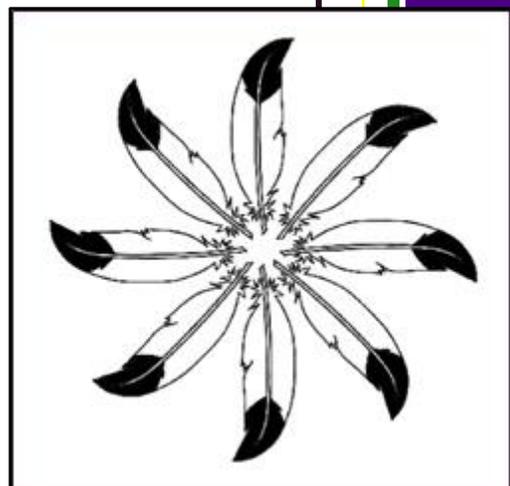


**Recommendations to Improve  
Quality and Access to  
End-of-Life Care in First Nations  
Communities:**

**Policy Implications from the “Improving End-of-Life  
Care in First Nations Communities” Research Project**

December 2014



## ACKNOWLEDGEMENTS

The research team, led by Dr. Mary Lou Kelley, Lakehead University, would like to acknowledge and thank the four First Nations community partners: Nootkamegwanning First Nation, Fort William First Nation, Peguis First Nation and Six Nations of the Grand River Territory. In addition, we would like to thank the Canadian Institutes of Health Research for their financial contribution and support of the research.

## CONTACT INFORMATION

**For more information, please contact:**

**Dr. Mary Lou Kelley**  
Principal Investigator  
Phone (807) 766-7270  
mlkelley@lakeheadu.ca

**Holly Prince**  
Project Manager  
Phone (807) 766-7274  
hprince@lakeheadu.ca

Centre for Education and Research on Aging & Health (CERAH)  
Lakehead University  
955 Oliver Road  
Thunder Bay, Ontario, P7B 5E1

[www.eolfn.lakeheadu.ca](http://www.eolfn.lakeheadu.ca)

## RECOMMENDATIONS TO IMPROVE QUALITY AND ACCESS TO END-OF-LIFE CARE IN FIRST NATIONS COMMUNITIES

The First Nations population is aging and the burden of chronic and terminal disease is increasing. The home and community care needs of Elders and chronically ill community members have significantly increased in the last ten years. Currently, First Nations communities lack the health services and other supportive community infrastructure to meet the growing demand for home care services for people with complex and high intensity care needs, in particular the very elderly, frail, and people at the end-of-life. A photovoice research study of aging in Grassy Narrows First Nation uses photographs by local Elders to clearly illustrate the lack of community health services and infrastructure in Canadian First Nations communities [Hester & Kelley. (2008). Photovoice: Exploring Health Barriers and Resources for Older People].

Our research “Improving End of Life Care in First Nations” conducted in Ontario and Manitoba indicates that if services were available and sufficient, the majority of First Nations people would prefer to receive their palliative and end-of-life care at home where they are surrounded by family, friends, and culture. This finding is similar to the stated preferences of Canadians in general and thus should not be surprising. In contrast, most First Nations people currently die in distant regional and urban hospitals and long term care homes. In our research, we have also found that taking end-of-life care out of the First Nation community disrupts family life and creates emotional, social, spiritual, and economic burden. A person dying outside of the community creates a barrier to normal grieving for family and community. First Nations people understand that grief is an important process and disruptions in appropriate grieving have negative effects on overall community, social, and economic wellbeing.

Addressing the unmet need for enhanced home and community care is a key obligation of the federal government since the federal government has the constitutional responsibility for the health of First Nations, Inuit and Metis people living in Canada. Enhancing Home and Community Care programs in First Nations communities will be required as a key component of implementing the proposed Pan Canadian Palliative Care Strategy (Bill M 456). The critical gap in community services that is preventing First Nations people from having the choice to die at home is the insufficient level of service and medical equipment within the First Nations Inuit Health Branch (FNIHB) Home and Community Care programs.

Building on and reclaiming their historical and cultural traditions of family and community caregiving, the communities involved in our research have demonstrated that First Nations communities can mobilize their own local capacity to provide palliative and end-of-life care given additional support. First Nations communities are willing and able to support community members and their families to receive a palliative approach to home care and to die at home if that is their choice. However, communities need facilitation at the local level to help organize and mobilize local capacity and create new collaborations with palliative care experts and services in the provincial and territorial health care system. They also require additional home care services and case management for clients with high intensity needs, including timely access to equipment and medication when life expectancy is short. Implementation of Jordan's Principle, which currently only applies to those under 18, for people of all ages in all situations involving care in the last year of life would help to address this need. Jordan's Principle (<https://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879>) calls on the government of first contact to pay for required end of life home care services and to seek reimbursement later so the person does not get tragically caught in the middle of government red tape.

Consistent with the Way Forward National Framework (Canadian Hospice Palliative Care Association, spring 2014) First Nations people would benefit by implementation of a palliative approach to home care at all stages of frailty or chronic illness, including but not limited to the end of life. Palliative care is no longer thought of as a discrete service offered to dying people when treatment is no longer effective. Rather, it requires an integrated approach to physical, psychosocial, and spiritual care at the primary care level that can enhance people's quality of life throughout the course of their illness or aging process, right until the end of their life. Our research has demonstrated that First Nations communities can develop unique, culturally appropriate, community-based palliative care programs through undertaking local capacity development efforts, creating new partnerships with regional health services, and coordinating existing First Nations' community health and social support programs (To hear a CBC radio interview related to this:

[http://www.cbc.ca/player/Radio/Local+Shows/Ontario/Up+North/ID/2599444641/?sort=MostRecent.](http://www.cbc.ca/player/Radio/Local+Shows/Ontario/Up+North/ID/2599444641/?sort=MostRecent) )

First Nations community capacity development to provide a palliative approach to home and community care requires local program development and client case management, palliative care education for health care providers and families in First Nations communities, creation of new palliative care service delivery partnerships with federal and provincial health services such as hospitals, home care and respite care, and an infusion of funding to fill existing gaps in home care services and equipment for people in the last year of life.

The basic framework to integrate a palliative approach into the home and community care program already exists (essential versus non-essential services); however, an infusion of enhanced federal funding is needed to increase home and community care services to the level required for people to remain living at home for the rest of their lives. Funding levels for Home and Community Care Programs

have not increased, with the exception of 3% cost of living increases, since the Home and Community Care program was established in 1999. HCC is intended to be community based and community-paced; however, services are no longer consistent with the pace of community care or community needs. Funding levels do not reflect the current number of clients with high intensity and complex care needs.

To advance the Pan Canadian Strategy for Palliative Care that adequately and equitably meets the needs of First Nations people, the federal government needs to:

- 1) Review the current service and equipment levels (essential and supportive services) for federally funded Home and Community Care programs in First Nations and adjust them to reflect the aging of the population, the increased burden of chronic and terminal disease and frailty, and the increased number of people with high intensity and complex care needs who require home care and intensive case management, especially in the last year of life.
- 2) Sponsor, support and resource local leaders in First Nations communities to facilitate local community capacity development that would integrate a palliative approach into all community health and social services and create local palliative care programs using existing services and new partnerships. The creation of palliative care programs involves conducting needs assessments and asset mapping, mobilizing and coordinating existing community resources and negotiating new regional partnerships with their provincial/territorial health services. The goal is to develop effective care pathways and provide culturally safe care for First Nations people who want to receive palliative and end of life care at home.
- 3) Ensure telemedicine is available in every First Nation community so that people with complex and high intensity needs, especially people who are dying, and their families can receive expert consultation

from regional palliative care teams and consultants at home; and First Nations' health care providers can receive palliative care education, consultation, and support in their day to day work in the community.

4) Review the current approval process within the Non Insured Health Benefit (NIHB) program to ensure there are "fast track" approval processes for clients in the last year of life, and implement Jordan's principle in any cases of funding disputes across jurisdictions. (<https://www.aadnc-aandc.gc.ca/eng/1334329827982/1334329861879>)