



# A New Era in Canadian Palliative and End-of-Life Care Research

## Historical Perspective

The term palliative care refers not only the care and management of patients approaching the end of life but also addresses the reduction of suffering throughout the course of illness and, for family, into bereavement. Palliative and end-of-life care, although traditionally associated with cancer care, intersects with a number of other clinical disciplines, such as cardiology, respiratory medicine, critical care, nephrology, pediatrics and neurology. As our aging population continues to grow and modern medicine provides the means to prolong the life of individuals with a variety of life-limiting diseases and conditions, society struggles with the ethical and legal questions around "appropriate" use of health care resources. Quality of care toward and at the end of life is also a significant issue. Many of the people who could benefit from palliative and end-of-life care do not receive it. All too often it is left to patients, their families and a loosely knit community of volunteer organizations to sort through the myriad of physical, psychological, spiritual and ethical choices.



The key to change lies in rigorous scientific research that will provide the evidence for informed decision making by clinical practitioners and policy makers. Historically, palliative and end-of-life care research has been underfunded in Canada and small groups of highly committed and dedicated researchers have struggled to obtain recognition for the field as an independent health discipline. In recent years more and more countries, including Canada, have recognized the importance of effective and timely palliative and end-of-life care and are preparing to build a strong research base that includes capacity building as a major component.

## Paving the Way

As part of the development of the Canadian Strategy for Cancer Control (CSCC) in 1999, the National Cancer Institute of Canada (NCIC), the Canadian Association of Provincial Cancer Agencies (CAPCA), Health Canada, and the Institute of Cancer Research of the Canadian Institutes of Health Research (ICR), formed a Research Alliance to identify cancer research priorities. The identification of palliative and end-of-life care as the number one priority for the Research Alliance provided an unprecedented opportunity to create a strong research base for palliative and end-of-life care.

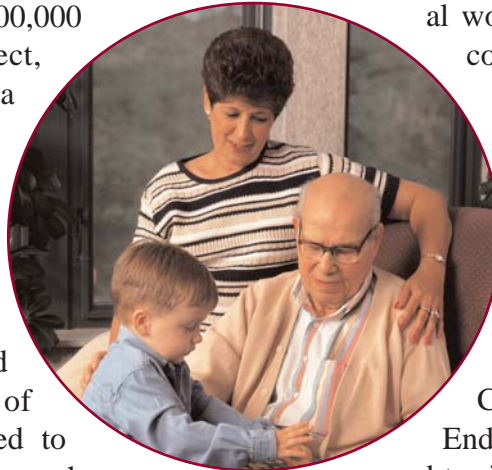




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Paving the Way (continued...)

As a first step, ICR immediately took advantage of the opportunity to partner on two programs already approved for CIHR funding. The first was a New Emerging Team (NET) project led Dr. Pierre Allard, from the University of Ottawa that focused on the structure, process, quality and outcomes of end-of-life care for older persons and how personal, social and environmental factors affect care. This \$300,000 per year five-year project, submitted in response to a Request for Applications (RFA) launched by the CIHR Institute of Aging (IA), was jointly funded by ICR and IA. The second was a CIHR Strategic Training Program grant led by Dr. Robin Cohen of McGill University designed to give students and new researchers exposure to all aspects of palliative and end-of-life care and train them to transfer their results quickly to the clinicians who work as front line contacts in palliative care. ICR and the NCIC partnered equally on the



funding of this \$300,000 per year six-year program.

The next step was to extend the focus of palliative and end-of-life care beyond the traditional boundaries of cancer research through the development of partnerships across a variety of health research disciplines. For example, the Institute of Circulatory and Respiratory Health (ICRH), in collaboration with the Heart and Stroke Foundation, convened a national workshop focused on the importance of communication in palliative and end-of-life care. Among the workshop recommendations was the need to better describe, understand, and improve patient-provider-family encounters in order to improve the experience of patients with terminal or advanced life-threatening disease and that of their families. Health Canada's Secretariat on Palliative and End-of-Life Care, working with provincial and territorial governments, and a broad range of stakeholders developed a strategy to strengthen palliative care across Canada. The strategy's key areas of focus were best practices and quality care, education for formal caregivers, public information and awareness, research, and surveillance.

## The Palliative and End-of-Life Care Initiative

In June 2003, CIHR and partners launched a palliative and end-of-life care initiative that reflected the multiple needs of the palliative care research community. The initiative was designed to support infrastructure development, enhance interdisciplinary research collaboration, encourage the development of early career researchers and attract trainees to this emerging area.

The three components of the initiative were:

- one-year Pilot Projects designed to target and assess innovative approaches in implementing palliative and end-of-life care;
- five-year New Emerging Team (NET) grants designed to build capacity and to promote the formation of new research teams or the growth of small existing teams; and
- one-year Career Transition Awards, intended to attract researchers wishing to change their research focus within the field of palliative care or to enter the field from another discipline



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The Palliative and End-of-Life Care Initiative (continued...)

This initiative along with the previously funded NET and Strategic Training Program funded 19 Pilot Projects, 10 NETs and one Career Transition Award for a total investment of \$16.5 million over six years into palliative and end-of-life care research.

This extraordinary investment was made possible by the contributions of the many partners listed, in alphabetical order, in Table 1. The support of the provincial cancer boards and agencies made it possible to fund research teams across the country, forming the basis of a national network in palliative and end-of-life care research.

The funded projects are listed in Appendix 1. The following five NET project descriptions provide an insight into the diversity of the research topics and the wide geographical distribution of funded teams:

**Table 1**

## Partners Supporting Palliative and End-of-Life Care Research

Alberta Cancer Board  
British Columbia Cancer Agency  
Canadian Breast Cancer Research Alliance  
CIHR Institute of Aboriginal Peoples' Health  
CIHR Institute of Aging  
CIHR Institute of Cancer Research  
CIHR Institute of Circulatory and Respiratory Health  
CIHR Institute of Gender and Health  
CIHR Institute of Health Services and Policy Research  
CIHR Institute of Human Development, Child and Youth Health  
CIHR Institute of Neurosciences, Mental Health and Addiction  
CIHR Knowledge Translation Branch  
CancerCare Manitoba  
Health Canada  
Heart and Stroke Foundation of Canada  
National Ovarian Cancer Association  
National Cancer Institute of Canada

- **Palliative and End-of-Life Transitions** - Transition from curative to palliative and end-of-life care is one of the most difficult tasks that face terminally ill patients, their families and other frontline caregivers. Dr. Peter Kirk and Dr. Francis Lau from the University of Victoria are leading a team of researchers and frontline caregivers, looking at transitions in end-of-life care. As Dr. Lau explains, "the goal is to tell the truth, without crushing hope." Developing the best possible tools to determine the prognosis of patients will give them and their caregivers better and more accurate information on survival. This research will also look at effective communication strategies to assist patients, families and clinicians in moving through these transitions together.
- **Family Caregiving** - Family caregivers have long been the backbone of the Canadian health care system, giving an estimated 75 - 85% of all care. Care giving can be a very rewarding experience, but the associated burdens can, over time, exceed the caregiver's capacity to cope. A team of researchers, led by Dr. Kelli Stajduhar of the University of Victoria and Dr. Robin Cohen of McGill University is addressing this important area of research which, according to Stajduhar, "strikes a cord with Canadian families". Dr. Stajduhar and her team have devised a series of studies that will ultimately optimize the family caregiving experience and reduce some of the devastating consequences that can result from long-term caregiving.



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The Palliative and End-of-Life Care Initiative (continued...)

- **Tackling Difficult Pain** - Although roughly 90% of cancer pain can be well controlled, pain management remains a serious public health issue in Canada and worldwide. Dr. Neil Hagen of the Tom Baker Cancer Centre in Calgary, Alberta, is leading a team of investigators that will form the Cancer Pain Research Network. Researchers will investigate the standardization of pain classification and assessment tools, develop innovative new cancer pain interventions, implement a new data base management system for rapid assessment, and develop a rigorous new graduate research training model. According to Dr. Hagen, the leadership shown by ICR and partners in support of palliative and end-of-life care research will enable his Network to develop a road map that will answer the question of "where we need to be in 10 years".
- **Cancer-Associated Cachexia and Anorexia** - Advanced malnutrition is a source of unnecessary suffering that contributes to death in many patients. A team of investigators led by Dr. Vickie Baracos of the University of Alberta will investigate the nutritional and psychological issues leading to malnutrition in advanced cancer patients and develop nutritional intervention therapies that will lead to an enhanced quality of life.
- **Vulnerable Populations** - Dr. Harvey Chochinov and his colleagues from the University of Manitoba will focus on the unique challenges and barriers often faced by vulnerable populations such as the frail elderly, people whose terminal illness is associated with a long trajectory of decline and limitations to their ability to function, and those with longstanding disabilities. Dr Chochinov has produced a detailed model for delivering "dignity-conserving care" at the end of life. His findings suggest that, in the care of dying patients, there are therapeutic options that reach far beyond the relief of pain and other symptoms.
- **Improving Communication and Decision-Making** - Dr. Daren Heyland of Kingston General Hospital and Queens University is leading a team of researchers at Queens and McMaster with affiliates at other universities and hospitals across Canada. This interdisciplinary and multi-institutional team will work from Intensive Care Units, to hospitals or home settings to enhance communication strategies, decision-making and care to yield the greatest improvements for families at end-of-life.



*For more information on this initiative, please contact:*

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## Building on Success

To support continued growth in palliative and end-of-life care research, and in response to a growing need within the research community, CIHR recently announced the creation of a new peer review committee that will evaluate all operating grant applications within the area of palliative and end-of-life care. Until now such applications have been reviewed by various other committees. It is anticipated that interest in palliative and end-of-life care research will continue to grow, and that the creation of a dedicated, multidisciplinary committee will better serve the needs of this growing scientific community.

The mandate of this committee will include:

- epidemiologic studies and surveys of problems related to palliative and end-of-life care;
- the development of methods for the early detection, prevention and management of suffering associated with life-limiting illness and prolonged morbidity resulting from any disease;
- studies on medical, physical, psychosocial and spiritual approaches to minimizing pain and stress for patients and families;
- training for care givers in innovative communication and decision-making processes;
- health services research, including the development of novel methods and tools; and
- the promotion of knowledge translation through informed policies and clinical practices aimed at improving the quality and dignity of life for patients

The committee will also review proposals that address critical evaluation of ethical, legal, economic and moral issues pertaining to the utilization of health care resources and quality of care.

ICR and partners are now exploring opportunities for international partnerships in palliative and end-of-life care research to build a truly international, multidisciplinary research network.





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## Appendix 1

### Palliative and End-of-Life Care: Five-Year New Emerging Team Grants

Principal Investigators	Institution Name	Project Title
Allard, Pierre	Elizabeth Bruyère Research Institute, Ottawa	Optimizing end-of-life care for seniors
Baracos, Vickie	University of Alberta	New Emerging Teams in palliative care: Cancer-associated cachexia-anorexia syndrome
Chochinov, Harvey; Stienstra, Deborah	University of Manitoba	End-of-life care and vulnerable populations
Doll, Richard; Kazanjian, Arminée	British Columbia Cancer Agency (Vancouver)	Palliative care in cross-cultural context: A NET for equitable and quality cancer care for ethnically diverse populations
Gagnon, Pierre	Université Laval	Developing, evaluating and implementing new interventions in palliative care
Hagen, Neil; Fainsinger, Robin; Brasher, Penelope	University of Calgary	A multidisciplinary cancer pain research network to improve the classification, assessment, and management of difficult cancer pain problems
Heyland, Daren	Kingston General Hospital (Ontario)	Understanding and improving communication and decision-making at the end of life
Kirk, Peter; Lau, Francis	Royal Jubilee Hospital (Victoria, UK)	Overcoming barriers to communication through end-of-life and palliative transitions
Siden, Harold	University of British Columbia	Transitions in pediatric palliative and end-of-life care
Stajduhar, Kelli; Cohen, S.R.	University of Victoria (British Columbia)	Family caregiving in palliative and end-of-life care: A new emerging team

### Palliative and End-of-Life Care: Six-Year Strategic Training Program Grant

Principal Investigator	Institution name	Project Title
Cohen, Robin	McGill University	Palliative Care Cancer Research

### Palliative and End-of-Life Care: One-Year Career Transition Award

Principal Investigator	Institution Name	Project Title
Wismer, Wendy	McGill University	Dietary patterns, perceptions of food and motivation to eat in palliative care cancer patients



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## Palliative and End-of-Life Care: One-Year Pilot Project Grants

Principal Investigator	Institution Name	Project Title
Alibhai, Shabbir	University Health Network (Toronto)	A pilot study to evaluate quality of life in patients age 60 or older with newly diagnosed acute myeloid leukaemia
Aubin, Michèle	Université Laval	Évaluation d'un programme de soulagement de la douleur chez les personnes âgées en perte grave d'autonomie vivant en milieu de soins de longue durée : projet pilote
Baracos, Vickie	University of Alberta	Nutritional supportive care: amino acids required to support maintenance and deposition of lean body mass in patients with advanced cancer
Barbera, Lisa	Sunnybrook and Women's College Health Sciences	Palliative and end of life quality indicators in lung cancer
Duggleby, Wendy	University of Saskatchewan	A pilot study of the hope focused program for informal caregivers of palliative home care patients
Fassbender, Konrad	Alberta Cancer Board	Patterns and predictors of palliative care service utilization
Gagnon, Bruno	McGill University	Characterizing cognitive failure, physical retardation and hypo-active delirium in advanced cancer patients, a pilot project
Grunfeld, Eva	Dalhousie University (Nova Scotia)	Quality indicators for end-of-life breast cancer care: is there agreement between stakeholder groups in two provinces
Grunfeld, Eva	Dalhousie University (Nova Scotia)	Quality indicators for end-of-life breast cancer care: testing the use of administrative databases in two provinces
Hampton, Mary	University of Regina (Saskatchewan)	Developing and piloting cross-cultural curriculum for delivery and utilization of end of life health care services
Kiceniuk, Deborah	Dalhousie University (Nova Scotia)	An examination of end-of-life health care costs in Nova Scotia
Leis, Anne M	University of Saskatchewan	Prevalence of palliative patients and their health services utilization in Saskatchewan: A feasibility study
Schondorf, Ronald	Sir Mortimer B. Davis Jewish General Hospital	Does autonomic nervous system dysfunction contribute to the morbidity of patients with advanced gastrointestinal and non small cell lung cancer? A pilot study
Simpson, John Steven	University of Calgary	A pilot project to assess the impact of a novel psychosocial intervention on the quality of life, attitudes to death and dying, and spirituality of palliative cancer patients
Vigano, Antonio	McGill University	Prognostic value of the angiotensin-converting enzyme gene polymorphism in advanced cancer: A pilot study
Viola, Raymond	Queen's University (Kingston, Ontario)	Community palliative cancer care - A pilot study using linked databases
Ward-Griffin, Mary	University of Western Ontario	Exploring client-family-nurse relationships in home-based palliative care for seniors
Widger, Kimberley	IWK Health Centre (Halifax)	Pediatric palliative care surveillance pilot project
Wing, Simon	McGill University	Role of lysosomal proteolysis in mediating the muscle wasting of cachexia