

Improving End-of-Life Care in First Nations Communities



Generating a Theory of Change to Guide Program and Policy Development

**Halifax, Nova Scotia
January 2011**



“I feel very strongly that this is greatly neglected in home care, especially First Nation homecare. There is an increasing rate of people choosing to die at home and there are not the services or resources to support these choices.”

Timeline

2003 - 2005

- Holly Prince's MSW project – pilot study of 2 FN communities based on an identified need from local health care providers

2005 - 2006

- Needs assessment expanded to include 13 First Nations communities in Treaty #3 - resulted in a series of recommendations

2006 - 2009

- Community development in Treaty #3

2009 - 2010

- Needs assessment expanded to 9 FN in the Robinson Superior Treaty and Treaty #9 areas
- Community development work ongoing for the Treaty #3 FN communities
- Integrative Framework article published in the JPC
- Proposal submitted to CIHR

2010-2015

- “Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development”



Palliative Care Needs Assessment

2003 – 2006 (Treaty #3)

2009 – 2010 (Robinson Superior/Treaty 9)



Communities

21 First Nations communities in Northwestern Ontario

- Treaty # 3 - 12 of the 28 FN
- Treaty # 9 - 3 of the 49 FN
- Robinson Superior - 6 of the 13 FN



Purpose

- To document current levels of awareness, understanding, and perceived access to palliative care among members of First Nations communities.
- To understand community beliefs and values related to death and dying, and the preferred place for receiving end-of-life care.
- To understand the service and educational needs of caregivers in First Nations communities.

Methodology

Quantitative and qualitative data were collected in a two stage process in each community

1. Key informant surveys (20 per community) by FN community project assistants
2. Focus Groups and individual key informant interviews

Content analysis on numerical data and thematic analysis on descriptive data

Respondents (21 FN's)

Survey

- Response rate of 87%
- 33% over the age of 51 (representing the largest age category)
- 62% female
- 13 local Research Assistants hired to collect survey data

Focus Group and Individual Interviews

- 19 focus groups with 137 participants
- 8 individual interviews
- Conducted by Aboriginal Researcher

Highlights of Results

- Communities had a good awareness and understanding of palliative care (components, location, areas of information on PC, experience in providing care)
- Treaty #3 communities had a broader definition of PC to include when care needs of the individuals are more than what the community can provide and the individual has to leave the community

Community Values and Beliefs

Attributes	Treaty #3	RS/Treaty #9
Talking about death and dying	54% acceptable	75% acceptable
	Not acceptable due to cultural teachings & taboos, fearing death and talking about dying is difficult	
Advance Care Planning	Approximately 60% felt that you should plan for EOL when you are healthy	
Choose to die in home community	68% yes	80% yes
Advantages of dying in the community	Comforting, practicing traditions, access to language and support people, empowering, hospital restrictions and leaving community create barriers, *cost*	

- Role of informal and formal caregivers are viewed as equally important
- Lack of resources and education relating to PC; lack of knowledge about the care system
- Health care providers “speak their own language”
- Providing pain management is a challenge in the communities as there are issues with substance abuse and keeping medications safe
- Will writing is not a common practice and in some cases the practice of “signing documents” is viewed as disempowering

- Diverse beliefs and practices within the communities, however collective culture is a cornerstone of all activities and values
- Strong emphasis on the role of family and community and viewed as an enormous strength
- Resiliency of individuals and communities in dealing with difficult situations
- Communities have a vision for change in wanting to improve the EOL care for their community member

Recommendations...

- To provide **culturally appropriate palliative care education** to community health care workers and family caregivers
- To facilitate the **development of palliative care programs** in First Nations communities using existing local resources.
- To **conceptualize a model** for developing palliative care in First Nations communities that would be applicable in other areas of Ontario and Canada.

Community Development

2006 - 2009

- Focus on increasing the palliative care knowledge, skills and confidence of those who provide care in the community
- Organized and delivered training workshops for FN health care providers
- Provided participants with curriculum materials and support to do community based education
- Developed educational resources based on need



- Workshop participants were expected to take **leadership** in developing a palliative care program in their FN
- **Community visits** to each FN community to begin to conceptualize/develop a palliative care team
- Make **linkages** to regional palliative care experts and services
- **Advocate** for the community resources needed to increase home deaths in First Nations communities

Keys to Success in this Project

- Dedicated people involved
- Collaborative relationships established regionally, nationally and internationally
- Understanding and accepting the process
- Working with people and communities where they are at
- Time and commitment

Journal of Palliative Care Spring 2010

*“An Integrative Framework for
Conducting Palliative Care Research
with First Nations Communities”*

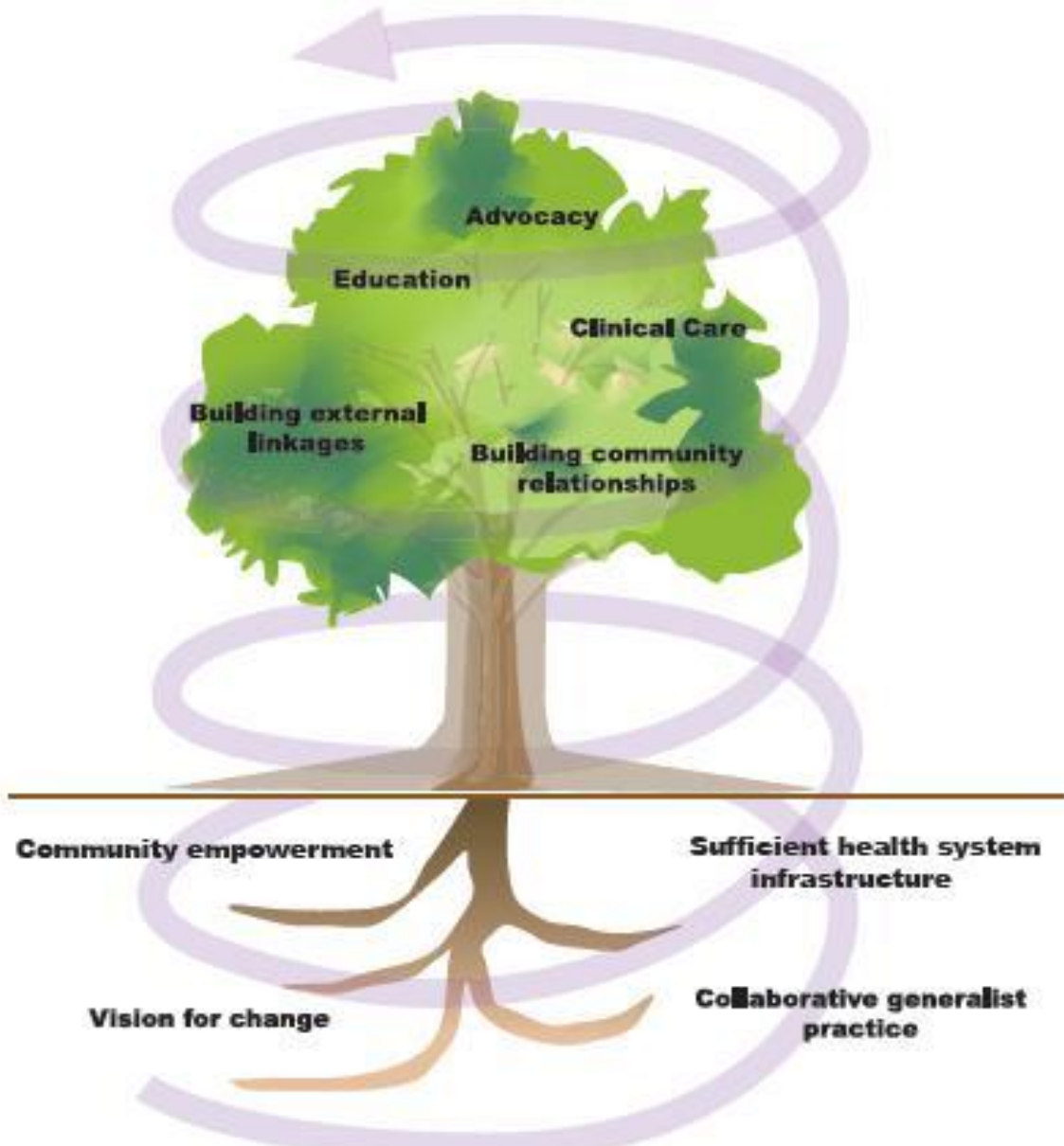
The Framework Consists of Five Components:

1. Community capacity development
2. Cultural competency and safety
3. Participatory action research
4. Ethics
5. Partnerships

Prince, H., & Kelley, M.L. (2010). An Integrative Framework for Conducting Palliative Care Research with First Nations Communities. *Journal of Palliative Care, Special Edition*, 26(1), 47-53.

Community Capacity Development

- The evolutionary process of change and adaptation that occurs from inside as individuals, groups and/or communities act to accomplish their goals.
- The method of promoting change is to enhance local capacity and not impose solutions from outside.



Process of Palliative Care Development

Sequential phases of the capacity development model:

4. Growing the Program

3. Creating the Team

2. Catalyst

1. Antecedent Community Conditions

Kelley ML. Developing rural communities' capacities for palliative care: a conceptual model. *J Palliat Care* 2007; 23(3): 143-153.

Cultural Competency and Safety

- Recognizes that the person and community are the experts of their own experience, and requires that researchers communicate competently with a person in that person's social, political, linguistic, economic & spiritual realm.
- Stresses the importance of recognizing and analyzing power imbalances to address inequities.

- Three primary strategies for navigating cultural differences:
 - Accepting differences and not attempting to mask them
 - Building respectful, equal, and trusting relationships among participants over the long term
 - Prioritizing our common goal — namely, to successfully develop community palliative care programs.

Participatory Action Research

- The research methodology is PAR:
 - **Participatory** means that those people and organizations who will benefit from the research also fully participate in it.
 - **Action** means that the goal of the research is to create social change.

- Based on the data collected, **knowledge was co-created** by the researchers and participants through a reflective spiral of activity
- Embedded in the PAR process is **knowledge transfer** to all stakeholders and participants.
- A PAR approach is appropriate for our research because it recognizes the expertise of First Nations community members and promotes integration of community values and practices into palliative care.

Ethics

- adherence to ethical guidelines for conducting research with human subjects, but also to specific guidelines for health research involving Aboriginal peoples, including the principles of OCAP (Ownership, Control, Access and Possession).
- These principles, ensure self-determination in all research concerning First Nations

- We worked directly with community Chiefs and Council members to explain the project and obtain consent to enter the communities.
- Adherence to the OCAP principles facilitates trust, encourages mutual decision making, and engages the community.
- It also ensures cultural safety by empowering the community, promoting self-determination in the development of palliative care programs, and minimizing misinterpretations and biases that result from differing cultural frameworks.

Partnerships

- Research needs to build on strong relationships between researchers, Aboriginal health organizations, and participating First Nations communities.
- At the outset, we formed a project advisory committee which was mandated to ensure:
 - that the project goals and objectives were met;
 - accountability to the partners;
 - that steady progress was made on all aspects of the research; and
 - adherence to the principles of OCAP.

- The committee oversaw all aspects of the research at every stage, assisting with community engagement, identifying appropriate informants and participants, reviewing preliminary data interpretation, and developing a dissemination plan.
- Contracts were signed early in the partnership between the University and the Kenora Chiefs Advisory (KCA) outlining the nature of the partnership. For the first two years, the KCA also held project funds at the request of the funder.

- Each component has a well-developed evidence base in the literature; however, integrating them provides a unique contribution.
- Together, they articulate a research approach that respects the unique needs and cultural mores of First Nations communities.
- This framework is offered as a resource to guide other researchers and First Nations communities who wish to conduct research to develop palliative care programs.

Current Research funded by CIHR

2010 – 2015

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- Utilizing the framework, we were recently awarded a 5 year 1.8 million CIHR AHI grant dedicated to improving palliative care services in First Nations communities.
- Goal: to improve end-of-life care in First Nations communities through developing palliative care programs and creating a culturally appropriate theory of change to guide palliative care program and policy development nationally.

Research Plan

- Comparative case study
- Participatory Action Research
- Community Capacity Development
- Based on a 4-phase model for developing palliative care

Researchers

Principle Investigators

- Dr. Mary Lou Kelley, Lakehead University
- Dr. Kevin Brazil, McMaster University

Co-Investigators

- Dr. Mary Hampton, Luther College, University of Regina
- Gaye Hanson, Hanson and Associates, Whitehorse, Yukon
- Mae Katt, CRaNHR, Lakehead University
- Dr. Bruce Minore, CRaNHR, Lakehead University
- Valerie O'Brien, McMaster University
- Holly Prince, CERAH, Lakehead University

First Nation Partners

- Fort William First Nation
- Nootkamegwanning First Nation
- Six Nations of the Grand River Territory
- Peguis First Nation

- Dilico Anishinabek Family Care
- Kenora Chiefs Advisory

Specific Objectives:

- To document Indigenous understandings of palliative and end-of-life care as a foundation for developing local palliative care programs.
- To generate a culturally appropriate theory of change in First Nations communities based on a 4-phase model of community capacity development.
- To create an evidence-based tool kit of strategies and interventions to implement palliative care programs in First Nations communities.

Specific objectives cont...

- To empower First Nations health care providers to be catalysts for community change in developing palliative care.
- To improve the capacity within First Nation communities by developing palliative care teams and programs, and strengthening linkages to regional palliative care resources.
- To develop knowledge and skills in participatory action research methodology for First Nations community members, graduate students and health professional trainees.

Research Partnerships

Each First Nation has developed a ***Project Advisory Committee***.

- 1) Ensure local control of the project
- 2) Oversee all aspects of the research process
- 3) Assist with community engagement, developing and reviewing data collection tools
- 4) Identify the appropriate key informants and participants
- 5) Review preliminary data interpretation
- 6) Develop an inclusive dissemination plan

- An ***Aboriginal Community Facilitator*** was hired by the Project Advisory Committees to lead local implementation of the project.
- With guidance from the research team, they will collect data, facilitate community interventions, (i.e. educational workshops, developing resources, assisting in policy development) and assist in data analysis
- ***Aboriginal Project Manager*** will oversee all work by the Aboriginal Community Facilitators

Project Management Committee consists of two members from each Project Advisory Committee, researchers, trainees, research assistants, and Aboriginal Community Facilitators

- 1) The project meets its goal and objectives
- 2) Adherence to the principles of OCAP and the CIHR Guidelines of Health Research Involving Aboriginal People
- 3) Accountability to the partners
- 4) That steady progress is made on all aspects of the research

- Researchers will work with the local Project Advisory Committee and the Aboriginal Community Facilitator to conduct a community assessment and develop a palliative care program.
- The community assessment will consist of data collected through: surveys, interviews and focus groups with Chief and Council, First Nations community health care providers, Elders, community members and external health care organizations; through discussions held at educational and planning workshops; and through participant observations in the communities.

- Based on the data collected, specific interventions will be identified by the First Nation community and implemented by the community over five years.
- These interventions will be evaluated for its effectiveness in contributing to the overall organizational change process
- The interventions will then contribute to a “tool kit” of evidence based strategies for developing organizational capacity to provide palliative care in First Nations communities

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