A mixed methods knowledge synthesis about nursing care delivery and practice supports for a palliative approach

PROJECT SUMMARY
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People with chronic illnesses often have complex and multifaceted needs associated with the life-limiting nature of their illness that arise at different points during the trajectory. They most commonly receive care from healthcare professionals within various healthcare sectors, including hospital, residential, and homecare settings. For good end-of-life care, it is important to ensure that principles of palliative care are adapted and integrated, regardless of the healthcare sectors in which the care is provided. We refer to this as a palliative approach to care. Broadly conceptualized, a palliative approach involves adapting the principles and values from specialized palliative care and embedding and integrating these into the particular illness trajectory of the person with an advanced life-limiting illness. A palliative approach requires an “upstream” orientation to care delivery that addresses the needs of the patient and family related to the advancing nature of life-limiting illness and necessitates the integration of care delivery systems and partnerships among service providers to address these needs across all sectors of care.¹

This health and nursing services research project was designed to inform a broad range of stakeholders about the integration of a palliative approach in nursing care delivery for people who have life-limiting illnesses and their family members. It specifically addressed the need for approaches to nursing care delivery, including practice support strategies and tools, that would facilitate the integration of a palliative approach for people with life-limiting chronic conditions and their families, including acute medical settings, residential care, and home health and across urban and rural geographic contexts. The project is part of the MSFHR BCNRI Team grant funded Initiative for a Palliative Approach in Nursing: Evidence and Leadership (www.ipanel.ca), which encompasses several primary research and integrated knowledge translation activities regarding a palliative approach.

This summary report provides a brief overview of the project’s objectives, methods, and results, and concludes with a table of key messages with the hope that it will inform the ongoing work of improving healthcare services to meet the needs of people who have life-limiting illnesses.

Dying to Care: iPANEL advisory board recommendations to BC Ministry of Health:
http://www.ipanel.ca/images/advisory_board/iPANEL_MOH_web_printable.pdf
**Research Questions/Objectives**

The purpose of this project was to synthesize knowledge relevant to the integration of a palliative approach in nursing care delivery and to inform the contextualization and integration of this knowledge in the delivery of nursing care for patients with chronic life-limiting illness and their families in British Columbia (BC), Canada. The project was specifically guided by the following research questions:

1. What approaches to nursing care delivery, including considerations of staffing and skill-mix, are most appropriate, feasible, and effective for the integration of a palliative approach in the care of patients with chronic life-limiting conditions and their families?
2. What practice support systems (coaching, mentorship, education, clinical tools for needs assessments and decision making) best facilitate the integration of a palliative approach in different contexts of nursing care delivery?
3. What are the outcomes (administrative and patient-reported outcomes) that should be considered when evaluating the appropriateness, feasibility, and effectiveness of recommendations pertaining to the integration of a palliative approach in different contexts of nursing care delivery, specifically home health, acute medicine and residential care?
4. How can nursing care delivery be adapted, implemented and monitored to best facilitate the integration of a palliative approach in the BC healthcare system and in particular nursing care settings?

**Methods**

This project involved the combined use of knowledge synthesis and integrated knowledge translation to contribute (a) synthesized knowledge (based on existing evidence from the literature) about a palliative approach to nursing care delivery, practice support strategies and tools, and outcomes regarding the integration of a palliative approach, and (b) contextualized knowledge (based on knowledge pertaining to BC contexts of nursing care delivery) about the application of knowledge about a palliative approach to healthcare in British Columbia, and (c) integrated knowledge translation involving nursing care providers and leaders to facilitate the contextualization and integration of emerging synthesis results within BC nursing care (including acute medical care, residential care, and home care). This was achieved through an iterative knowledge synthesis and translation approach consisting of the four components that each addressed different aspects of the research questions. The first component, focusing on synthesized knowledge, involved a systematic synthesis of current literature about nursing care delivery, practice support strategies and tools, and outcomes relevant to a palliative approach. Contextualization of knowledge was achieved by conducting secondary analyses of the iPANEL province-wide nursing survey about a palliative approach and interviews with key informants across the province. Contextualization was further informed by two integrated knowledge translation activities: (a) engagement of stakeholders through a
province-wide symposium, and (b) two pilot demonstration projects that built our understanding of effective ways to work with nurses to identify and implement nursing care delivery approaches and practice tools that facilitate a palliative approach. The goals for each project component are shown in Table 1.

**Table 1: Project components and goals**

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<td></td>
<td>Mixed-methods knowledge synthesis</td>
<td>Secondary analysis of survey and key informant interviews</td>
<td>Provincial symposium</td>
<td>Demonstration projects</td>
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1. Contribute to the development of recommendations about (a) approaches to nursing care delivery, (b) practice supports that facilitate the integration of a palliative approach within various healthcare contexts, (c) and outcomes for a palliative approach.

2. Identify approaches and challenges pertaining to the integration of a palliative approach in BC healthcare and to use this knowledge to adapt knowledge from the literature to BC contexts of nursing care delivery.

3. Establish consensus on emerging findings and inform ongoing analysis.

4. Explore how a palliative approach to nursing care delivery could meet the needs of patients, residents, clients, and their families.

The overall integrated analytical approach involved several iterations of relating synthesized knowledge from the literature to experiences and perspectives of nurses within BC healthcare contexts, and conversely evaluating the extent to which knowledge arising from the BC context is consistent with synthesized knowledge from the literature. A heuristic overview of the analytic processes integrating these four components and the linkages with the overarching iPANEL team and the strategy for end of life care in BC is provided in Figure 1.
RESULTS

SYNTHESIZED KNOWLEDGE

Nursing care delivery. From the literature, it appears that nursing has not fully engaged with the concept of a palliative approach, thus far. Synthesis of the literature in relation to nursing care delivery systems for a palliative approach has not revealed any one model or framework that demonstrated a palliative approach to care. There is a significant gap in knowledge regarding the integration of nursing expertise and considerations of nursing staffing and skill-mix within existing interdisciplinary care delivery systems to best facilitate a palliative approach.

Practice supports. Evidence from the literature synthesis indicates that nurses feel a lack of competencies and training in terms of providing quality palliative care for patients with life-limiting conditions. A system with supportive management, clear communication, effective interdisciplinary team work and appropriate clinical tools will greatly assist nurses to integrate a palliative approach into their practice. Further, education is needed not only for nurses, patients and their families but also the public around palliative care issues.
Outcomes. From an administrative outcomes perspective, a palliative approach and palliative care are not well delineated in the literature, where the primary focus is on the delivery of a service. The 7Cs of the Gold Standards Framework are frequently referenced as the basis for program evaluation: communication, coordination, control of symptoms, continuity, continued learning, carer support, and care in the dying phase. Outcome evaluation initiatives emphasized nursing and interdisciplinary team views to assess the impact of models of care on patients, families, providers, and care processes. Patient and family perspectives were sought to conceptualize good care and quality of life, and to gather information about care they received.

Contextualized Knowledge

The findings for this component were derived by secondary analyses of the iPANEL province-wide nursing survey about a palliative approach and interviews with key informants across the province to address the research questions with a specific focus on the BC nursing context.

Nursing care delivery. A palliative approach needs to be embedded within the nursing care delivery in practice settings providing care for patients with chronic life-limiting illnesses and their families and contextualized to these settings of care. Rather than a specific care delivery model, the data suggested that a palliative approach be embedded at all levels, the system, the care delivery of each setting and the roles of providers. The nursing staffing and skill mix then support a patient-centered orientation to care that addresses patients’ needs appropriate to the care context. Nurses discussed the importance of sufficient time, numbers of staff, the culture of their work environment, and a team approach as important conditions that facilitated a palliative approach. However, the quantitative survey results indicated time and work environment were not among the most significant predictors of the extent to which nurses apply a palliative approach. The provision of a palliative approach was predominantly predicted by nurses’ belief that patients would benefit from a palliative approach and by nurses’ self-perceived competence and knowledge in dimensions of care relevant to a palliative approach. In addition, language congruent with the care context is needed to support the integration of a palliative approach. Currently, there is inconsistency in how the term ‘palliative’ is understood and used; dependent on the setting, nurses tend to interpret “palliative” as referring to a specific patient population for a policy, or patients who are actively dying or receiving specialized palliative care.

Shining a light on the concept of ‘life-limiting’ by including decline and death as part of the chronic illness trajectory is foundational to the application of a palliative approach within nursing care delivery. A palliative approach to care involves ensuring patient and family support throughout the life-limiting illness and at end of life with the family and patient as full partners in decision making to meet changing and progressive needs related to care, quality of life and to sustain patient autonomy. Providing this care requires skills in cultivating relationships with patients and families, gaining knowledge about their perceptions, and enabling nurses and other members of the interdisciplinary team to interpret concerns and anticipate needs. A palliative approach requires an interdisciplinary care team collaborating
with patients and family and forming those decisions and goals of care into a living care plan that is shared across sectors.

**Practice Supports.** Education, personal support such as debriefing, and input from interdisciplinary team members, including palliative care consultation teams, were viewed as important support for their practice. Leadership supports practice by offering opportunities for professional development, organizing and managing day to day operations, decision making and providing experience and mentorship.

**Outcomes.** Practicing nurses strongly emphasized patient- and family-oriented outcomes, including their quality of life and dying.

**INTEGRATED KNOWLEDGE TRANSLATION**

**Symposium.** Participants at the symposium created a number of recommendations related to nursing care delivery, practice supports and outcomes in three contexts of care: residential, acute medicine and home care. The importance of ministry level/provincial support for a palliative approach was highlighted. The *Provincial End of Life Action Plan for British Columbia* that outlines the vision, policies, standards, indicators and outcomes has potential to direct the integration of the palliative approach at all levels and across all sectors. Developing intersectoral indicators and competencies of a palliative approach including knowledge, skills, abilities, and attitude, is important. There is a need for a paradigm shift, to build capacity and sustainability at all policy and practice levels, that is based on an understanding of why a palliative approach is beneficial to the citizens of BC.

At the practice level, this cultural shift would be promoted through education and mentoring of inter-professional teams who embrace a collaborative, person-centered palliative approach, reflected in shared care planning. To facilitate a shared care plan, the use of clinical tools and documents that cross all sectors could be embedded in the daily workflow of the inter-professional teams. Developing the infrastructure to support documentation and communication between and among all members of the care team across sectors is important. Further, creating a system that will empower direct care nurses to know clients/patient’s wishes and goals of care would help to assure care recipients that their goals of care are being met. The collection and use of patient and family-caregiver outcomes data was recommended.

**Demonstration Projects.** Two projects (one at residential care setting and with a home health case managers) demonstrated how aspects of a palliative approach could be integrated into existing care delivery systems while using current resources with minimal research support added. Leadership for the projects was based within the participating organizations and, although the formal project evaluation has been completed, the work is continuing, illustrating the appropriateness and feasibility of a palliative approach. Both projects supported reflective practice, exploring how a palliative approach might benefit

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residents/clients and families, and modified care processes to support integration of a palliative approach. The residential project focused on the work of the interdisciplinary team, using daily “huddles” to identify resident and family needs and concerns and engage in goals of care conversations. The home health case managers reflected on client and family needs that were not well met by the current system, and developed strategies to work collaboratively with home care nurses in planning care, to “wrap the care around the person”.

Findings from focus groups within each demonstration project confirmed the relevance of a palliative approach as well as the need to contextualize the language and strategies to each setting. The importance of person-centered goals of care, developed collaboratively with an interdisciplinary team and shared across settings of care, was identified. Nursing roles such as anticipatory care, guiding and preparing, and advocating for informed decision making were described as well as the challenges and barriers to this work.

CONCLUSIONS

The findings from this project are summarized in the table of key messages regarding the integration of a palliative approach in nursing, which, together with knowledge from other projects, will inform the development of higher-level recommendations arising from the Initiative for a Palliative Approach in Nursing: Evidence and Leadership (www.ipanel.ca). The current document provides a general summary of a complex and multi-faceted project. The full project report and related publications will provide detailed information on all of the components.
### THE INTEGRATION OF A PALLIATIVE APPROACH: KEY MESSAGES

#### SYNTHESIZED KNOWLEDGE FROM THE LITERATURE

#### CONTEXTUALIZATION TO BC

**How can models of nursing care delivery be adapted, implemented and monitored to best facilitate the integration of a palliative approach in the BC healthcare system and in particular nursing care settings?**

<table>
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<tr>
<th>What kind of models of nursing care delivery, including staffing models and skill-mix models, are most appropriate, feasible, and effective for the integration of a palliative approach in the care of patients with chronic life-limiting conditions and their families?</th>
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<tr>
<td>We did not find any particular nursing care delivery model for a palliative approach. Rather, a palliative approach needs to be integrated within existing systems.</td>
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<tr>
<td>There is interest to integrate a palliative approach within existing care systems. The palliative approach is not dependent on any particular nursing care delivery model or healthcare structure.</td>
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<tr>
<th>The term “palliative approach” was not widely used in regards to the models or systems of care for people with chronic life-limiting illnesses.</th>
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<td>Implementation of a palliative approach to nursing care is challenged by how “palliative” is commonly defined within a particular practice context, which has implications for service delivery allocations and creates barriers to the comprehension of what a palliative approach entails.</td>
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<th>The operationalization of a palliative approach for nursing practice needs to be contextualized to different healthcare environments. This is currently more developed in home care and residential care.</th>
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<td>Nurses in residential care facilities increasingly recognize that residents have progressive chronic life-limiting illnesses and have begun to integrate a palliative approach from admission onward. The application of a palliative approach is less frequent in acute care. Although the concept of a palliative approach resonates strongly with home and community care, some current policies and practice structures are not aligned well with nursing care delivery for a palliative approach. There are initiatives that could facilitate the integration of a palliative approach (e.g., advance care planning and Medical Orders for Scope of Treatment (MOST)).</td>
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<th>There are descriptions of innovative approaches to nursing care related to particular life-limiting conditions, such as dementia care and general frailty.</th>
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<td>Examples in BC include the “Breathe Well” initiative and the palliative approach in dementia care.</td>
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Nursing care delivery for a palliative approach must have capacity (including structure, leadership, resources, and permission) to provide person-centered care (versus a task-oriented approach) that is oriented to the needs of patients and families on a chronic life-limiting illness trajectory.

The need for capacity building was emphasized in all data sources. Permission for a clear legitimized nursing voice in decisions about a palliative approach is foundational to operationalization in practice.

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<th>What practice support systems (coaching, mentorship, education, clinical tools for needs assessments and decision making) best facilitate the integration of a palliative approach in different contexts of nursing care delivery?</th>
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<td>There are pathways and guidelines for interdisciplinary management of particular chronic diseases throughout the life-limiting illness continuum, which implicitly include nursing.</td>
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<td>There has not been enough development, use and evaluation of practice support systems to recommend widespread adoption. However, the demonstration projects illustrated how contextualized tools (i.e., developed for a particular setting) were fundamental to a palliative approach to support team communication, goals of care, and conversations.</td>
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<tr>
<td>Most practice support tools focus on particular aspects of care that are relevant to a palliative approach. Examples include tools for advance care planning, identification of patients, and pathways for care for last days of life.</td>
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<td>Within BC, similar tools have been developed within particular practice environments to support the integration of a palliative approach.</td>
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<td>Though there are significant educational initiatives that focus on end-of-life nursing care, there is a lack of clarity about what education is needed to support nurses in integrating a palliative approach.</td>
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<td>To facilitate the integration of a palliative approach in BC requires a comprehensive knowledge translation strategy rather than relying exclusively on education. There are practitioners in residential, home health and acute care who are supporting a palliative approach through education and the development of practice support tools.</td>
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What are the outcomes (administrative and patient-reported outcomes) that should be considered when evaluating the appropriateness, feasibility, and effectiveness of recommendations pertaining to the integration of a palliative approach in different contexts of nursing care delivery, specifically home health, acute medicine and residential care?

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<tr>
<th>There is a need for clearly defined outcomes of a palliative approach. Most commonly, program evaluations focused on the 7Cs of the Gold Standards Framework (communication, coordination, control of symptoms, continuity, continued learning, carer support, and care in the dying phase). However, there is no information about which outcomes are particularly relevant to nursing care delivery.</th>
<th>There is no widespread coordinated effort to systematically identify and track outcomes of a palliative approach in nursing care delivery.</th>
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<tr>
<td>There are no outcomes evaluations that focus specifically on the appropriateness of a palliative approach within diverse populations.</td>
<td>There is some evidence of incongruence in certain outcome measures that were identified as potential barriers to a palliative approach (e.g., monitoring weight in residential care).</td>
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<td>Measures of feasibility include those pertaining to economic evaluation (cost and service use) and implementation of particular practices.</td>
<td>Although there were no specific examples, the need for evaluation of feasibility was emphasized.</td>
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<td>There is little research regarding the effectiveness of a palliative approach with respect to patient- and family-centred outcomes.</td>
<td>Patient- and family-centered outcomes (including quality of life and dying) are foundational to a palliative approach.</td>
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