmonton Regional Palliative Care data base. Data from the Alberta Cancer Registry are provisional as some deaths may be registered in subsequent years.

^cAll acute care hospitals in Capital Health Region, tertiary palliative care unit, and cancer center.

^dIncludes all continuing care level facilities such as nursing homes and auxiliary hospitals.

ing services were gathered from the records of the existing palliative care services in 1992, and from the program database in 1996 and 1997.

The total number of cancer deaths per year is reported from the Alberta Cancer Registry by site of care. Cancer deaths occurring in acute care facilities decreased significantly between 1992/1993 and 1996/1997. Table 1.3 describes the number and location of cancer deaths in acute care (tertiary, community, and cancer hospitals), palliative hospices, continuing care facilities (all levels including nursing home, and auxiliary) and in the home between 1992/1993 and 1996/1997. Primarily the shift in care was to palliative hospices and to the home.

Average length of stay in acute care also decreased significantly over the same time period (Table 1.4). The cancer center is a separate region from the acute care facilities in the Edmonton region and is therefore reported separately. The decrease in acute care deaths and in length of stay significantly decreased the number of acute care patient days.

The corresponding decrease in costs for palliative care in the use of palliative hospice beds at \$161.70/day (1996/1997) and home care (costs not available) versus acute care medical beds \$508/day (Department of Finance, Capital Health Authority) is significant, given the shift of care to hospice. However, further research is required to show actual cost savings realized, particularly costing of care in the home (including the shift of care to family caregivers).

Another indicator for the program is the number of physicians who consulted the program each year. During 1996/1997, 372 distinct physicians referred patients to consultants. Family physicians represented 77% (287) of all physicians referring. Of the 840 family physicians registered in the Edmonton region, 35% referred to the program. In 1996, 240/268 (89%) of palliative care cancer patients discharged from the cancer center chose to stay with their family physician, when asked if they wanted to change, or had no designated physician. For the 28 patients who requested a new family physician, one was found within 24

Table 1.4. Length of stay and number of patient days of last hospitalization before death in the Edmonton Region (Capital Health Authority)

	1992/1993 ^a	1996/1997 ^a	1997/1998 ^a	p
Acute Care Hospital^b				
Total number of deaths (%) ^c	825 (63%)	403 (32%)	373 ^d	<0.0001
Mean length of stay in days (± SD) ^e	27 ± 16	15 ± 7	16 ± 7 ^f	<0.0001
Total number of patient days	22,608	6,085	6,036	N/A
Cancer Center^g				
Total number of deaths (%) ^c	130 (10%)	95 (7%)	115 ^d	0.02
Mean length of stay in days (± SD) ^e	15 ± 21	9 ± 10	11 ± 11 ^h	<0.005
Total number of patient days	1,958	875	1,275	NA

^aBased on fiscal years April 1–March 31.
^bData from Capital Health Authority: Evaluation, Information, and Research.
^cPercentage of cancer deaths in acute care over total number of cancer deaths in region.
^d*p* value not possible for 1997/1998 because the proportion of acute care deaths over total number of deaths is not available.
^eSD, Standard deviation.
^f*p* < 0.0001 for 1992/1993 versus 1997/1998.
^gData from Cross Cancer Institute, Health Records (cancer center).
^h*p* = 0.059 for 1992/1993 versus 1997/1998.

hours from the list of 150 physicians who volunteered to take care of new patients.⁵¹

A survey of family physicians was completed in 1999. A return of 39% (327/840) was received following two mail outs. Of the returned surveys, 72% (234) had referred to the program, and 35% (113) had cared for a patient in a hospice setting. There was strong agreement (6 or 7 on 7-point likert scale) that the palliative care physician consult improves patient care (83%), and helps a patient be cared for in their preferred setting (82%).

Outcomes by level of care

The establishment of outcome criteria prior to the initiation of the program was helpful in describing the direction, effect, and changes expected throughout all areas in the health care system in the region for palliative care. The collection and data entry of clinical data about the patient's symptoms assists us in monitoring the clinical status of the patient population.

Table 1.5 describes clinical outcomes for the levels of care. Specific data for home care patients are not available for the time period reported. Clinical data from consultant referrals do occur in the home (47%), but refer to a more severe population within the home, since a consultation had been requested. The outcomes for each level of care are discussed below:

1. The tertiary palliative care unit, as one of two sites to access palliative care in 1992, cared for 168 patients that year. The change expected in a regionalized

Table 1.5. Clinical outcomes^a by site of care for patients discharged November 1, 1997–October 31, 1998

Site of care	TPCU ^b	Acute care ^c	Hospice ^d	Consultant ^e	Chi square
Number of Patients	163	664	499	924	
Age (mean \pm SD) ^f	61.5 \pm 13.9	68.6 \pm 14.3	72.3 \pm 12.6	70.6 \pm 13.1	
CAGE ^g	26 (34/129)	11 (69/605)	N/A	21 (128/604)	$p < 0.0001$
Pain Stage 2 (ESS) ^h	64 (81/126)	34 (207/603)	N/A	N/A	$p < 0.0001$
Pain % ⁱ	57 (89/156)	32 (207/603)	36 (145/407)	54 (326/566)	$p < 0.0001$
Activity %	70 (107/154)	77 (483/624)	59 (254/431)	85 (471/564)	$p < 0.0001$
Nausea %	24 (37/152)	11 (69/636)	15 (55/368)	20 (115/571)	$p < 0.0001$
Depression %	43 (64/148)	28 (159/573)	29 (113/391)	36 (177/497)	$p = 0.0004$
Anxiety %	53 (81/152)	31 (178/583)	31 (125/403)	41 (199/490)	$p < 0.0001$
Drowsiness %	53 (81/154)	45 (282/621)	49 (204/417)	56 (308/548)	$p = 0.0026$
Appetite %	66 (121/152)	70 (431/617)	60 (257/428)	70 (386/551)	$p < 0.0001$
Wellbeing %	61 (89/147)	50 (270/540)	46 (184/404)	68 (256/379)	$p < 0.0001$
Shortness of Breath %	29 (45/153)	30 (132/630)	22 (88/393)	32 (177/560)	$p < 0.0001$
MMSE % ^j	40 (57/143)	39 (239/606)	58 (152/324)	28 (139/503)	$p < 0.0001$

^aData from Regional Palliative Care Program.^bTertiary Palliative Care Unit.^cPatients referred for palliative consultations in tertiary referral centres: Royal Alexandra and University of Alberta Hospitals.^dIncludes 57 palliative hospice beds.^ePatients referred for palliative consultation in community and community hospitals. Unique data for palliative home care not available.^fMean \pm standard deviation.^gPercentage of patients with positive CAGE Questionnaire ($\geq 2/4$), indicating risk for chemical coping.^hPain Stage: percentage of patients with pain stage 2 or 3, indicating poor prognosis for pain management, as measured by the Edmonton Staging System (ESS) for cancer pain.ⁱScore ≥ 5 for 0–10 ESAS (Edmonton Symptom Assessment Scale) indicating severe symptom for patient. First ESAS completed at site.^jAbnormal Mini-Mental Stage Examination (MMSE) $\leq 80\%$ of answers correct. First MMSE completed at site. Indicator for cognitive impairment.

program, with enhanced community palliative care, was that the unit would care for more patients, address complex symptoms, and then discharge the patient to the most appropriate setting, resulting in a shorter length of hospital stay. Slightly fewer patients would die on the tertiary unit, since other options for palliative care would exist.

In 1997, the number of patients and the length of stay did not decrease. However, as options for admission to the most appropriate setting of care existed, the acuity of the patients admitted to the unit was higher. There will continue to be a subset of patients on the unit with higher acuity and poor coping mechanisms who will remain on the unit, as no other site of care can provide acute enough management (Table 1.5). The patients are younger (average age 62 versus 72 in the hospices) with a higher incidence of stage 3 pain (72%) indicating a poorer prognosis for pain management. Positive CAGE Questionnaire scores are higher (26% versus 14% for acute care consultants), indicating poor coping mechanisms on this unit.

The patients on the tertiary unit have significantly higher scores of all symptoms measured by the ESAS. Table 1.5 outlines the first measurement of ESAS scores at the different levels of care. Because of the large number of corrections of comparison, the correction factor of Bonferroni was used. A score of 0.004 was accepted as significant.

2. Acute Care Hospitals: Palliative care nurse/physician consult teams in the two large referral hospitals provided consultation for 656 cases in 1997. These consultants tend to see patients earlier in their illness trajectory and provide skilled advice in symptom management, communication and discharge planning. In 1996/1997, 36% of patients were discharged home, 18% to hospice, 8% to the tertiary unit, 18% to other sites and 20% died.⁴⁷

3. Palliative Hospice: The largest shift of care was the transfer of patients into the palliative hospices, the majority coming from the home (41%) and from acute care (38%). The average length of stay was much shorter than anticipated (42 versus 66 days). With a median length of stay of 22 days, half the patients were staying for short periods, increasing the acuity for the hospices. There were increased admissions, family conferences and preparation for death. Occupancy of the hospice beds was 92% in 1996/97.⁵² This number allows for rapid admission to the hospices as required. As expected, incidence of cognitive impairment is highest in this setting (Table 1.5), and is often listed as a primary reason for admission.

4. Home: A small shift of care has occurred in cancer deaths occurring at home, much lower than the planned 40% (126 versus 227, an increase of 8% from 1992 to 1996). Further enhancements to palliative home care continue to occur in delivery of care. Access to lab and medication (community pharmacies available 24 hours/day, and will courier medications) have been resolved. It is unclear to what extent the availability of hospice bed influences patient and family choices for a home death. Hinton (1994)¹⁷ describes how the availability of hospice beds permitted more confident perseverance at home, where people received 90% of the palliative care. However, further research is needed to determine to what extent patients and families prefer a home death in a regionalized system of palliative care, with palliative hospice available, as they move within a continuum of care.

Consultants are available to visit patients in the community. Consultants also support home care case managers through telephone consultation and education. Beginning February 1, 1999, the Alberta government introduced a palliative care drug plan that provides immediate medication coverage for those patients (primarily under 65 without health insurance) who do not have a drug plan.

Discussion

The outcomes outlined at the beginning of the program have generally been met in the first 3 years of operation. Access to palliative care, as measured by pallia-

tive care consultation, increased significantly, to 87% of cancer patients. The program is not exclusive to oncology (Table 1.2); patients with other diagnosis who require active palliative care to alleviate their symptoms are cared for and admitted to the program. In 1996/1997, 8.2% of patients' primary diagnoses were other than cancer. This does not include home care, which has a higher proportion of other diagnoses. However, the cancer population is used to determine outcomes because it is a population that is definable and most prevalent. The definition of palliative care, particularly in acute care facilities is not consistent. The population seen by the program is definable, but not every palliative care patient requires consultation and is therefore not recorded in the program database.

Data are collected from the Information Office for the region, the Capital Health Authority, on overall cancer deaths in acute care facilities. Data are also collected from the Cross Cancer Institute given that the Edmonton cancer center has inpatient oncology beds. (Table 1.4). Table 1.3 shows a discrepancy in the number of cancer deaths reported by the Alberta Cancer Registry and the Capital Health Authority for both the 1992/1993 and 1996/1997. This difference noted is 955 and 498 for the 1992/1993 and 1996/1997 period from the Capital Health Authority, verses 1119 and 633 for 1992/1993 and 1996/1997 for the Alberta Cancer Registry. The difference is most likely because of different methodologies of definition of cause of death (admission and discharge summaries verses death certificates). However, using either data source, a large and significant decrease in the number of cancer deaths has occurred in acute care facilities.

The model of care utilizing the family physician as the primary caregiver, with consultant support, is the most common and realistic in a regionalized model of care. However, involvement of the family physicians throughout the continuum of care, when care is shifted to the community, results in increased involvement of family physicians in both simple and complex cases. Issues of reimbursement, education, and a willingness to provide home or hospice visits and 24-hour coverage need to be addressed. Involvement of 35% of the family physicians per year, and more than 600 distinct physicians since the program began 3.5 years ago suggests family physicians are providing palliative care. Ongoing and creative methods of education are required, given that the average family physicians will only see 1–2 patients per year with a cancer death population of approximately 1300/year. Data collection is ongoing in determining what percentage of physicians follow patients into hospice settings. Determination of family physicians willing to care for new patients and measurement of physician satisfaction with palliative consultant and care options must be ongoing indicators of the program. Initial family and physician satisfaction was positive following 1 year of operation.⁵³ The survey of family physicians completed in 1999 supported the role of physician consultants in improving patient care.

Patient and family satisfaction data are collected at some settings within the program, but there is need for a unified measurement of satisfaction from both

patients and family. This very important indicator will add to the overall outcomes of the program.

A primary outcome of any program is the clinical outcome of care. In palliative care, this is a comparison of symptom management from prior to initiation of the program to the present. Issues of access and site of death, although important, are put into context by the clinical indicators of good symptom management. Unfortunately, this comparison is not possible since data collection on symptom management in the acute care facilities, where most of the deaths were occurring in 1992/1993, did not occur. Today, measurement of symptom distress is recorded on patients referred to consultants in acute care, but not on every palliative care patient. The other issue for palliative care is the interpretation of symptom measurement in a population where clinical deterioration is the expected course.^{24,29,54} This issue can only be confirmed in prospective studies assessing physical and psychological symptom management.

The criteria for admission and model design for the Edmonton area program has attempted to clearly articulate the patient population and options for care, based on patient need and preference (Table 1.2). This assists any type of program in planning for resources and measuring outcomes, particularly in palliative care, where definitions and standards of care are still developing consensus. As recent literature in Canada and elsewhere discusses the need for palliative care earlier in the illness trajectory^{54,55} and to increase access of palliative care beyond oncology,⁶ the Edmonton area program continues to discuss and define its mandate in relation to this particular community and patient population.

Conclusion

The Edmonton Regional Palliative Care Program is one example of model development in a regionalized program using both generic services complemented by specialized services. Other programs throughout Canada have developed to meet the needs of their communities. Many programs have begun the process of regionalized program of care only in the last few years. The process and results of consensus building toward national definitions and standards in palliative care continue to influence the direction and comprehensiveness of palliative care services in Canada.

Acknowledgment

The authors greatly appreciate the statistical and editorial assistance from Catherine Neumann, M. Sc., Division of Palliative Medicine, University of Alberta.

References

1. Doyle D, Hanks G, MacDonald N. Introduction. In: Doyle D, Hanks G, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press, 1998:3–8.
2. Kristianson L. Generic versus specific palliative care services. Final report. Health Care and Issue Division Systems for Health Directorate. *Health Canada*, 1997.
3. Wilson DM, Anderson MC, Fainsinger RL. Social and health trends influencing palliative care and the location of death in twentieth-century Canada. Final Report. *Health Canada. National Health and Research Development Program*, 1998.
4. Doyle D, Hanks G, MacDonald N. The provision of palliative care. In: Doyle D, Hanks G, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press, 1998:3–8.
5. Report to Cancer 2000 task force. The Expert Panel on Palliative Care, 1991.
6. Ferris FD, Cummings I, eds. *Palliative Care: Towards a Consensus in Standardized Principles of Practice. First Phase Working Document*. Ottawa Ontario: Canadian Palliative Care Association, 1995.
7. Report of the working group on special services in hospitals. *Palliative Care Services in Hospitals, Guidelines*. Ottawa, Ontario: National Health and Welfare Canada, 1981.
8. Report of the subcommittee on institutional program guidelines. *Guidelines for Establishing Standards. Palliative-Care Services*. Ottawa, Ontario: Health and Welfare Canada, 1989.
9. LaPerriere B. Proceedings of the invitational symposium on palliative care: provincial and territorial trends and issues in community-based programming. *Health Canada. Health System and Policy Division*. 1997.
10. World Health Organization. *Palliative Cancer Care: Policy Statement Base on Recommendations of a WHO Consultation*. Leeds, February 1987. Copenhagen. World Health Organization, 1989.
11. Canadian Palliative Care Association. Board of Directors. *Avisco* 1999; Spring 27:2.
12. Task Force on the Allocation of Health Care Resources of the Canadian Medical Association (Watson J, chair). *Health, a need for redirection*. Ottawa: Canadian Medical Association, 1983.
13. Scott JF. Palliative care 2000: mapping the interface with cancer control. *J Pall Care* 1992; 8(1):13–16.
14. Of Life and Death. Report of the Special Senate Committee on Euthanasia and Assisted Suicide. Ottawa: *Senate of Canada*. 1995.
15. Chochinov HM, Kristianson L. Dying to pay: the cost of end-of-life care. *J Pall Care* 1998; 14(4):5–15.
16. Emanuel EJ. Cost savings at the end of life. What do the data show? *JAMA* 1996; 274(24):1907–1914.
17. Goodwin PJ. Economic factors in cancer palliation—methodological considerations. *Cancer Treat Reviews* 1993; 19:59–65.
18. Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer and their relatives? *Pall Med* 1994; 8:183–196.
19. McWhinney IR, Bass MJ, Orr V. Factors associated with location of death (home or hospital) of patients referred to a palliative care team. *Can Med Assoc J* 1995; 152(3):361–367.

20. Cantwell P, Turio S, Brenneis C, et al. Predictors of home death in palliative care cancer patients. *J Pall Care* 2000; 16(1):23–28.
21. Downing GM, Braithwaite DL, Wilde JM. Victoria BGY model—a new model for the 1990's. *J Pall Care* 1993:26–32.
22. Lindop E, Beach R, Read S. A composite model of palliative care for the UK. *Int J Pall Nurs* 1997; 3(5):287–292.
23. Stjernsward J, Colleau SM, Ventafridda V. The World Health Organization cancer pain and palliative care program past, present and future. *J Pain Symptom Manage* 1996; 12(2):65–72.
24. Broadfield L. Evaluation of palliative care: current status and future directions. *J Pall Care* 1988; 4(3):21–28.
25. Maltoni M, Travaglini C, Santi M. Evaluation of the cost of home care for terminally ill cancer patients. *Supp Care Canc* 1997; 5:396–401.
26. Scott JF. Palliative care 2000: what's stopping us? *J Pall Care* 1992; 8(1):5–8.
27. Munn B, Worobec F. Data collection as the first step in program development: the experience of a chronic care palliative unit. *J Pall Care* 1997; 13(2):39–42.
28. Cummings Ajemian I. Palliative Care in Canada: 1990. *J Pall Care* 1990; 6(4):47–58.
29. Jarvis H, Burge FI, Scott CA. Evaluating a palliative care program: methodology and limitations. *J Pall Care* 1996; 12(2):23–33.
30. Degner LF, Henteleff PD, Ringer C. The relationship between theory and Measurement in evaluations of palliative care services. *J Pall Care* 1987; 3(2):8–13.
31. Ferris FD, Adams D, Balfour HM, et al. How close are we to consensus? A report on the first cycle of the national consensus-building process to develop national standards of practice for palliative care in Canada. Ottawa, Ontario: *Canadian Palliative Care Association* 1999.
32. Canada Health Act. 1984., c. 6, s. 1. pp. 1–12.
33. O'Donnell NM. A regional approach to palliative care services. *J Pall Care* 1992; 8(1):43–46.
34. Bruera E, Neumann C, Gagnon B, et al. Edmonton Regional Palliative Care Program: impact on patterns of terminal Cancer Care. *Can Med Assoc J* 1999; 161:290–293.
35. *Guidelines for Developing an Integrated Palliative Care Service*. Saskatchewan Health. April 1994.
36. Quality End-of-Life care: The right of every Canadian. Subcommittee to update “of life and death” of the Standing Senate Committee on Social Affairs, Science and Technology. *Senate of Canada* June, 2000
<http://www.parl.gc.ca/36/2/parlbus...m-e/upda-e/rep-e/repfinjun00-e.htm>.
37. *Palliative Care: A Policy Framework*. Alberta Health. December 1993.
38. Bruera E, Kuehn N, Miller MJ, et al. The Edmonton symptom assessment system (ESAS): a simple method for the assessment of palliative care patients. *J Palliat Care* 1991; 7(2):6–9.
39. Folstein MF, Fetting J, Labo A, et al. Cognitive assessment of cancer patients. *Cancer* 1984; 53(suppl 10):2250–2257.
40. Bruera E, Miller MJ, McCallion J, et al. Cognitive failure (CF) in patients with terminal cancer: a prospective study. *J Pain Symptom Manage* 1992; 7:192–195.
41. Bruera E, Moyano J, Seifert L, et al. The frequency of alcoholism among patients with pain due to terminal cancer. *J Pain Symptom Manage* 1995; 10(8):599–603.
42. Moore R, Bone L, Geller G, et al. Prevalence, detection and treatment of alcoholism in hospitalized patients. *JAMA* 1989; 261:403–407.