

Happenings

The Promise of Quality Care at the End of Life Takes a Leap Forward

Doris Howell

Serious quality-of-care problems in the delivery of palliative and end-of-life care continue to be documented across North America (Desbiens & Wu, 2004; Teno et al., 2004; Tolle, 2000). Consequently, improving the quality of palliative and end-of-life care has become a national priority and is considered an entitlement for all Canadians (Carstairs & Beaudoin, 2002). Widespread change has been slow, unfortunately, as palliative care populations are unable to demand the changes that are needed. As noted in testimony at the Senate Subcommittee hearings (Chochinov, 2000), there is no vocal constituency in end-of-life care since the deceased are no longer here to speak, the dying are often too ill to speak, and the bereaved are too overcome by their loss to speak. Reports of poor quality of care at the end of life will continue until we improve access to appropriate evidence-based care, evaluate the quality and effectiveness of care, and develop performance indicators to hold health organizations accountable for the quality of the care they deliver. In order to meet these priorities, we urgently need advancements in the scientific basis of palliative care interventions and health-service research focused on the evaluation of new and existing ways of delivering care at the end of life. Palliative and end-of-life research is one of the most promising avenues for improving the quality of care and will help to ensure that the voices of patients and families are heard regarding the quality of care they experience.

Until recently, limited access to funding specifically for palliative and end-of-life research has greatly hampered our ability to improve the scientific basis of palliative care and to evaluate the quality of care delivered. Since 1999, both the Canadian Strategy for Cancer Control and the Canadian Hospice Palliative Care Association have been advocating for dedicated funds to build research capacity and for funding of investigator-driven palliative care research. Strides have recently been made in terms of recognizing the need for excellence in palliative care research. In 2003, the Canadian Institutes of Health Research (CIHR) launched

its initiative to support innovative palliative and end-of-life research as its number-one priority through the Institute of Cancer Research. Funding from this initiative was announced in 2004, supporting nine teams of interdisciplinary researchers who will advance palliative care knowledge in the following areas (only team leaders are listed):

- Cancer Associated Cachexia/Anorexia Syndrome (Vickie Baracos, University of Alberta)
- End of Life Care and Vulnerable Populations (Harvey Chochinov and Deborah Steinstra, University of Manitoba)
- Palliative Care in a Cross-Cultural Context: A Net for Equitable and Quality Cancer Care for Ethnically Diverse Populations (Richard Doll and Araminee Kazanjian, University of British Columbia)
- Developing and Evaluating New Intervention in Palliative Care (Pierre Gagnon, Université Laval)
- A Multidisciplinary Cancer Pain Research Network to Improve the Classification, Assessment and Management of Difficult Cancer Pain Problems (Robin Fainsinger and Penelope Brasher, University of Calgary)
- Understanding and Improving Communication and Decision-Making at the End of Life (Daren K. Heyland, Queen's University)
- Overcoming Barriers to Communication Through End of Life and Palliative Transitions (Peter Kirk and Francis Lau, University of Victoria)
- Transitions in Pediatric Palliative and End-of-Life Care (Harold Siden, University of British Columbia)
- Family Caregiving in Palliative and End-of-Life Care: A New Emerging Team (Kelli Stajduhar and Robin Cohen, University of Victoria)

Palliative care as a health-research discipline in its own right was further acknowledged in 2005 with the establishment of a grants peer-review committee under the auspices of CIHR, which will evaluate all applications for operating grants in the area of palliative and end-of-life care. As noted by Dr. Phil Branton, scientific director of CIHR, this support will radically change the face of palliative care research across Canada. Increased funding in palliative and end-of-life research comes as welcome news to palliative care nurse researchers, who have been contributing greatly to empirical knowledge development in the field. Palliative care nurse researchers across Canada have been integral to the evolution of the science of palliative care, making a significant contribution to our knowledge in decision-making/communication (Hack et al., 2003), domains of quality end-of-life care (Howell & Brazil, in press),

symptom distress (Lobchuk & Degner, 2002; McClement, Woodgate, & Degner, 1997), symptom experience for children (Woodgate, Degner, & Yanosky, 2003), and the needs of family caregivers (Stadjahur, 2003). These are just some examples of palliative care nursing research endeavours in Canada. These nurse researchers will be further empowered with funding from the CIHR's Institute of Cancer Research in their quest to advance the scientific basis of care that is vital to practising nurses and health-care teams in improving the quality of palliative and end-of-life care.

Another important advancement in palliative care nursing research is the recent establishment of an endowed research chair position in cancer nursing. Early in 2004, a Chair in Oncology Nursing Education and Research was established at the University Health Network. Dr. Doris Howell assumed the Chair position, which is supported with funding from the Royal Bank of Canada Financial Group and established through a partnership between the University Health Network, the University of Toronto, the Canadian Cancer Society (Ontario Division), and Cancer Care Ontario. Dr. Howell is cross-appointed by the Faculty of Nursing at the University of Toronto and the comprehensive cancer centre at Princess Margaret Hospital, the oncology program site of the University Health Network. The Chair will be responsible for leading a program of oncology and palliative care nursing research and development of a specialty oncology stream in the Acute Care Nurse Practitioner Program as well as a clinical stream in the master's program of the Faculty of Nursing at the University of Toronto. The Chair position will become a fully endowed research chair in approximately 3 years. Dr. Howell is developing a patient-focused outcomes-research program that will have two foci: effectiveness of health-care delivery, and nursing intervention research in symptom assessment and management.

The research cluster around effectiveness of health-care delivery will examine integrated models of interdisciplinary care delivery specifically in palliative and end-of-life care, with an emphasis on the integral role of advanced practice nursing in the provision of care. The impact of advanced practice nursing and integrated delivery systems on symptom-relief outcomes, reduction in unmet needs, continuity of care, and quality of living and dying will be examined as part of the research focus on health-service effectiveness. A randomized trial and two demonstration evaluation studies are currently in progress to evaluate nursing roles, specifically as they relate to patient outcomes of care continuity, unmet needs, psychosocial distress, and quality of life. In addition, two models of integrated interdisciplinary palliative care delivery focused on building primary care capacity are being evaluated. Theory-based evaluation is

being used to evaluate these models using domains of quality end-of-life care developed from a metasynthesis of qualitative research on patient and family perceptions of what constitutes quality care (Howell & Brazil, in press).

The research cluster around nursing intervention symptom assessment and management will evaluate interventions based on an integrative biopsychosocial-spiritual approach to symptom assessment and management, one that emphasizes nursing's empirical and therapeutic contribution to symptom-relief outcomes. A patient-centred focus, in order to elicit patients' perceptions of their symptom experience and build this perspective into nursing interventions, will be an important aspect of the research. In addition, this area of research will seek to understand nurses' therapeutic roles and their influence on meaning of illness, suffering, symptom distress, and psychosocial distress. Integrative bio-psycho-social-spiritual interventions in symptom management are important for development and further evaluation, since it is known that symptoms are multidimensional experiences. In the multidimensional symptom-management model developed by Dodd and colleagues (2001), symptoms comprise both the biological basis of the symptom and the symptom experience, including the individual's perception of the symptom, evaluation of the meaning of the symptom, and response to the symptom. This theory of symptom experience calls for interventions that address the totality of patients' symptom and illness experience. Consequently, effective symptom control has an impact not only on the biological basis of symptom problems often reflected in symptom-intensity measures, but also on symptom experience, perception, and the meaning of symptoms to the individual often reflected in distress measures and in clinical observations of suffering. Earlier work on lung-cancer dyspnea by the author and colleagues using an intervention designed to address the totality of the illness experience, inclusive of the meaning of symptoms for individuals facing the end of life, demonstrated promising improvements in symptom distress and quality of life. This study replicated integrative breathlessness interventions in lung cancer found to be effective, in randomized trials in the United Kingdom, in reducing dyspnea severity and distress and in improving quality of life (Bredin et al., 1999). Finally, an underlying assumption in both of these research clusters is that the adoption of interventions is paramount to effectiveness. Pilot research is currently underway to examine strategies that support evidence-based practice in symptom management using innovative approaches such as reflection-on-practice and mindfulness-based education.

This evolving program of symptom intervention and health-service research by the RBC Financial Group Chair in Oncology Nursing

Education and Research is positioned to significantly improve the quality of palliative and end-of-life care, adding to the cadre of exemplar palliative care nursing scientists in Canada. The program will emphasize the preparation of nurse scientists in cancer care nursing research, an important aspect of building capacity in oncology and palliative care nursing research.

Canada has taken a leap forward with recent developments in the establishment of palliative care research as a health-research discipline in its own right with dedicated funding and focused peer-review activities. These developments and the establishment of a second Chair in Oncology Nursing Research in Canada will improve our ability to deliver quality care across the continuum of cancer, including palliative care, enabling us to ensure that quality end-of-life care is an entitlement for all Canadians.

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