



i PANEL

INITIATIVE FOR A
PALLIATIVE APPROACH IN NURSING:
EVIDENCE & LEADERSHIP

Improving Palliative and End-of-Life Care in British Columbia: Cost Effective Strategic Innovations for a Sustainable Health Care System

Submitted to:

The Legislative Assembly of British Columbia
Select Standing Committee on Health

By:

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

December 2014

iPANEL: Who We Are

The Initiative for a Palliative Approach in Nursing: Evidence and Leadership (iPANEL) is a diverse group of nationally and internationally recognized nursing researchers, clinical leaders and administrators. Funded by the Michael Smith Foundation for Health Research (MSFHR), BC Nursing Research Initiative (BCNRI), its goal is to explore the best ways to integrate a palliative approach into the care of people with advancing chronic life-limiting conditions. The iPANEL vision for transformative service delivery to this patient population is powered by the front line work of a team dedicated experts who are at the forefront of palliative and end-of-life care in British Columbia. A list of team members can be found at the end of this overview, and more information about this collaboration can be found at www.ipanel.ca.

Improving Palliative and End-of-Life Care in British Columbia: Cost Effective Strategic Innovations for a Sustainable Health Care System

Executive Summary

- **ISSUE:** Our aging population means that living and dying with chronic disease is increasing. Innovative best practices must be implemented in order to meet these health care needs and maintain a sustainable health care system.
- **CURRENT KNOWLEDGE:** There is good evidence that embedding a palliative approach within current systems, as well as improving community-based health care, can increase satisfaction with care and reduce health care costs.
- **RECOMMENDATIONS:**
 1. Implement an integrated palliative approach across the health service continuum
 2. Extend and expand chronic disease management and primary care strategies to include an integrated palliative approach to care
 3. Apply a population focus in community, acute care and residential care settings in order to support persons through transitions in care

Introduction: What We Know

The most sustainable health care system is one that keeps all British Columbians as healthy as possible for as long as possible.

- For decision-makers this challenge is here now, but will grow much larger:
 - Population aging has led to people living longer with chronic conditions, and consequently to an increase in the number of people dying each year of chronic disease.
 - Patients with advancing chronic life-limiting conditions fill emergency rooms, occupy acute care hospital beds and languish at home or in residential care with less than ideal care at the end of life.
- Good evidence exists for ways to improve these care realities. Full service, continuity-rich, community-based health care, coupled with effective advance care planning and support for family caregivers, can lead to increased satisfaction with care and a decreased demand on the health care system.
- Benefits include reduced emergency room visits and hospital admissions, facilitation of patients' preferred location of death, improved symptom management and quality of life, reduced caregiver burnout, and increased family satisfaction with end of life care.

A Palliative Approach: Meeting Changing Care Needs

Palliative care is not just for the end of life; it is designed to relieve suffering at all stages of a person's advancing illness, and should match each patient's needs, depending on illness, beginning at the time of diagnosis. This is referred to as a palliative approach, and it can help British Columbians live well until the end of life. A palliative approach takes the principles of palliative care and adapts them to the care of people with chronic advancing life-limiting conditions. This adapted knowledge and expertise is embedded "upstream" into the delivery of care across different healthcare sectors and professions.¹ A

¹ Sawatzky, R., Stajduhar, K. I., & Porterfield, P. (in preparation). A palliative approach: A concept in need of clarity.

palliative approach does not require expanded specialized services because it is embedded within current systems, contexts and settings of care.

What We Need to Do

In order to keep people as healthy as possible despite illness, cost effective strategic innovations are needed in order to integrate appropriate care throughout the health care system to meet the needs where they exist.

- We desperately need innovative and integrated models of care and intervention in order to meet increasing demands for humane palliative and end-of-life care that will result from the aging of our population.
- In order to be sustainable, our health care system must be effective and patient-centred, and must provide excellent and equitable access. Such a system would lead to the best outcomes for patients, their families, providers, and the healthcare system itself.
- British Columbians who suffer from chronic advancing life-limiting conditions such as heart disease, lung disease, kidney disease, cancer, dementia and frailty require care that is responsive to their individual needs and that promotes quality of life until death.

Recommendations that we propose and that are contained in the iPANEL *Dying to Care* report, attached, will assist in preventing British Columbians who are the sickest—patients with advancing chronic life-limiting conditions—from continuing to dwell in the “indistinct zone of chronic illness that has no specific care delivery system”² and will move us forward in creating a sustainable health care system that is responsive to the needs of people who are dying and their family members.

A Smart Step Forward: Best Practices to Improve End-of-Life Care

On June 27, 2014, iPANEL leaders presented a report to Ministry of Health Associate and Assistant Deputy Ministers of Health (attached) entitled: *Dying to Care: How can we provide sustainable quality care to persons living with advanced life limiting illness in British Columbia?* The report contains numerous recommendations, based on iPANEL research, for improving care organization and delivery toward a sustainable health care system. The three top recommendations address priorities 1, 3, 4, 7 and 8 of *Setting priorities for the B.C. health system* (Ministry of Health, February 2014). These recommendations were developed after extensive consultation throughout British Columbia with clinical experts, health system administrators and decision and policy-makers:

1. Implement an integrated palliative approach to care across the health service continuum
2. Extend/expand chronic disease management and primary care strategies to include an integrated palliative approach to care
3. Apply a population focus in community, acute care and residential care settings in order to support persons through transitions in care

² Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. In Improving end of life care: Why has it been so difficult? *Hastings Center Report Special Report*. 35(6), S14-S18.

These recommendations are the initial steps to achieve effective and sustainable palliative and end-of-life care. They are specific to British Columbia, but reflect recommendations in other jurisdictions:

- Canadian sources – Quality End-of-Life Care Coalition of Canada: *The Way Forward national framework: A roadmap for the integrated palliative approach to care*
- United Kingdom – Department of Health: *End of life care strategy: Promoting high quality care for adults at the end of their life* and The Gold Standards Framework
- Australia – National Palliative Care Strategy
- United States – Institute of Medicine: *Dying in America: Improving quality and honoring individual preferences near the end of life*

Conclusion: Improving Palliative and End-of-Life Care is a Win-Win

Enacting these recommendations is a win-win for a sustainable health care system and better health outcomes for patients and families. Benefits of an integrated palliative approach include:^{3,4,5,6,7}

- **Better care:** inclusion of excellent symptom management and attention to quality of life, greater satisfaction with care, reduced caregiver burnout
- **Lower costs:** fewer hospital admissions, shorter hospital stays, reduced intensive care unit use, better use of hospice services, reduced inappropriate or futile treatments, fewer hospital deaths

Demand for amount and quality of care continues to increase. To maintain a sustainable health care system, these improvements are needed now.

The iPANEL Team

Members of the iPANEL team have been working in palliative and end of life care for many years, and have evidence and expertise beyond what is included in this submission. They are active in academic and practice communities; have presented to local, national and international audiences; and have served on expert committees that advise on research and policy agendas related to palliative and end of life care. We invite you to contact the lead investigators for further information or discussion. We would welcome the opportunity to give a verbal presentation to the Select Standing Committee on Health

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³ The Way Forward (2012). *The Palliative Approach: Improving care for Canadians with life-limiting illnesses*. Retrieved October 13, 2014, from <http://www.hpcintegration.ca/resources/discussion-papers/palliative-approach-to-care.aspx>

⁴ The Way Forward (2012). *Cost-effectiveness of Palliative Care: A Review of the Literature*. Retrieved October 13, 2014, from <http://www.hpcintegration.ca/resources/discussion-papers/economic-review.aspx>

⁵ Seow, H., Brazil, K., Sussman, J., Pereira, J., Marshall, D., Austin, P. C., Husain, A., Rangrej, J., & Barbera, L. (2014). Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: A pooled analysis. *BMJ*, *348*, p.3496.

⁶ Stajduhar, K. I. (2011). Chronic illness, palliative care, and the problematic nature of dying. *Canadian Journal of Nursing Research*, *43*(3), 7-15.

⁷ Stajduhar, K. I., & Tayler, C. (2014) Taking an “upstream” approach in the care of dying cancer patients: The case for a palliative approach. *Canadian Oncology Nursing Journal*, *24*(3), 144-153.

Below is a list of all current investigators on the iPANEL team. This does not include advisory board members, affiliates or students who all continue to build knowledge about best practices for palliative and end of life care in British Columbia.

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Dying to Care:

How can we provide sustainable quality care to persons living with advanced life limiting illness in British Columbia?

- ▶ Implement an Integrated Palliative Approach to Care across the Health Service Continuum
- ▶ Extend/Expand Chronic Disease Management and Primary Care strategies to include an Integrated Palliative Approach to Care
- ▶ Apply a Population Focus in Community, Acute Care and Residential Care Settings in order to support Persons through Transitions in Care

INTRODUCTION

Around the world, the oldest segment of the population is expected to grow the fastest. Within the OECD (Organisation for Economic Co-operation and Development) countries the population share of those 80 years and over is expected to increase from 4% in 2010 to 9.4% in 2050.¹ As of July 1, 2010, seniors aged 65 years and over accounted for 14.1% of the Canadian population. Projections show that seniors could account for more than 20% of the population as soon as 2026 and could exceed 25% of the population by 2056. Seniors aged 80 years and over now represent 3.9% of the total Canadian population; the number of people over 80 residing in Canada by the year 2061 is projected to be 5.1 million. In addition, the fastest growing age groups within the 2009/2010 period were people aged 90 years and over.²

As a consequence of the aging of our population, more people are living with advancing, chronic and life-limiting illness and often with multiple, interacting medical and social problems. At some point in this advancing illness trajectory, people die, and about 80% of these deaths will be caused by end stage chronic diseases such as cardiovascular, lung, and kidney disease, cancer,

and dementias.³ In Western Canada, however, only 16% to 30% of people who die are identified as dying and receive palliative care services.⁴ The majority who access these services have cancer, a unique chronic disease as it can often be predicted when the end of life may be approaching. This is not the case with most chronic diseases. Consequently, most individuals with advancing chronic life-limiting conditions such as heart disease, chronic obstructive pulmonary disease, kidney disease and dementias, do not access palliative care services but dwell “in the indistinct zone of chronic illness that has no specific care delivery system”.⁵

While specialist palliative care services are critical for those with complex care needs, such a model, alone, cannot meet current and future demand for the larger population outside of the traditional recipients of cancer care. The result is that many people who require and would benefit from a palliative approach are not served by specialized palliative care. Historically, these specialized models were not developed for those with advancing chronic non-malignant disease and such models are neither feasible nor desirable for the larger numbers affected by and dying from chronic illness.



¹ Colombo, F. et al. (2011). *Help Wanted? Providing and Paying for Long-Term Care*. OECD Publishing www.oecd.org/health/longtermcare/helpwanted. Retrieved May 27, 2014.

² Statistics Canada. (2011). *Report on the Demographic Situation in Canada*. (Catalogue no. 91-209-X). Retrieved May 27, 2014, from Statistics Canada: <http://www.statcan.gc.ca/pub/91-209-x/2011001/article/11511-eng.pdf>

³ Statistics Canada. (2010). *Leading Causes of Death in Canada 2007*. (Catalogue no. 84-215-X). Retrieved June 6, 2011, from Statistics Canada: <http://www.statcan.gc.ca/pub/84-215-x/2010001/tbl/t001-eng.pdf>

⁴ Canadian Institute for Health Information. (2007). *Health Care Use at the End of Life in Western Canada*. Ottawa: CIHI. Retrieved June 1, 2011, from https://secure.cihi.ca/free_products/end_of_life_report_aug07_e.pdf

⁵ Lynn, J. (2005). *Living long in fragile health: The new demographics shape end of life care*. Supplement to Improving End of Life Care: Why has it been so difficult. Hastings Center Report Special Report. 35(6), S14-S18. Retrieved June 1, 2011 from <http://www.thehastingscenter.org/pdf/living-long-in-fragile-health.pdf>



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In 2011, the Michael Smith Foundation for Health Research (through the British Columbia Nursing Research Initiative) funded a team of nurse researchers, clinical leaders and administrators (Appendix A) to explore how to best integrate a palliative approach into the care of people with advancing chronic life-limiting conditions. iPANEL (Initiative for a Palliative Approach in Nursing: Evidence & Leadership – www.ipanel.ca) is an applied nursing health services research initiative aimed at generating, translating and disseminating research to answer the following broad question:


How and in which contexts can a palliative approach better meet the needs of patients with an advancing chronic life-limiting illness and their family members and guide the development of innovations in health care delivery systems to better support nursing practice and the health system in British Columbia?

Broadly conceptualized, a palliative approach involves adapting the principles and values from specialized palliative care and embedding and integrating those 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.^{6,7}

While iPANEL is ongoing and studies to address the aforementioned question are underway, some key findings are emerging from iPANEL studies (Appendix B) and from the deliberations at three knowledge translation events that engaged clinical experts, health system administrators and decision makers, and policy makers across British Columbia.

⁶ Sawatzky, R., Stajduhar, K.I., & Porterfield, P. (in preparation). A palliative approach: A concept in need of clarity.

⁷ Stajduhar, K. I. (2011). Chronic illness, palliative care, and the problematic nature of dying. *Canadian Journal of Nursing Research*, 43(3), 7-15.



⁸ Stajduhar, K.I., & Doane, G. (2011) Knowledge translation in action: Improving the quality of care at the end of life in acute and long term care settings. Paper presented at the Canadian Hospice Palliative Care Conference, St. John's, Nfld.

⁹ Stajduhar, K.I. & Doane, G. "The last best place to die": Provider perspectives on dying in acute care. Paper presented at the 20th International Congress on Palliative Care, Montreal, Quebec.

EMERGING FINDINGS

Integrating Chronic Disease Management and Palliative Care

Care delivery models for chronic disease management and for palliative care exist, but they mainly exist in isolation of each other. While efforts are being made in the province in most health authorities to create partnerships and continuity of care between the chronic disease management system and the palliative care system they lack sufficient development and depth to adequately support patients and families. This continuity is a key component to enable providers to integrate a palliative approach into their practice. Of key importance is the recognition of individual patient trajectories across systems and places of care. Our findings suggest that there is little system support that follows individuals throughout their trajectories, and through their transitions of advancing illness to death.

Within the residential care sector, nursing care providers were more likely to interpret “palliative” as referring to a set of standardized medical orders activated when a resident was actively dying, in the last days and hours of life. Within acute care medical units, providers were most likely to refer to palliative as a shift in the goals of care from curative to sup-

portive. And, within home care, if those with chronic life-limiting conditions are referred to home-based palliative services, it is often later in the illness trajectory. We found little evidence of the capacity for an integrative nature of a palliative approach where principles of chronic disease management would be incorporated into palliative knowledge (or vice versa), further upstream so that careful and anticipatory planning could occur.

Integrating a Palliative Approach: The Challenge of Acute Care^{8,9}

iPANEL findings suggest that integration of a palliative approach is challenging in all contexts of care (home and community care, residential care, and acute care medical units) particularly because people with advancing chronic life-limiting conditions have not traditionally been considered as being on a dying trajectory until the final weeks and sometimes hours of life. There has been limited uptake of the idea of a palliative approach into these contexts of care, but in comparison to home care and residential care, where there is some recognition that a palliative approach might benefit patients and families, acute care is particularly problematic.



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Interviews with nurses, allied health professionals and physicians, confirm a prevailing sentiment that people with chronic life limiting illness do not “fit” or “belong” in the cure focused environment of acute care, yet neither is there an understanding of “fit” with a palliative approach.

In addition to perceived time constraints, communication breakdowns between and among the inter-professional team, and challenges in symptom management, there appear to be differing perspectives, particularly between physicians and nurses, on what constitutes quality care for people with advancing chronic life-limiting conditions. Many nurses report that this difference in perspectives influences patient and family care in negative ways. Nurses in our iPANEL studies have reported being placed in positions of having to negotiate power relationships with physicians, describing the need to manipulate, demand or negotiate with physicians to get end-of-life needs met for their patients. In addition, “getting on the same page” in terms of the plan of care for the patient and family is challenging. Part of this seems to be related to the unpredictability of the disease trajectory, but reports of discontinuity of care, fractured inter-professional working relationships, and the prioritization

of acutely ill patients over those with chronic life-limiting conditions, creates situations where neither the health care team nor the patient and family are clear on the plan of care. This results in confusion and the risk that care is mismanaged. The blurring of distinctions between palliative care and treatment plans also prevents providers from communicating with each other and aligning patient and family goals of care. It is not always clear to them when palliative care should begin.

Within the acute care sector, hospice palliative care is conceptualized as a place or a service – an inpatient unit where people go to die and where they are cared for by nurses who specialize in care of the dying. There seems to be little acknowledgement that, because people die in all locations in the health care system, all health care providers have a responsibility for providing care to these patients. Rarely is there evidence of a palliative philosophy within approaches to care in many settings. This mismatch between understanding and actual practice has resulted in a general belief, particularly in acute care, that dying patients “don’t belong.”

KEY ASPECTS OF A PALLIATIVE APPROACH

A palliative approach

- Is oriented to knowing that the person has a progressive life-limiting condition and is in need of 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 the life-limiting condition.
- Adapts knowledge and expertise from specialized palliative care and embeds it in care delivery and care processes rather than developing a new program of care or adding it on to specialized palliative care services.
- Necessitates the integration of care delivery systems and partnerships among service providers to address patient needs across all sectors of care.

Sawatzky, R., Stajduhar, K.I., & Porterfield, P. (in preparation). A palliative approach: A concept in need of clarity.



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RECOMMENDATIONS FOR ACTION ▶

Based on iPANEL findings, confirmed and developed through extensive consultations with clinical experts, health system administrators and decision makers, and policy makers across British Columbia, we present our top recommendations for action:

¹⁰ **Expert Panel Suggested Membership:** Representatives from the following organizations: College of Registered Nurses of British Columbia; Association of Registered Nurses of British Columbia; British Columbia Nurses Union; British Columbia Hospice Palliative Care Association; Patient Voices Network, as well as Knowledge Users (senior level and sector specific); Key Researchers; Key Clinical and Nursing Leaders; Policy Leaders; Chief Nursing Officers; British Columbia Centre for Palliative Care, Doctors for British Columbia; MD or Nurse Ethicist.

¹¹ Palliative Care Australia, *A guide to palliative care service development: A population based approach*, Palliative Care Australia, Editor. 2005, Palliative Care Australia: Canberra

1 Implement an Integrated Palliative Approach to Care across the Health Service Continuum

▶ British Columbia MOH Priority Setting Priorities 1: Provide Patient Centered Care

Establish a Provincial Palliative Approach Expert Panel¹⁰ (PAEP) to develop and implement a 5 year plan for a palliative approach in British Columbia. The expert panel will report to the Provincial Palliative Care Steering Committee, with accountability for establishing and defining palliative care service levels within each component of the population needs-based triangle,¹¹ recommend provincial tools and education strategies and suggest performance metrics/reporting requirements related to a palliative approach.

..... *TIMELINE: November 1, 2014*

2 Extend/Expand Chronic Disease Management and Primary Care Strategies to include an Integrated Palliative Approach to Care

- ▶ British Columbia MOH Priority 3: Implement a provincial system of primary and community care built around inter-professional teams and functions.
- ▶ British Columbia MOH Priority 4: Strengthen interface between primary and specialist care and treatment.

Develop a Provincial Palliative Approach Clinical Working Group (PACWG) (as a sub-committee of the PAEP) which includes consumers to:

Develop care plans and best practice guidelines for high priority populations.

.....TIMELINE: January 2015

Ensure access to best practice tools and web resources for clinicians in the province (example, British Columbia Health Quality Network)

.....TIMELINE: June 2015

Develop palliative approach competencies and influence/develop curriculum with a focus on aspects of a palliative approach such that areas such as spiritual care, ethical and legal frameworks and psychosocial aspects of care are highlighted.

.....TIMELINE: June 2016

Build systems for front line health care professional peer-to-peer mentoring and support.

.....TIMELINE: June 2017

3 Apply a Population Focus in Community, Acute Care and Residential Care Settings in order to support Persons through Transitions in Care

- ▶ British Columbia MOH Priority 7: Examine the role and functioning of the acute care system, focused on driving inter-professional teams and functions with better linkages to community health care.
- ▶ British Columbia MOH Priority 8: Increase access to an appropriate continuum of residential care services.

Provincial Palliative Approach Expert Panel to link with and support the existing work being done by the MOH/HA Provincial EOL Working Group: Sub-Committee on EOL Care in Residential Care

.....TIMELINE: September 2014

Standardized Goals of Care or MOST (or a similar tool) be implemented provincially and be used to increase conversations about goals of care and advance care planning for vulnerable groups in acute care.

.....TIMELINE: June 2015

MOH to define standards related to tertiary and palliative care consultation services and ensure they are available to generalist care providers in all settings.

.....TIMELINE: June 2016



CONCLUSIONS

An integrated palliative approach to care is a vision that should be adopted by the province. Leaders in British Columbia health authorities recognize the limits of the current system in meeting the needs of those with chronic advancing life-limiting illness. Emerging results from iPANEL research and engagement across British Columbia suggest that integration of a palliative approach into home, residential and acute care settings is an efficient, safe and humane way to serve patients with chronic conditions and their family members and fill a costly unmet need for the British Columbian population.





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APPENDIX A – iPANEL TEAM MEMBERS

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APPENDIX B – IPANEL FUNDED RESEARCH PROJECTS

Completed projects _____

Knowledge Translation in Action: Improving the Quality of Care at the End of Life

Principal Investigators: Kelli Stajduhar & Gweneth Hartrick Doane
Funded by: Canadian Institutes of Health Research

The Interpretation and Practice of Family Empowerment in Home Care Nursing: Palliative and Chronic Illness Contexts

Principal Investigator: Kelli Stajduhar
Funded by: Canadian Institutes of Health Research

Educating for a Palliative Approach to Care: A mixed method scoping review, environmental scan, & philosophic analysis

Principal Investigator: Barbara Pesut & Barbara McLeod
Funded by: Canada Research Chair & Michael Smith Foundation for Health Research (BCNRI)

A Palliative Approach in Rural Nursing: A qualitative secondary analysis

Principal Investigator: Barbara Pesut
Funded by: Faculty of Health and Social Development Grant – UBC Okanagan

A Mixed-Methods Survey about a Palliative Approach in British Columbia Nursing Care Settings

Principal Investigators: Richard Sawatzky, Sheryl Reimer-Kirkham, Della Roberts
Funded by: Michael Smith Foundation for Health Research (BCNRI)

A Mixed Methods Knowledge Synthesis of a Palliative Approach

Principal Investigators: Kelli Stajduhar, Richard Sawatzky
Funded by: Canadian Institutes of Health Research

Current projects

A Mixed Methods Knowledge Synthesis about Nursing Care Delivery and Practice Supports for a Palliative Approach

Principal Investigators: Richard Sawatzky, Pat Porterfield
Funded by: Michael Smith Foundation for Health Research (BCNRI)

Enhancing Educational Capacity for a Palliative Approach in Rural Nursing: A Research Demonstration Project

Principal Investigators: Barbara Pesut, Gail Potter
Funded by: Michael Smith Foundation for Health Research (BCNRI)

Integrated Knowledge Translation: Examining a Collaborative Knowledge Translation Approach

Principal Investigators: Sheryl Reimer-Kirkham, Elisabeth Antifeau, Gweneth Hartrick Doane
Funded by: Michael Smith Foundation for Health Research

Patient- and family-reported experience and outcome measures for elderly acute care patients: A knowledge synthesis.

Principal Investigators: Richard Sawatzky
Funded by: Technology Evaluation in the Elderly Network

Supporting Family Caregivers of Palliative Patients at Home: The Carer Support Needs Assessment Intervention

Principal Investigators: Kelli Stajduhar and Richard Sawatzky
Funded by: Canadian Cancer Society Research Institute & Technology Evaluation in the Elderly Network

Access to End of Life Care for Vulnerable and Marginalized Populations

Principal Investigator: Kelli Stajduhar
Funded by: Canadian Institutes of Health Research

Integrating Quality of Life Assessments into Acute Care for Older Adults with Chronic Life-limiting Illness

Principal Investigators: Richard Sawatzky, Kelli Stajduhar, Robin Cohen
Funded by: Technology Evaluation in the Elderly Network



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