

## *Health Policy Research Program Summary of Research Results*

**Title:** Integration of End of Life Care: A Health Canada Synthesis Research Project

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**Research Category:** Synthesis

**Institution:** University of Alberta

**Project Number:** 6795-15-2002/4780004

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### *Summary*

#### **Introduction**

Most of the 220,000 Canadians who die each year now, principally of old age and progressive ill health, do not have access to integrated end-of-life (EOL) services. Although growing in number, hospice and palliative care programs are unevenly distributed across Canada, most are small with regard to service capacity, and the services provided differs from one program to another. Many dying Canadians are thus in the difficult position of having to actively seek the health and social services that could ease their passage through the final days or weeks of life, while most are at risk of uncoordinated and therefore potentially inadequate EOL care.

Among all vulnerable persons, dying persons are arguably the most vulnerable. The dying process is often difficult, as a result of emotional and physical challenges. All too often, given the uncoordinated state of EOL health and social services in Canada, dying persons must rely on family and friends to support them through the EOL process. Although the loving support of family and friends when available is irreplaceable, EOL care is an important public obligation.

#### **Overview of Synthesis Research Project**

The aim of this October 2002 through September 2003 synthesis research project was to identify EOL care delivery models or approaches that would best foster integrated EOL care in Canada. Four objectives guided this research:

1. To determine how developments toward increased health system integration and/or regionalization have affected the delivery of health care services to persons with terminal illnesses.
2. To evaluate the impacts and outcomes of integrated EOL programs compared to traditional EOL care for terminally-ill individuals, their families, health care providers, and health care administrators.
3. To identify and describe best practice models or approaches from the point of view of the infrastructure or components needed to support effective integrated health systems that ensure quality EOL care for terminally-ill persons and their families.
4. To identify the policy implications for federal, provincial, territorial, regional, and municipal governments in Canada of a shift toward the provision of EOL care in the context of integrated health care/delivery systems.

### **Research Methods**

An interdisciplinary international team undertook four interrelated research activities.

1. An extensive literature search and review. In total, 27 literature reviews were written.
  - Canadian End-of-life Care Programs, Models, and Approaches
  - International End-of-life Care Delivery Models or Approaches
  - The Needs of Dying Persons The Needs of the Families of Dying Persons
  - Pediatric End-of-life Care
  - Gender Differences in the Experience of the Dying Process
  - Culture and End-of-life Care
  - Aboriginal End-of-life Care
  - End-of-life Spiritual and Psychosocial Issues
  - Bereavement
  - Managing End-of-life Pain and Other Symptoms Through Non-Pharmacological Means
  - End-of-life Prognostication
  - Literature Reviews That Have Focused on End-of-life Care
  - End-of-life Topics Addressed In Randomized Controlled Clinical Trials Research
  - Continuity of End-of-life Care
  - End-of-life Case Management
  - The Home as a Place of End-of-life Care
  - End-of-life Care in Acute Care Hospitals
  - End-of-life Care in Intensive Care Units
  - End-of-life Care in Residential Continuing-Care Facilities
  - End-of-life Care in Rural or Remote Areas
  - Palliative Day Care
  - End-of-life Respite Care
  - Volunteers Involved in End-of-life Care

- Outcomes and Evaluation of End-of-life Care
  - Education in Canada for End-of-life Care
  - New Developments in End-of-life Care
2. The creation of three web-based questionnaires to gather current EOL needs and issues information from persons near the end of life, their families and friends, and EOL health care providers and care planners.
  3. The analysis of a complete set of provincial home care data, data that reflect home care client and service trends over a 10-year period (April 1, 1991 – March 31, 2001) in Alberta.
  4. Site visits to gather information about EOL care programs. Site visits were made to a broad selection of programs in five countries or global regions: New Zealand, Australia, United Kingdom and Republic of Ireland, United States, and Canada.

### **Key Components of a Canadian Best Practice Integrated End-of-life Care Model or Approach**

A considerable number of EOL care delivery models and approaches exist, both in Canada and other countries. For many reasons, the research team rejected all models or approaches that involve for-profit EOL care, and private pay or private insurance methods of payment for EOL care. Instead of identifying a single model or approach as superior above all, the research team identified key components within the various models and approaches that are essential for fostering a best practice integrated EOL care model or approach in Canada. There are four such components:

1. Universality
2. Care Coordinator
3. A Broad Range of Basic and Advanced End-of-life Services, and
4. An Assurance of End-of-life Services Regardless of Care Setting.

#### **Universality**

A broad range of health care and social support services need to be available to all persons who are near the end of life (EOL) and their significant family members or friends.

#### **Definitions**

“Persons who are near the end of life” are individuals experiencing a decline in health that could reasonably be expected to lead to death within the next 12 months.

“Significant family members or friends” are those persons who are actively involved in planning or providing support to persons who are near the end of life.

## **Justification**

Much public and professional concern has existed for many years in Canada over EOL care. This concern has led to the ad hoc creation and growth of palliative care programs, hospices, and EOL services across Canada. The result of this necessary but largely grass roots and voluntary effort is an uneven distribution of EOL programs across Canada, considerable differences in the EOL services that are available to Canadians who are near the end of life and their significant family members or friends, unmet care needs, and largely uncoordinated EOL care services. Furthermore, public funding for EOL care varies considerably across Canada and also within provinces/territories, with most EOL programs today relying heavily on private or charitable donations to address their capital and operating costs.

Although death and dying may be intensely personal matters, EOL care is an important public obligation.

Given the value that Canadians place on universal health and social programs, EOL services for persons who are near the end of life and their significant family members or friends should not be limited by personal financial resources or geographic location within Canada; nor should EOL services be limited on the basis of age, gender, the condition that will lead to death, the presence or absence of social resources such as significant family members or friends and the ability to speak one or both official languages of Canada, and any other relevant factors - such as time of day or day of week.

## **Policy Implications**

Given the current state of EOL care in Canada, and projected as well as growing difficulties in the absence of collective and concerted policy leadership on EOL care, the development of a pan-Canadian End-of-life Care Network to further EOL care and program developments, including clear working practice guidelines and organizational components, such as mandatory accreditation, is needed as soon as possible in Canada to ensure a broad range of health care and social support services are available to all persons near the end of life and their significant family members or friends.

### **This initiative will require the following:**

- A. Intersectoral planning to ensure EOL care is a priority for federal, provincial, and territorial governments across Canada.
- B. Intersectoral planning to ensure a common set of publicly-funded EOL services are available across Canada for all persons near the end of life, and their significant family members or friends.
- C. Intersectoral planning to identify end-of-life (EOL) care delivery models or approaches that would best foster integrated EOL care in Canada. Full-service

programs offer all health and social services that may be needed by persons near the end of life and their significant family members or friends, with service provision thus integrated within one program. Limited-service EOL programs offer some of the health and social services that are needed by persons near the end of life and their significant family members or friends, and employ a Care Coordinator to ensure EOL service integration.

- D. Intersectoral planning to secure sustained federal government funding for accredited EOL programs or program components, and ensure ongoing provincial/territorial and/or regional fiscal support of accredited EOL programs or program components.
- E. Targeted federal research funding to strengthen EOL services and EOL programming, including research in the areas of: voluntary sector versus public sector provision of EOL care services, the value of alternative therapies for persons near the end of life, the amount and types of formal home care needed to prevent informal caregiver burnout, the amount and types of health and social services needed to support home deaths when these are desired, the amount and types of health and social services needed by the frail elderly who live in private residences, the amount and types of additional health and social services needed by persons living in residential continuing-care facilities who are near the end of life, EOL staffing trends and issues, and outcome measures for EOL care.
- F. Intersectoral planning to further existing and additional EOL initiatives, while supporting the growth and development of Canada's national EOL association – the Canadian Hospice Palliative Care Association.
- G. Intersectoral planning for the development and maintenance of a toll-free EOL telephone service and/or website for the provision of information on EOL services and accredited EOL programs to persons near the end of life, their significant family or friends, and others such as EOL care providers. This information service should be a key resource to ease access to EOL services for persons near the end of life and their significant family members or friends, and a major EOL information source for health care providers and planners.
- H. Intersectoral planning for public service advertising to further public knowledge and acceptance of the toll-free telephone and/or website service, and End-of-life Care Network.

### **Care Coordinator**

EOL services for persons who are near the end of life and their significant family members or friends should be arranged through an EOL Care Coordinator - an individual with specialized EOL knowledge and skills, such as a palliative care nurse, a nurse practitioner, a palliative care physician, a community-based home care or public health nurse, social worker, hospital-based case manager, or another salaried individual who can: (a) assess EOL needs and required EOL services, (b) plan and prescribe needed

EOL services, (c) evaluate EOL services and care outcomes, (d) work within a team or through a team concept where the person who is near the end of life and their significant family members or friends are the first and most significant team members, and (e) be accessible and accountable at all times personally or through a pre-arranged designate to each person who is near the end of life and their significant family members or friends.

### **Justification**

Most, if not all, EOL care programs in Canada and those visited outside Canada employ a Care Coordinator in a salaried position, almost always a Registered Nurse with advanced EOL care skills and knowledge. This person performs the intake assessment and develops the initial care plan in conjunction with the person near the end of life and their significant family members or friends. This Care Coordinator then maintains a relationship with the person who is near the end of life and their significant family members or friends. The Care Coordinator also provides ongoing specialized EOL care services, such as symptom assessment and management. Service integration and care coordination are common outcomes of having a distinct person made responsible and accountable for fulfilling this role. Persons near the end of life and their significant family members or friends benefit by having an enduring contact point through which EOL care can be arranged.

A major issue, however, with regard to Registered Nurse and other non-medical Care Coordinators is their lack of legislated and/or organizationally-approved ability to prescribe common EOL medications and services, including the admission and discharge of persons near the end of life from health care facilities. This issue has at least four serious implications: (a) timely access to needed EOL services is reduced, (b) some needed EOL services may never be obtained, (c) fee-for-service family physicians are placed in the position of having to take on the time-consuming and difficult role of the Care Coordinator, and (d) palliative care physician specialists are not used as efficiently or effectively as they could be if they worked in partnership with a skilled EOL Care Coordinator who can assess and manage the majority of EOL concerns, and recognize when specialist palliative care physician services are required.

Timely care is critical to the identification of potential or existing problems, the prevention of problems, and the early and successful resolution of problems. Furthermore, timely communication is one of the most fundamental necessities for integrated, high quality EOL care. A single EOL Care Coordinator, as opposed to a mesh of care providers, is one of the most critical factors for ensuring the communication that is needed by persons near the end of life, their significant family members or friends, and their health care providers.

Although some comprehensive EOL care programs exist in various parts of Canada and offer integrated EOL care, with these programs often located within geographically-defined areas, EOL care is more often provided as a distinct entity within a distinct care setting, such as an acute care hospital, nursing home, or private residence. Integrated EOL care is much more likely to be ensured, in the presence or

absence of comprehensive EOL care programs, when a single individual with EOL specialist knowledge and skills is responsible for assisting the person near the end of life and their significant family members or friends.

### **Policy Implications**

- A. Intersectoral planning is needed to ensure nurse practitioners and other non-medical health care professionals with recognized EOL specialization credentials can work to their full capacity within an expanded scope of practice; a scope of practice that includes prescribing from within a standard EOL medication formulary (list) and prescribing other commonly needed services for persons near the end of life and their significant family members or friends, including admitting and discharging persons near the end of life from acute care hospitals and other health care settings, such as residential continuing-care facilities or freestanding hospices that provide inpatient, respite, or day program EOL care.
- B. Intersectoral planning is needed to ensure EOL programs employ Care Coordinators on a salary, as opposed to fee-for-service, basis.

### **A Broad Range of Basic and Advanced End-of-life Services**

A broad range of health and social services are needed by persons near the end of life, and their significant family or friends, including the health and social support services that are currently available in Canada and additional EOL services. Additional EOL services are both basic and advanced health care and social support services designed to meet the unique needs of persons near the end of life, and the unique needs of their significant family members or friends.

### **Definitions**

Basic EOL services are those services that are provided by persons who do not specialize in EOL care. Basic EOL services are needed by most persons who are near the end of life, and their significant family members or friends. Basic EOL services are also needed throughout most EOL processes.

Advanced EOL services are those services that are provided by persons who specialize in EOL care. Advanced EOL services are normally only needed by a small proportion of persons near the end of life and their significant family members or friends. Advanced EOL services are also normally needed during only a proportion of most EOL processes.

### **The basic and advanced EOL services that need to be readily available and publicly funded are:**

- A. EOL care coordination through a person with EOL specialization, with this care coordination following a request for EOL care from a person near the end of life, a significant family member or friend, or a health care provider.

- B. Sufficient formal home care, equipment, and medication to enable home-based EOL care, in cases where this is the current living arrangement for the person near the end of life and/or the desired place for EOL care.
- C. Sufficient support, including financial and/or employment-related support, to enable a significant family member or friend to provide home-based EOL care, in cases where a private residence is the current living arrangement for a person near the end of life and/or the desired place for EOL care, and this family member or friend is willing to act as a home-based EOL caregiver. A home-based EOL caregiver provides needed physical and emotional care to a family member or friend in a private residence.
- D. Respite care in designated residential continuing-care facilities, freestanding hospices, acute care hospital units, or other care settings for periods of 1 to 7 days and/or nights. Respite care should be available on both a planned and unplanned or emergency basis.
- E. Day support programs, designed as half day or day-long programs that involve access to a comprehensive range of social and health care services within a communal setting; such as public health offices, community centres, palliative care units or hospice wings within acute care hospitals, residential continuing care facilities, and/or freestanding hospices.
- F. Spiritual and psychosocial support for the person who is near the end of life, their significant family members or friends, and their care providers.
- G. Bereavement support for significant family members or friends, and their care providers.
- H. Rapid assessment and treatment of pain and other symptoms in acute care hospitals, residential continuing-care facilities, or hospices; settings that are also prepared to provide end-stage comfort-oriented inpatient EOL care when the person near the end of life is determined to be experiencing the last hours of life.
- I. On-call EOL specialists, for emergency consultation, and to assist EOL care planning and provision. This will require the development of tele/video conferencing for consultation with remote areas.
- J. EOL care and EOL program information via a 24 hour, 7 days a week, toll-free telephone line, and/or website.
- K. Other supports in keeping with each unique dying person's culture, gender, age, illness, health beliefs, personal interests and values, and other important EOL care factors. This may include alternative therapies for promoting comfort, such as massage or aromatherapy.



## **Justification**

The needs of persons who are near the end of life vary greatly, with these needs ranging from minimal (as in the case of a sudden and unexpected death, or the case when a decline in health is accompanied by few symptoms or symptoms that can be addressed rapidly or without difficulty by non-specialists) to extensive (as in the case of severely distressing symptoms and multiple or extreme needs that require the attention of one or more specialists, or specialist teams). The needs of persons who are near the end of life may also vary from day to day, and hour to hour. Five EOL needs, however, normally must be assessed and addressed: (a) pain and symptom management, (b) assistance with activities of daily living, (c) communication, including timely and relevant information, (d) spiritual needs, and (e) psychosocial needs.

The needs of significant family members or friends may also vary greatly, and these needs may similarly vary from day to day and hour to hour. Six common needs, however, normally need to be assessed and addressed: (a) the need for timely and compassionately-delivered information about their family member or friend's ongoing state of health, (b) the need for emotional support prior to the death, (c) the need to ensure their family member or friend's comfort, (d) the need to be satisfied with formal care services and the work of both professional and non-professional care providers, (e) diverse needs related to enabling their work as direct or indirect caregivers, and (f) other needs that arise from their cultural background, living circumstances, or other unique factors.

All significant family members or friends will be bereaved following the death, with some individuals severely bereaved. This bereavement experience needs to be planned for prior to the death, with support provided both before and following the death. This support should be provided by a qualified bereavement counselor when this bereavement is deemed by the EOL Care Coordinator or others to be difficult or prolonged. Bereavement services should be based on the knowledge that the level of and type of pre-death support for significant family members or friends, as well as their satisfaction with the care of their loved one prior to death, are critical factors in the bereavement that will be experienced post death.

Site visits to EOL programs, and a review of the literature on (unpaid) EOL volunteers, revealed a significant potential role for volunteers. Volunteers can fulfill many different functions to support persons near the end of life and their significant family or friends, and/or support EOL care programs or services.

Site visits to EOL programs also revealed the need to recognize as special individuals the persons who are employed there, as they understand and act to further the philosophy and work of hospice/palliative care. Staff education is a form of recognition for EOL program employees, while educating other staff and the public are important for advancing EOL care.

## **Policy Implications**

- A. Targeted federal funding and other initiatives are required to ensure an adequate level of EOL care content in all entry level post-secondary health and social service educational programs, to ensure all graduates possess the knowledge and skills needed to provide basic EOL care to persons near the end of life and their significant family members or friends, and all graduates are able to determine when advanced EOL care is required.
- B. Targeted federal funding and other initiatives are required for 15 years (2003- 2018) to increase the number of EOL specialists, and ensure substantial growth in the number of EOL specialists within all health and social service disciplines, so as to prepare for a substantial increase with population aging and population growth in the number of Canadians near the end of life. Increased educational offerings and increased accessibility of education are both needed to ensure interested persons are not deterred from pursuing advanced EOL education.
- C. Targeted federal funding and other supports are needed in the form of scholarships, bursaries, training allowances, and/or loan mechanisms for the individuals choosing to pursue advanced EOL education. Advanced EOL education must be affordable, so as to not deter persons interested in pursuing advanced EOL education.
- D. Intersectoral planning is needed to develop a common and successful strategy for attracting, screening, training, and retaining (unpaid) EOL volunteers.

## **An Assurance of EOL Services Regardless of Care Setting**

EOL services should not be limited by care setting. EOL care must be provided in all settings where a person near the end of life temporarily or permanently resides.

## **Justification**

For some time now in Canada, the location of EOL care and death has been one of the most significant issues for persons near the end of life and their family members or friends. Unfortunately, minimal EOL home care supports and informal caregiver burnout have often led to hospital-based EOL care and death.

In cases where there is a desire for home-based EOL care by the person near the end of life, and/or their significant family members or friends, sufficient home care services need to be provided to enable EOL care and death in the home. However, if the desire of the person near the end of life and/or their significant family members or friends is to avoid death in the home, then an appropriate alternate setting is needed. Appropriate alternate settings for the final stage of life are purposely-designated palliative care wards or hospice wings in acute care hospitals, residential continuing-care facilities, and/or freestanding hospices. In rural or remote areas, designated beds within such facilities may also be appropriate alternate settings.

Few freestanding hospices currently exist in Canada. Freestanding hospices are buildings designed as home-like places for EOL care planning and provision. In some countries, freestanding hospices are the centre for an integrated and broad range of EOL health and social services that are provided within a defined geographic area. Freestanding hospices normally have few inpatient beds, and some have no inpatient beds. Most freestanding hospices, as well as most palliative care and hospice programs provide the bulk of their services in private residences, as home-based care. Furthermore, most hospice and palliative care programs aim to make home deaths possible. Regardless of care setting, palliation is the philosophy that needs to guide EOL service planning and provision.

### **Policy Implications**

- A. Intersectoral planning is needed to ensure EOL programs provide EOL services wherever the person near the end of life temporarily or permanently resides. In most cases, this will be within private residences.
- B. Intersectoral planning is needed to distinguish those acute care hospitals, residential continuing-care facilities, and hospices that develop the capacity to provide EOL inpatient, respite, on call, and/or day program services.
- C. Intersectoral planning is needed to secure federal, provincial/territorial, and/or regional funding for residential continuing-care facilities with designated EOL beds, hospice wings or palliative care units, and/or advanced EOL services.
- D. Intersectoral planning is needed to ensure existing acute care hospital and residential continuing-care facility capacity is used for EOL care purposes; with freestanding hospices an option for providing inpatient, respite, and/or day program services in cases where there is limited capacity for EOL care in existing acute care hospitals or residential continuing-care facilities.

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## **Disclaimer in Regard to the “Final Report. Integrated End-of-Life Care: A Health Canada Synthesis Research Project”**

The interpretation and conclusions contained herein are those of the Researchers and do not necessarily represent the views of the Government of Canada nor Health Canada. Neither the Government of Canada nor Health Canada express an opinion in relation to this study.

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- The print version of the full report can be obtained in the language of submission from the Health Canada Library through inter-library loan.
- An electronic version of the report in the language of submission is available upon request from Health Canada by e-mailing [rmddinfo@hc-sc.gc.ca](mailto:rmddinfo@hc-sc.gc.ca).

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