

## Clinical Investigation

# Optimizing Research on End-of-Life Care for Seniors

## The Collective New Emerging Team on End of Life Care for Seniors University of Ottawa, Institute of Palliative Care

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**Background:** End-of-life care for seniors is an important and neglected area of research. The University of Ottawa Institute of Palliative Care has expanded its research capacity by developing a Canadian Institutes of Health Research (CIHR) funded new emerging team on end-of-life care for seniors. This initiative brings together an interdisciplinary team of researchers from palliative care and geriatrics to develop a comprehensive program of research.

**Methods:** 1) A variety of investigators from the fields of palliative care and geriatrics and disciplines of epidemiology, medicine, nursing, psychology and social work will collaborate on the development of a research agenda focussed on end-of-life care for seniors. 2) The conceptual model for the research program consists of 4 broad inter-related domains that are congruent with the CIHR themes of health services, clinical issues, population health and psychosocial, cultural, spiritual and ethical issues; this framework will guide the research program and all studies emanating from the program. 3) Research studies will focus on 5 areas of inquiry that are central to end-of-life care for seniors: palliative end-of-life care for rural seniors, care settings, burden, role of volunteers, and delirium.

**Results:** This new team has the potential to obtain peer-reviewed funding, recruit and train a new generation of researchers, and build a network of concerned researchers.

**Conclusions:** The new team should ultimately contribute to an improved quality of care for seniors who are approaching death.

**Key words:** Elderly, end-of-life care, multidisciplinary approach

## INTRODUCTION

While the needs of persons who are approaching death have come under increasing scrutiny during

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the past decade, issues related to seniors who require end-of-life care have only recently been addressed.<sup>1</sup> It is well known that death and dying are increasingly associated with advanced age.<sup>2</sup> Indeed, the majority of people who die in any year in Canada are  $\geq 65$  years of age.<sup>3</sup> Although seniors are one of the fastest growing segments of the Canadian population,<sup>4</sup> research on end-of-life palliative care for seniors remains a neglected area of inquiry. Also, despite the increasing availability of specialists in geriatrics and palliative care, there is little evidence of collaboration between researchers from these two disciplines. Consequently, those concerned with ensuring an optimal quality of life for seniors who are approaching death are provided with little direction regarding their practice. There is a need for high-quality research on end-of-life care for seniors.

In 2000, the Senate Report entitled Quality End of Life Care: The Right of Every Canadian<sup>5</sup> and the development of the Secretariat on Palliative and End of Life Care within Health Canada comprised the beginnings of a national strategy to improve end-of-life care for all Canadians. The Canadian Institutes of Health Research (CIHR) and the Institute of Cancer Research assumed a leadership role in building research capacity in the area of palliative end-of-life care. This initiative provided an opportunity for researchers concerned with end-of-life care for seniors to advance their knowledge in this area of practice. Three opportunities for funding included 1) the development of new emerging teams, 2) pilot project grants, and 3) career transition awards. The University of Ottawa Institute of

Palliative Care was successful in its proposal to develop a *New Emerging Team* (NET) to research issues associated with end-of-life care for seniors.

The NET aims to further the long-term issue of capacity building within the field of palliative and end-of-life care for seniors, by providing the opportunity to conduct research and train new investigators and/or students within a multidisciplinary team. More specific objectives are to:

- 1) bring together an interdisciplinary team from the fields of palliative care and geriatrics that comprises researchers and collaborators, mentors from the disciplines of epidemiology, medicine, nursing, psychology, social work and spirituality;
- 2) develop a comprehensive program of research on end-of-life care for seniors; and,
- 3) contribute to the delivery of high-quality care for seniors who are approaching death.

This paper describes the purposes and objectives of the NET and the approaches to achieving these.

## METHODS

### Team Development

A variety of new and mid-career researchers will participate on the NET as investigators of issues related to end-of-life care for seniors. They include new researchers from nursing and social work and mid-career researchers from epidemiology, medicine and psychology. All investigators hold faculty positions at their respective institutions (Universities of Ottawa, McMaster and Lakehead). Students at the masters and doctoral level will also participate and receive clinical training and instruction in research on end-of-life care for seniors. To optimize the research potential of the NET, well-established researchers from nursing, social work, psychology and oncology will act as collaborators and mentors to junior investigators and students. The Director of the Sisters of Charity Institute on Health of the Elderly will also participate as a collaborator and mentor.

### Conceptual Framework

The framework for the program is based on the Stewart et al<sup>6</sup> model for assessing quality of end-of-life care. This framework provides a dynamic, integrated model for conducting research and consists of 4 broad interconnected domains:

- 1) Personal and social environments within which patients and families seek end-of-life care

(patient and family situation, health status, social support). These environments affect and are affected by the other three domains.

- 2) Structure of how care is provided (organization of care, formal and informal support services, access to care).
- 3) Process of providing care (decision-making, trajectory of care, role of interdisciplinary team).
- 4) Outcomes (quality of care, clinical care, patient and family satisfaction with care).

This framework is congruent with the CIHR themes of health services, clinical issues, population health and psychosocial, cultural, spiritual and ethical issues.

### Overall Research Plan

Five areas of end-of-life care for seniors will intersect with the 4 domains of the Stewart et al<sup>6</sup> framework:

#### 1) Palliative end-of-life care for rural seniors.

Rural Canada has a higher percentage of seniors than more urban areas<sup>7</sup> and less accessibility to palliative end-of-life care services and programs.<sup>8</sup> An overall shortage of health and social service professionals further contributes to a lack of specialized services for seniors who live in rural and isolated communities and who need end-of-life care.<sup>9</sup> In addition, a preliminary model developed for palliative care in rural settings needs further testing.<sup>10</sup> To address these issues, a series of community-based studies that extend previous research on end-of-life care for seniors will be conducted over 5 years. Three rural communities in different parts of Ontario that differ with respect to socio-demographic characteristics, availability of formal health services, and current capacity to deliver palliative end-of-life care will participate.

#### 2) Care settings.

This component of the NET will focus on the provision of care at home and in long-term care facilities. New models of care emphasize home-care, on the premise that informal caregivers are key players in the provision of services.<sup>11</sup> Informal caregivers, however, are often spouses or others who are experiencing the consequences of aging and are in need of services themselves. This aspect of the research program will examine the impact of family caregiving at home on the pattern of end-of-life care for seniors and determine the most effective ways to support family caregivers of terminally ill seniors. Also, the quality of end-of-life care in long-term care facilities is of concern,

especially during the terminal period of life. Studies in facilities with differing characteristics will be conducted to determine the facilitators and barriers to the provision of high quality end-of-life care. Strategies to improve end-of-life care in long-term care facilities will be developed.

**3) Burden.** Seniors are concerned with being a burden to others, in particular their family. They also wish to maintain their independence for as long as possible with the assistance of their families. Families, however, often experience feelings of burden related to the provision of physical care, substitute decision-making and witnessing the death of a loved one.<sup>12</sup> Also, the aftermath of the death of a loved one can significantly affect the health and well-being of family members.<sup>13</sup> Building on past research, the burden experienced by seniors and their families will be studied.

**4) Role of Volunteers.** Volunteers form an essential part of the infrastructure of palliative care services.<sup>14</sup> Little, however, is known about the unique role that volunteers play, especially for seniors. Studies will determine how volunteers perceive their contributions to end-of-life care for seniors and their role in the interdisciplinary palliative care team. Investigations will identify the volunteer initiatives and types of involvement that are best suited to assisting seniors who are nearing death.

**5) Delirium.** Delirium is an extremely distressful condition characterized by disturbances in level of awareness, attention, thinking, cognition, perception, psychomotor behaviour and sleep/wake cycle (DSM-IV). Delirious patients are often confused and agitated and have limited ability to communicate. Pain and symptom management is seriously compromised.<sup>15</sup> Seniors are highly susceptible to the deliriogenic aspect of drugs used for pain relief and control of co-morbid conditions. The overall purpose of this component of the research program is to evaluate the efficacy of a multicomponent intervention in reducing the incidence of delirium in terminally ill seniors with cancer. In collaboration with partners from 7 centres of palliative care in Ontario and Quebec, studies will investigate how exposure to multiple drug treatment affects the risk of delirium in seniors at end-of-life. Also, the impact of delirium on decision-making regarding care pathways and location during the senior's last year of life will be studied.

## COMMENT

The development of a research program in end-of-life care for seniors was strongly endorsed in the Guide to End of Life Care for Seniors (2000) and by the National Symposium on End of Life Care for Seniors (2000). The CIHR has allowed for this palliative end-of-life care research dedicated to the reality of dying in later life. This research is integral to the national strategy on palliative end-of-life care. The NET has the infrastructure to function with an interdisciplinary approach, and is positioned to obtain sustainable peer-reviewed funds beyond the 5-year period. It is also positioned to recruit and train a new generation to expand the research on end-of-life care for seniors and to promote networking between the academic institutions to which investigators are affiliated. The CIHR grant has provided recognition by the scientific community that end-of-life care for seniors is an important area of research that merits long-term funding, to improve the quality of care received by seniors who are dying and their families.

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