

Improving End-of-Life Care in First Nations Communities: Outcomes of a Participatory Action Research Project

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First Nations hold an enormous amount of traditional and community-based knowledge and expertise in negotiating the personal, familial, and community experiences of end of life. However, health systems that have been imposed on them typically do not support these non-mainstream approaches to care. Unfortunately, for First Nations, aging and the burden of chronic and terminal disease are increasing.

First Nations communities currently lack health services and other supportive community resources to meet their growing need for palliative care, especially for people with complex and high intensity care needs and people at the end of life. As a result, most First Nations people currently die in distant, regional and urban hospitals and long-term care homes. The need to access end-of-life care thus separates dying people from their family, friends, community, and cultural supports at a very vulnerable time of their lives. Further, lack of access to local palliative care robs First Nations communities of important opportunities for supporting, grieving, and healing as they adapt to losing an Elder or community member.

One strategy to improve access to palliative care services in First Nations communities is to create local palliative care programs that are designed to be culturally- and contextually-appropriate; however, barriers exist in funding, policy, and research. Thus, First Nations communities are often forced to develop palliative care programs without sufficient federal funding for their home and community care programs. Palliative care programs offered by provincial and territorial health services do not normally provide services in First Nations communities due to jurisdictional issues. In addition, there is little research evidence to guide the development of culturally- and contextually-appropriate palliative care programs within First Nations communities.

Our research project, *“Improving End-of-Life Care in First Nations Communities”* (EOLFN), was funded by the Canadian Institutes of Health Research through an Aboriginal Health Intervention Grant (2010-2015) and was conducted in partnership with four First Nations communities in Ontario and Manitoba. The research team was based at the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University in Thunder Bay, Ontario. Principal Investigator, Dr. Mary Lou Kelley, and Project Manager and co-investigator Holly Prince led the team of researchers that included Dr. Christopher Mushquash, Dr. Kevin Brazil, Valerie O’Brien, Gaye Hanson, and Mae Katt.

The goal of the project was to improve end-of-life care in the four First Nations communities by developing community-based palliative care programs and teams, as well as to create a practical *Workbook* of research informed strategies for developing palliative care programs applicable to other First Nations communities. We employed a participatory action research approach in which participants in the project controlled all aspects of the research process. Advocacy, education, and action were the core elements. The research also followed the principles of OCAP (Ownership, Control, Access, and Possession) to ensure self-determination throughout all aspects of the research.

We began with a needs assessment in each community. Findings showed that if services were available and adequate, the majority of First Nations people would prefer to receive their palliative and end-of-

life care at home, in familiar settings, where they would be surrounded by family, friends, and culture. They want the opportunity and choice to die in the communities where they have lived all of their lives. Local assets, cultural traditions, and other community strengths were documented, and challenges within the community and externally in the relationships with regional hospitals, home care programs, and other health services were identified. Gaps in resources required to provide quality palliative care at home, such as access to medications and specialized equipment, were also identified. These needs assessment findings became the foundation for each First Nation community to begin to create a local palliative care program that would address their unique needs and circumstances and advocate for the necessary resources.

To be successful, each community needed strong, dedicated local leadership and a facilitator from within the community. This facilitator helped the community leaders to organize and mobilize local community capacity, and helped create new collaborations with palliative care experts and services in their provincial health care system. The communities also required enhanced resources such as home care services and intensive case management for clients with complex care needs, including timely access to medications and specialized equipment when life expectancy was short.

Over five years, the research project created locally designed and controlled palliative care programs in four First Nations communities; created a national alliance of over 125 stakeholders; developed policy documents to guide health care decision makers and the federal/provincial/territorial governments; and created a Workbook of over 80 research-informed community development strategies and program resources for use by First Nations communities across the country. Examples of resources included in the Workbook are community development strategies, palliative care program descriptions, a journey mapping guide to create a palliative care pathway, and educational curricula for health care providers, clients, and community members. For example, there is a Grief and Bereavement workshop to help care providers in First Nation communities provide healthy, safe, grief and loss support to individuals, families, and their loved ones. There is also culturally appropriate education for advanced care planning. These resources are all available at no cost on the project website.

Given the interdisciplinary nature of health care delivery and the growing need for culturally- and contextually-appropriate end-of-life care for First Nations, psychology can play a significant role in bringing necessary skills in clinical service provision, research, and policy into partnerships that move beyond an individual differences, variables approach to developing and delivering ethical palliative and end-of-life care to First Nations, while respecting the immense knowledge First Nations hold.

To learn more about this project, please visit: www.eolfn.lakeheadu.ca