

# Taking an “upstream” approach in the care of dying cancer patients: The case for a palliative approach

by Kelli I. Stajduhar and Carolyn Tayler

## Abstract

*Advances in technology and drug therapy have resulted in cancer patients living longer with malignant disease. However, most of these patients will face the end of life much sooner than the general population. Adopting a “palliative approach” is one innovation that has the potential to promote anticipatory planning and promote enhanced end-of-life care. Yet, in much of the western world, this upstream orientation has rarely been achieved. An emphasis on providing palliative care late in the illness trajectory has resulted in many challenges for the care of people with advanced cancer. We highlight a nursing research initiative, The Initiative for a Palliative Approach in Nursing: Evidence and Leadership (iPANEL), that aims to develop evidence to inform the integration of a palliative approach into the care of people with advancing chronic life-limiting conditions. Oncology nurses have an important role to play in facilitating a palliative approach, transforming the ways in which cancer patients are cared for within our health care system.*

## Introduction

Demographic changes in Canadian society will undoubtedly require a shift in the ways in which care is conceptualized and delivered to people with advancing chronic life-limiting conditions. By 2036, seniors will account for about 25% of the total population in Canada, almost double their current proportion (Statistics Canada, 2012). Consequently, more people will be living with advancing chronic life-limiting conditions, including cancer, and require more support from the health care system than they ever have before. Lynn (2005) contends that most of these individuals do not spend their time accessing palliative care services, but “dwell in the indistinct zone of chronic illness that has no specific care delivery system” (p. S15).

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In Canada, as in much of the Western world, palliative care has become equated with service provision, rather than with its original intent, as a philosophy and approach to care. Instead of an upstream orientation, where palliative care begins at the time of a diagnosis of cancer (Hauser et al., 2011), care has tended to focus on the last months and weeks of life (Zimmerman et al., 2014; Temel et al., 2010). However, with the advent of technologies and new drug therapies, cancer patients are living much longer with metastatic disease (Schofield, Carey, Love, Nehill, & Wein, 2006). As such, determining when these patients might be on a “palliative care road” and require the specialized services that have now become associated with palliative care has become challenging. Like other chronic illnesses, it is increasingly recognized that people with cancer will die without a defined period of time before an expected death and, as such, may not be identified as people who could benefit from the application of the philosophies and principles of palliative care.

While there is inconsistency in the ways in which a palliative approach is defined, there is an evolving understanding that it involves taking an “upstream” orientation to care, applying the principles of palliative care earlier in the illness trajectory. A palliative approach does not link care provision too closely with prognosis but, rather, promotes early interventions aimed at having conversations with patients and their family members about their goals of care, comfort measures, and needs and wishes (Coventry, Grande, Richards, & Todd, 2005; Jackson, Mooney, & Campbell, 2009; Kristjanson, 2005). The concept of a palliative approach has particularly taken hold as it applies to people with non-malignant disease (Kristjanson, 2005; Stajduhar, 2011). However, it is now recognized that people with advanced cancer could also benefit from receiving support from health care providers who have the skills and knowledge required to facilitate quality care. Indeed, the World Health Organization (2014, p.7) has recently suggested that a palliative care approach be adopted by all, not just specialist health care professionals, and that “general palliative care” be provided by primary care professionals who have a good basic understanding of palliative care principles. The WHO also emphasizes the need for specialist palliative care to be provided by specialized teams. Within oncology, this seems to be the prevailing model with promising research highlighting the potential benefits of “early palliative care”, a phrase used to denote early involvement of specialized palliative care services as a standard of care for all patients with cancer (Bakitas et al., 2009; Temel et al., 2010; Zimmerman et al., 2014).

Specialized palliative care is often required to meet the needs of cancer patients, particularly for those experiencing complex symptomatology and/or psychosocial and spiritual concerns. Research demonstrates, however, that referral to palliative care often occurs too late, or not at all (Lamont & Christakis, 2002; Osta et al., 2008). The focus on impeccable pain and symptom management, psychosocial and spiritual care, and an interdisciplinary team approach, which are defining hallmarks of comprehensive palliative care services (Mitra & Vadivelu, 2013) is, unfortunately, not realized for many patients and their

family members. The integration of a “palliative approach” is one mechanism to promote better care for cancer patients. Oncology nurses are in key positions to facilitate this upstream orientation to care, promoting quality end-of-life care for those they serve.

## Challenges of an upstream orientation in the context of advanced care

In the 1960s in London, England, Cicely Saunders introduced a new way of treating the terminally ill, which she called “hospice care”. Saunders, a trained nurse, social worker, and medical doctor, held that humans should be able to die with dignity and at peace. Saunders founded St. Christopher’s Hospice in 1967, and began a program of care for the dying that has now been emulated around the world. In the definitive book on Saunderson’s life and writings, David Clark, the editor, notes that she laid down the basic principles of modern hospice care: systematic pain control in terminally ill patients with close attention to their social, emotional and spiritual needs (Saunders, 2006, p. xv). St. Christopher’s has attracted thousands of health care providers who came to experience the hospice vision and to develop clinical skills with a view to establishing a hospice movement in their own countries. In Canada, the Canadian surgeon and palliative care pioneer, Balfour Mount, introduced the term “palliative care” and established one of Canada’s first palliative care programs at the Royal Victoria Hospital in Montréal, Québec (Widger, Cadell, Davis, Siden, & Steele, 2012). Similar activities occurred in the United States under the leadership of Florence Wald, a nursing professor at Yale University. While linked with the monastic hospice tradition, modern palliative care emerged in response to the complex unmet needs of terminally ill patients and their families (Mathew, Cowley, Bliss, & Thistlewood, 2003; Waller & Caroline, 2000). Today, palliative care is a global movement with 136 of the world’s 234 countries having one or more palliative care services established as of 2011 (World Health Organization, 2014).

While there are innumerable variations among the ways that palliative care services are conceptualized, organized, and delivered, and to and by whom, much of the development of modern hospice palliative care has arisen in the context of care for cancer patients and has tended to focus on end stage illness (Gofton, Jog, & Schulz, 2009). This has created several barriers to the implementation of the upstream orientation associated with a palliative approach. Hardin and colleagues (2008) argue that the original definitions of palliative care have created misperceptions, leading health care professionals to believe that palliative care was only appropriate for people actively dying. While they were referring to the care of patients with chronic obstructive pulmonary disease where disease trajectories are often unpredictable, these same misperceptions apply to cancer care. As Schofield and associates (2006) point out, patients with advanced cancer such as breast and prostate cancer are sometimes given chemotherapy, radiotherapy, and hormone treatments that can be used to prolong life for many months and even several years. Under these conditions, cancer can be seen as a chronic illness, displaying a trajectory similar to that of other chronic diseases (Lynn, 2005). Because of this, the demarcation of when a cancer patient is deemed “palliative” has become increasingly less clear. Within medicine, and perhaps within nursing, there has been a tendency to take on a dichotomous, mutually exclusive approach to the care of cancer patients: either cure the disease with the goal to prolong life, or relieve suffering and promote comfort care (Morrison & Meier, 2004). This positioning leaves little room for consideration of an upstream orientation to care.

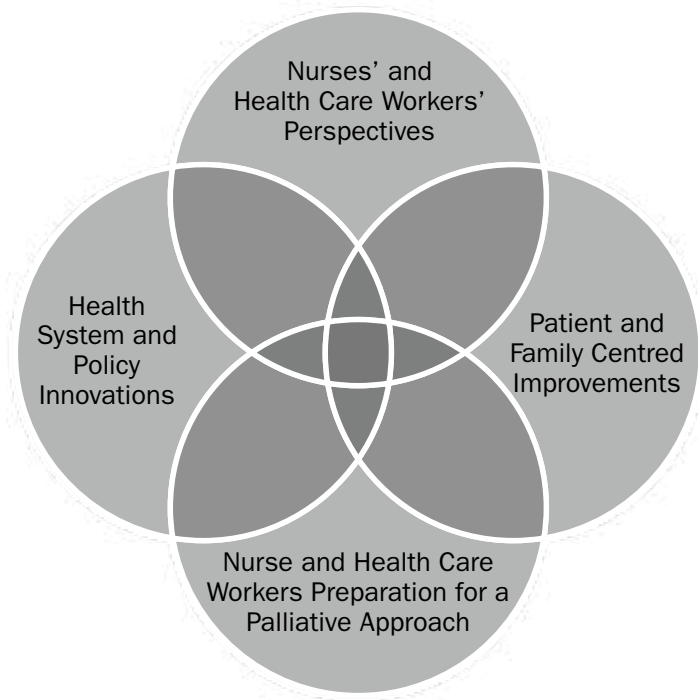
Communication challenges also present barriers to the implementation of a palliative approach in cancer. It is well documented that poor communication with health care professionals creates distress for patients with cancer and their family members (Davis, Kristjanson, & Blight, 2003). This is especially the case when patients are balancing the tensions between hope and despair within a cancer care system that sometimes disenfranchises them (Gattellari, Voigt, Butow, & Tattersall, 2002). Poor communications between the doctor and the patient and family about transitions to palliative care have been cited as one of the primary reasons for late referral to palliative care (Morita et al., 2004). Indeed, when it comes to communicating about the need for palliative care, research suggests that some cancer patients only learn that they have been deemed palliative on referral to a palliative care service (Ronaldson, & Devery, 2001). In a study examining cancer patients’ perceptions of their disease and its treatment, about one third of cancer patients who were receiving palliative care believed that their care was cure-focused. Physicians in this study believed they had given accurate information to the patient and were unaware that the patient had misunderstood it (Mackillop, Stewart, & Ginsberg, 1988).

Nurses have identified honest communication as an important factor in the provision of effective family-centred care (Davis, Kristjanson, & Blight, 2003). Still, studies report of the difficulties nurses often face in their communication encounters with cancer patients and their family members. In a study of nurses caring for advanced cancer patients in the acute care setting, one of the major challenges was communication with other team members (usually physicians) related to treatment plans, commonly articulated as delineating goals of care for the patient (Davis, Kristjanson, & Blight, 2003). In particular, communication problems were evident when there was no clear treatment plan or the communication of the treatment plan was poor. There are numerous studies that highlight the difficulties that oncologists, and physicians in general, have in communicating with their patients about goals of care and treatment when treatments are limited (Thorne & Stajduhar, 2012; Stajduhar, Thorne, McGuinness, & Kim-Sing, 2010; Wenrich, Curtis, Shannon, Carline, Ambrozy, & Ramsey, 2001). While nurses play important roles in discussing treatment plans and goals of care with cancer patients and their family members, physicians still have a key responsibility to initiate these conversations. Research has shown that oncologists may not be adequately trained in this domain (Buss, Lessen, Sullivan, Von Roenn, Arnold, & Block, 2007), and there is ample evidence suggesting that cancer patients are not always satisfied in their communications with physicians about end-of-life issues (Zachariae, Pedersen, Jensen, Ehrnrooth, Rossen, & von der Maase, 2003; Liang et al., 2002). The challenge in implementing a palliative approach in this context is two-fold: patients and families may be resistant to such conversations, thinking that “nothing more can be done”, and physicians and other health care professionals may be reluctant or uncomfortable to bring forward sensitive issues because they are either uncomfortable and lack adequate training to do so, or they are not wanting to dispel hope for the patient and family.

## Initiative for a Palliative Approach in Nursing: Evidence and Leadership (iPANEL)

In 2011, iPANEL ([www.ipanel.ca](http://www.ipanel.ca)), an applied nursing health services research initiative, was formed with the intent of developing a beginning body of evidence to inform the ways in which a palliative approach could be integrated into the health care system in British Columbia. Funded by the Michael Smith Foundation

for Health Research through the BC Nursing Research Initiative, iPANEL aims to create new knowledge about how nurses can further integrate palliative philosophies and services into non-specialized settings that provide end-of-life care. Our research team, composed of nurse researchers, practitioners, and administrators, work in a collaborative manner to ensure our research is informed by clinical practice and that the evidence we gather is relevant, useful, and well-communicated to nurses and other stakeholders. We currently conduct research in the contexts of home and community care, residential care, and acute medicine, and our research is organized around four intersecting research strands (See Figure 1): (1) Health system and policy innovations that are required to support nurses to enact a palliative approach, including staffing and skill mix models and the use of practice support tools; (2) Preparing for a palliative approach, which includes studies to explore how to best prepare nurses and health care workers to integrate a palliative approach into their everyday practice and determine the educational strategies to support this; (3) Patient and family-centred improvements, which examine opportunities that nurses can build upon to guide and support patients and families throughout the many transitions of chronic life-limiting illness; and a focus on (4) Nurses and health care worker perspectives where studies are designed to better understand nurses' and health care workers' perspectives about their experiences in a palliative approach.



**Figure 1: iPANEL Research Strands**

iPANEL team members have completed, or are in the process of completing several studies that inform these research strands (See Table 1). We have conducted a provincial survey of nursing care providers to obtain baseline descriptive information relevant to the integration of a palliative approach in a variety of nursing care settings that do not specialize in palliative care. We are completing several knowledge synthesis projects that investigate core characteristics of a palliative approach, nursing care delivery systems for a palliative approach, and syntheses

on specific populations such as renal patients and those from diverse cultures. We are completing knowledge demonstration projects, one of which involves developing and testing a model for knowledge translation at the point-of-care and, in doing so, learning about ways in which we can translate and integrate what we know about a palliative approach into everyday nursing practice. And we are embarking on studies with family caregivers and structurally vulnerable populations that focus on access issues and practice support tools to enable integration of a palliative approach.

While findings from iPANEL studies are in the process of being finalized and written up for publication, we have learned, in general, that the integration of a palliative approach is more complicated than we originally conceived. Ideally, all health care providers, including nurses, would understand the inherent benefits that could be achieved for patients and families through the integration of an upstream orientation to care that emphasizes anticipatory planning and open conversations about goals of care in the context of advancing chronic life-limiting illness. Ideally, systems of care such as chronic disease management, cancer care, and palliative care would work collaboratively, in an integrated fashion to promote a palliative approach to care. Ideally, health care administrators and providers, particularly in acute and residential care, would recognize that many of the patients they serve are on a trajectory that will lead to death in the not-too-distant future. And, ideally, institutions that educate health care professionals would be incorporating key content into their curricula to prepare future graduates with the knowledge required to care for an aging population with advanced disease. Clearly, through iPANEL research, we are seeing amazing innovations around a palliative approach that are occurring in pockets throughout B.C. But, we are far away from integration.

## Implications for oncology nursing

Oncology nurses are in primary positions to facilitate the integration of a palliative approach into the care of patients with advanced cancer. Oncology nurses see patients in all stages of their cancer illness trajectory and are often asked questions by patients that provide potential openings for discussions that would promote anticipatory planning about goals of care and delineation of patient needs and wishes. Questions about when “specialized” palliative care should begin are, of course, sensitive, as are questions about treatment plans and goals of care. Navigating the sometimes tenuous space between other health care professionals and patients and families to find nurses’ unique contributions in this realm is challenging, particularly in a cancer control system focused on “cure” and where patients do not always see themselves as on a dying trajectory. A palliative approach is one way of offering care without the necessity of abandoning hope or severing the relationship with cancer care professionals.

The Canadian Association of Oncology Nurses (CANO) has set out practice standards and competencies for the specialized oncology nurse (2006). Within these standards and competencies, palliative care and end-of-life care is a standard and competency that stands alone, not concretely embedded and integrated within the various components of care. Exploring the concept of a palliative approach and its applicability to care for advanced cancer patients, and embedding it into the competencies and day-to-day practice expectations of oncology nurses would, perhaps, help us move toward integration such that a palliative approach—an upstream orientation to the care of advanced cancer patients—would promote better service planning, better care, and better outcomes for cancer patients and their family members.

Research that examines a palliative approach in relation to oncology nursing practice could also establish a baseline

**Table 1: List of research studies led by iPANEL Team members that address various aspects of a palliative approach**

Title of Research Project	Principal Investigator/s	Funding Agency/ies
Knowledge Translation in Action: Improving the Quality of Care at the End of Life	Kelli Stajduhar, Gweneth Doane	CIHR
The Interpretation and Practice of Family Empowerment in Home Care Nursing: Palliative and Chronic Illness Contexts	Kelli Stajduhar	CIHR
Educating for a Palliative Approach to Care: A mixed method scoping review, environmental scan, & philosophic analysis	Barb Pesut, Barbara McLeod	CIHR, MSFHR—BCNRI
A Palliative Approach in Rural Nursing: A qualitative secondary analysis	Barb Pesut	UBC-O
A Mixed-Methods Survey about a Palliative Approach in BC Nursing Care Settings	Rick Sawatzky, Della Roberts, Sheryl Reimer-Kirkham	MSFHR—BCNRI
A Mixed Methods Knowledge Synthesis of a Palliative Approach	Kelli Stajduhar, Rick Sawatzky	CIHR
A Mixed Methods Knowledge Synthesis about Nursing Care Delivery and Practice Supports for a Palliative Approach	Rick Sawatzky, Pat Porterfield	MSFHR—BCNRI
Enhancing Educational Capacity for a Palliative Approach in Rural Nursing: A Research Demonstration Project	Barb Pesut, Gail Potter	MSFHR—BCNRI
Integrated Knowledge Translation: Examining a Collaborative Knowledge Translation Approach	Sheryl Reimer-Kirkham, Elisabeth Antifeau, Gweneth Doane	MSFHR
Patient- and family-reported experience and outcome measures for elderly acute care patients: A knowledge synthesis.	Rick Sawatzky	TVN
Palliative approach and quality of life outcomes in care for elderly Chinese patients and families	Joyce Lee—Supervisor Rick Sawatzky	TVN—Interdisciplinary Fellowship
Access to Residential and End-of-Life Care: Exploring South Asian Older Adults' and Family Caregivers' Perspectives	Sherin Jamal—Supervisor Kelli Stajduhar and Karen Kobayashi	CIHR
Supporting Family Caregivers of Palliative Patients at Home: The Carer Support Needs Assessment Intervention	Kelli Stajduhar, Rick Sawatzky	TVN, CCSRI
Access to End of Life Care for Vulnerable and Marginalized Populations	Kelli Stajduhar	CIHR

understanding of the current level of confidence that oncology nurses perceive in applying a palliative approach, and identify those cancer patients who could most benefit from its application. Research into the skills and competencies required of oncology nurses to enhance a palliative approach would allow for the development of educational programs to facilitate learning and comfort in this area. Development or identification of existing practice support tools, such as those currently available related to advance care planning, is needed to better support oncology nurses in their practice with patients who could benefit from the application of a palliative approach.

## Conclusion

Cancer patients and their families across the cancer trajectory experience many physical, psychosocial and spiritual concerns. Oncology nurses have contributed substantially to the evolving field of palliative care (Ferrell, Virani, Malloy, & Kelly, 2010), and can pave the way for new innovations in care that promote better upstream planning and care. The need for a palliative approach within the context of cancer care will intensify in the future. Models of care and strategies to effectively educate and support oncology nurses to provide a palliative approach will be needed to prepare them to deliver compassionate care that addresses the unique needs of patients with advanced cancer and their family members. ☒



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