

## Discourse

# **Chronic Illness, Palliative Care, and the Problematic Nature of Dying**

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Nurses encounter people with life-limiting illness in virtually every sector of the health-care system. In the care of the dying, the role of nurses is central, as the goal typically moves from one of cure to one of care (Coluzzi & Rhiner, 1996). Nurses spend more time with people who are dying than any other health professional (Baggs, 1993; Fakhoury, 1998; Murray Frommelt, 1991) and are, therefore, perfectly positioned to influence the care that dying people and their family members receive. Palliative care nurses pride themselves on adopting a “whole person” approach to care, an approach that promotes quality of life along the illness trajectory, across the lifespan, and with a focus on both the dying person and those who are significant to him or her (Beckstrand & Kirchhoff, 2005; Coyle, 2006). Key concepts associated with palliative nursing have been defined. They include dignity, hope, comfort, quality of life, knowing the patient, teamwork, suffering, and care and caring (Seymour, 2004). Palliative care nursing has emerged as a specialty alongside other nursing specialties such as critical care nursing, perinatal nursing, emergency nursing, and gerontological nursing (Canadian Nurses Association, 2011).

As palliative care nursing practice has developed, palliative care research undertaken by nurses has also emerged. By the early 1960s some of the first studies conducted by nurses were published, providing evidence pertaining to the social and clinical aspects of dying in contemporary society (Clark, 2004). Nurses’ contributions to research in palliative care have included studies on the prevalence of symptoms, the needs and experiences of patients and family caregivers, bereavement care, health-service needs, communication skills, and, to a lesser extent, nursing interventions (Bottorff, Kelly, & Young, 2005; Ingleton & Davies, 2004). Research in palliative care, including that conducted by nurses, has focused on people with cancer and their families. Nursing and other research has informed care and resulted in vast improvements in symptom management and psychosocial and spiritual care. And yet a story recently told by a woman who participated in a study I led

(Stajduhar et al., 2010; Stajduhar et al., in press) poignantly illustrates the problems that persist for dying people and their families within our health-care system:

Catherine is the bereaved daughter of Sarah, an 89-year-old woman brought in to the ER with progressive weakness, confusion, and diarrhea. After 5 days in the ER, Sarah was admitted to a private room on an acute-care medical ward where she required isolation after being diagnosed with hospital-acquired diarrhea. Twenty-four hours later, Sarah was moved to a four-bed room, as another priority patient required the private room. Catherine came to the hospital to help her mother move, and when she arrived she found an unsettling scene: Sarah was sitting on a commode in the hallway of the medical ward, with a nurse draping a blanket around her. As in many busy hospitals, visitors and staff were walking by, noise levels were high, and the nurse needed to attend to another patient. As Catherine approached her mother, she saw that Sarah was visibly upset, crying and pleading to be moved into her room. Sarah, while waiting in the hallway for her room to be cleaned, urgently needed to go to the bathroom. The nurse placed Sarah on a commode in the hallway; Sarah was expected to defecate with all the sounds and smells that go along with this made public. The nurse apologized, saying that in her 25 years of nursing she had never done anything like this. Four days later Sarah died. Catherine recalls this incident as one that haunts her today; deeply stitched in her memory is a vision of her mother sitting on the commode in full public view and pleading to simply have some privacy.

Disturbing though it is, this is a story I have heard frequently in my research. While other types of health care are typically rated as highly satisfactory, patients and families report that there is much room for improvement in the quality of care at the end of life (Heyland et al., 2005; Stajduhar, 2003; Stajduhar & Davies, 2005; Stajduhar et al., 2010).

### **Why Does Care of the Dying Continue to Be Problematic?**

The hospice/palliative care movement has, without question, irreversibly improved the standards of care for the dying. So successful has this model been that specialized palliative care programs have proliferated worldwide. Initially focused on those with terminal cancer, these programs have recently expanded to include people with other terminal diagnoses (Zimmerman, Riechelmann, Krzyzanowski, Rodin, & Tannock, 2008). With palliative care programs becoming increasingly part of mainstream health care, at least in the Western world, and with specialty services such as palliative consultation teams, inpatient units, and bereavement and spiritual care programs offered in many settings, it is surprising to learn that quality end-of-life care is not always accessible. Even in Canada, with its

well-established palliative care programs, only 16% to 30% of the population has access to palliative services (Canadian Institute for Health Information, 2007). Many reasons have been cited for the persistence of care-quality issues. Our health-care system continues to operate within an acute, cure-focused ideology (Thorne, 2008), with minimal value placed on and attention given to the needs of dying people and their families. Coordination of care and the integration of care-delivery systems to support dying people continue to be problematic (Stajduhar, 2003). Many hospice programs are underfunded or funded by donor dollars and lack the resources needed to support the ever-increasing numbers of people requiring palliative care (Higginson & Foley, 2009). Finally, many health-care providers are ill-equipped and/or unprepared to care for people who are dying, do not know how best to support the family members of those people, or simply do not realize that their patients could benefit from application of the principles of palliative care (Addington-Hall, 2002; Chang & Daly, 1998; Chung, Lyckholm, & Smith, 2009).

In teaching an undergraduate palliative care elective to (mostly) post-RN students, I was struck by how many believed that palliative care is a *place*, an inpatient unit where people go to die and where they are cared for by nurses, physicians, and counsellors specializing in palliative care. These students, mostly nurses working in critical care, acute medicine, emergency, or long-term care, did not know that they could provide quality palliative care *where they were*, or that their many patients with chronic life-limiting conditions could benefit from application of palliative care principles. Palliative care is for people with cancer, they believed — people who are best cared for by those who specialize in this form of care, in places (hospices, palliative care units, home) where dying people *should* be cared for. These notions are reflected in interviews with acute-care nurses participating in a knowledge translation study currently being carried out by our research team. These nurses believe that where they work is the “last best place” for people to die — even though most Canadians, in fact, die in inpatient health-care settings. The moral distress felt by these nurses when they are not able to access specialized palliative services on behalf of their patients is palpable. Reliance on specialized services is partly responsible for the nurses believing that they are not equipped to care for the dying or that care of the dying is not within their remit.

### **Who Is in Need of Palliative Care?**

Specialized models of palliative care have historically been developed for cancer patients. It is now recognized, however, that individuals with

chronic conditions such as heart disease, stroke, chronic respiratory illness, diabetes, dementia, and renal disease could greatly benefit from application of the principles of palliative care (Kristjanson, 2005). Chronic conditions account for 46% of the global burden of disease (World Health Organization [WHO], 2002) and are by far the leading cause of mortality worldwide, representing 60% of all deaths (WHO, n.d.). The rising number of people facing old age makes it likely that serious chronic and life-limiting illness will be a dominant challenge for health-care delivery in the next half century. By 2026, one in five Canadians will be a senior (Williams, 2005), and planning for end-of-life care for these and other individuals living with life-limiting chronic illness is vital to a well-managed and person-focused health-care system.

Current models of palliative care — primarily specialist models — are not necessarily appropriate to meet the needs of the expanding population of people who could benefit from application of the principles of palliative care. A “palliative approach” has been recommended as one way of applying specialized knowledge in the field of palliative care to a wider range of patients, with a variety of diagnoses, cared for in a variety of settings, at earlier stages in the illness trajectory (Kristjanson, 2005). A palliative *approach* takes the principles of palliative *care* and applies them to the care of any sick person, regardless of their illness (Katz & Peace, 2003). A palliative approach does not closely link the provision of care with prognosis, but focuses on conversations with patients/families about their needs and wishes; comfort measures; support for psychosocial, spiritual, and cultural issues; information requirements; and provisions for death and for care after death (Coventry, Grande, Richards, & Todd, 2005; Jackson, Mooney, & Campbell, 2009). A palliative approach recognizes that, although not all people with life-limiting illness require specialized palliative services, they do require care that is aimed at improving quality of life by preventing and relieving suffering through early identification, assessment, and treatment of physical, psychosocial, and spiritual concerns (Kristjanson, Toye, & Dawson, 2003). In short, a palliative approach differs little from respectful, compassionate, knowledgeable nursing care for patients and their families at any point in the health-illness trajectory.

### **Will a Palliative Approach Fix the Problems?**

The adoption and integration of a palliative approach may be a welcome direction for nurses and others who have struggled to care for the dying outside of or without the support of specialist models. Nurses working in rural settings, for example, where access to specialist services is limited or non-existent, have been practising for many years using what is now defined as a palliative approach. But will such an approach work in all settings? It is clear that something must be done to address poor-quality

care and under-recognition of those people who could benefit from a palliative approach. However, the evidence base for a palliative approach is limited, and it cannot be assumed that models of specialist palliative care are directly applicable to the large and expanding chronically ill population.

To address this issue, a team of nurses in British Columbia was recently funded by the Michael Smith Foundation for Health Research to examine if, how, and in which contexts a palliative approach might better meet the needs of people with chronic life-limiting conditions and guide the development of innovations in health-care delivery to better support nursing care of the dying. Our team, iPANEL (Initiative for a Palliative Approach in Nursing: Evidence and Leadership; [www.ipanel.ca](http://www.ipanel.ca)), is pursuing this line of inquiry through a survey of nursing-care providers across the province (registered nurses, licensed practical nurses, care aides, and community support workers) and through three substantive research strands, each co-led by a university-based nurse researcher and a clinical practice leader.

We are synthesizing the existing research in this area, grappling with the complex definitional issues in our field (Bennett, Davies, & Higginson, 2010), studying nurses' perceived competency in palliative care, and examining the staffing and skill-mix models required to integrate a palliative approach. In the process, we are developing methodologies relevant to the conduct of applied nursing health-services research. We are focusing on three areas — acute care, long-term care, and home and community care — that traditionally have not been a focus of research at the end of life. And, despite the increasing interdisciplinarity of research in palliative care (Desa et al., 2009), our team is composed entirely of nurses, because we believe that nursing scholars and nursing administrative and clinical leaders ought to be at the forefront in the study of care-delivery models that are germane to nursing practice. We are not ignoring the crucial contributions of our non-nursing colleagues, but, rather, positioning research that is essential for nursing practice within nursing scholarship.

We are embarking on our research with a critical eye, seeking to both problematize and examine the opportunities that a palliative approach can bring to the care of people with life-limiting chronic conditions. Our ultimate aim is to contribute to the evidence base on health-system reforms that will enhance nursing practice and, ultimately, result in improvements in the care of the dying.

### **Is a Palliative Approach Enough?**

It would be naïve to think that integration of a palliative approach alone will “fix” the problems that dying people and their families face in

seeking support from the health-care system. Developing models of care that will serve dying people in a range of settings, in different circumstances, and with a variety of diseases and prognoses will require well-designed research that capitalizes on the skills and abilities of researchers concerned with the dying and that also addresses research shortfalls in our field. In those areas of study where we know a lot, we need to move beyond small-scale descriptive studies, synthesize what we know, identify the gaps, and move forward with the development and testing of interventions. In those areas where we know little, we need to engage in research examining subjective experience, in order to understand the “human” dimensions of the illness process. We must also examine what we have learned from the cancer experience and determine the applicability of this evidence to the population of people with chronic life-limiting illness. And we need to consider approaches to the care of vulnerable people who are dying, such as the marginalized and homeless, Aboriginal peoples, people with disabilities, and people from a variety of cultural and ethnic groups.

Nurses are poised to contribute to the creation of an evidence base that informs health-system developments and reforms. Nurses’ knowledge of the inner workings of health care affords a unique angle of vision from which to identify questions that have relevance — those that inform both health-system developments and nursing practice at the bedside. Identifying relevant questions and undertaking research that will inform the “real life” world of decision-making and practice is something that nursing scholars have always done well. But relevant knowledge is useful only when placed in the hands of those who need it most. Much attention has been given to generating knowledge to improve the experience of those who are dying. There has been less focus on understanding how to best translate that knowledge and the contexts in which knowledge translation occurs. Knowledge translation is, by definition, designed to influence health-care practice, policy, and program development. Its primary goals are to help knowledge users to become aware of new knowledge and to actively facilitate use of that knowledge to improve health, health services, and health-care systems, narrow the gap between what we know and what we do, and move knowledge into action (Graham & Tetroe, 2010). It is the moving knowledge into action that ought to become the focus of our inquiries, particularly as it influences nursing practice directly. It is becoming obvious that transferring knowledge to nurses in traditional ways — through peer-reviewed publications, conference presentations, and the like — is not producing the kind of sustainable change that we would hope to see relative to end-of-life care. We need to better understand the contextual realities of nursing practice and the facilitators of and barriers to the clinical uptake of

knowledge. This could be a step towards the achievement of quality end-of-life care for all.

### **Conclusion**

In her reflections in the *Textbook of Palliative Nursing*, Cicely Saunders (2006), who is widely recognized as the founder of the modern hospice movement (and who trained as a nurse and social worker prior to becoming a physician), asserts that nurses remain “the core of the personal and professional drive to enable people to find relief, support, and meaning at the end of their lives” (p. v). Virginia Henderson (1961) writes that hospice nursing is the “essence of nursing” (p. 42). The primary goal of palliative care is to improve the quality of life and quality of dying and death for individuals facing life-limiting illness and to support them and their families through the provision of excellent care. Such care is enhanced when supported by a strong evidence base, including an understanding of the strategies needed to translate findings into clinical practice and health-care policy and decision-making. Nurses are perfectly positioned to become leaders in forging new research initiatives and partnerships to maximize the uptake of knowledge. This will ultimately move us towards the development of clinical practices and a care-delivery system that better supports people with chronic life-limiting conditions who face the end of life.

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