

Improving End-of-Life Care in First Nations Communities:

Research to Guide Palliative Care Program and Policy Development Nationally

**CHCA 2011 Home Care Summit
October 24, 2011**

Acknowledgements



Peguis First Nation



Fort William First Nation



Addressing the Need





“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.”

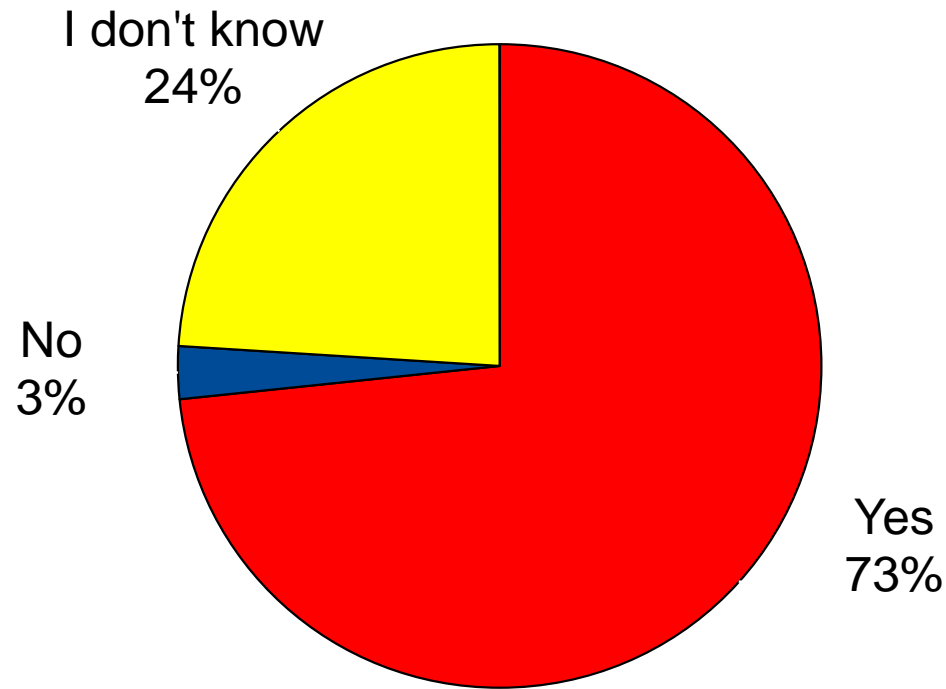
Previous Research 2005-2010

- 22 First Nations communities in NW Ontario
- Objectives
- Data collection (4 key groups of participants)
 - Key informant surveys (383 participants for a 87% response rate)
 - 19 focus groups (137 participants)
 - 8 individual interviews

53% of survey respondents had either personally cared for or knew of a family member who had provided care for someone who was dying.

- The majority of care was provided in the home (77%)
- Over half of the people (53%) who provided care reported using some form of palliative care services
- Participants who used services generally reported being satisfied

In your opinion, if services were available and adequate, would more community members choose to die at home?



Advantages of Staying in the Community

Comforting and Familiar

“I think when they want to die at home, its because they are familiar, they are familiar with their surroundings and the people around them, and the people around them know them, know their moods, their habits, their whatever...”

Feeling Empowered

“...she had already known that she wasn’t going to make it. It was just a matter of a couple of days after they (hospital staff) finally allowed her to go home and she went home, a couple of days later she passed away. Seeing her garden in front of the window, that’s all she wanted. It was kind of, for myself, I felt good that it happened at home where she wanted to be. It was peaceful for her and in a way it was peaceful for me too, knowing that she was where she loved to be.”

Unrestricted Access

“We want to come in here, 10 people at a time coming to visit – no, no, we’ve got no space for that, eh, hospitals do that, only two people when the person is dying in the hospital. You have to hang out in the hallway and wait your turn.”

Language accessibility and cultural practices

“She was totally, 100% culture, we’d drum for her, we’d sage, like I said, we set the alarm off with the sage...I don’t think the nurses knew that was going to happen either, they didn’t know.”

“We took her to [name of community] to see a medicine man...we had to go through, the procedures, check out, sign her out you know, passes, whatever, and they all knew where she was going and then all of a sudden, bang...the nurses were telling us she lost her bed [in the hospital].”

Challenges in Staying in the Community

Lack of Resources

“There isn’t any actual hands-on nursing and then there’s two PSW’s and there is then a VON nurse but she just goes around to do blood pressures and checks on people’s dressings and stuff like that, like the medical services really are lacking.”

Lack of Knowledge

- People lacked knowledge of both the care system and the dying process
- Health care professionals were described as “speaking their own language”
- Navigating through differing health care providers

Lack of Family Support

- On average, it was estimated that 95 hours per week would be required to care for a dying loved one at home
- More than half (55%) said they could not devote this amount of time
 - Time already committed to other things
 - Not having the necessary resources
 - Not being physically capable

Lack of Community Well-Being

- Complex political dynamics
- Needs to be a level of trust between the family, the workers and the community
- Issues with substance misuse

“...about the medication, they are really afraid that it’ll go into other hands and they are telling [name of person] to watch it because we have bad addictions here so that’s why they were saying, watch it closely.”

Educational Needs

- Greater education of the dying process
- Education about the programs and services currently available
- Increased education for care providers on the provision of care

“it’s more important that we educate our people that they know that there is stuff that we can help them, that the education is there and then somebody that has the knowledge to help them...”

Policies and Programs

- Prepared and supported community palliative care teams
- Improved communication strategies
- Grief and bereavement programs

Facilities and Cultural Space

“When my uncle...passed away, he was a very spiritual and traditional man, he had his own pipe and one of his last wishes was to have the pipe smoked for him so we had asked but they would not allow. We had to make other arrangements to take our Elder to another building, it couldn't be done inside. But he was very ill, he was dying of cancer and we couldn't move him. He was in so much pain so we had to arrange for someone could smoke his pipe just outside his room so the other person could be outside and some are inside with him. But you know, that was very sad that on that part that they wouldn't do that for him.”

Equipment

- Hospital beds

“...we have a [specialized hospital-type] bed here [in our community] and somebody else was using it so it had to come all the way from Thunder Bay. That boy that was just here... he went and got it that night...he delivered it at 12:00 a.m. and she came home at 3:30 a.m....that’s how we work together as family.”

- Availability of supplies and equipment

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.

The Framework Consists of Five Components:

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

Improving End-of-Life Care in First Nations Communities:

Generating a Theory of
Change to Guide Program and
Policy Development



Research Goal

- To improve end-of-life care in four First Nations communities through developing palliative care programs
- Create a culturally appropriate process to guide palliative care program and policy development nationally

First Nation Partners

Fort William First Nation

- Karen Bannon and Luanne Maki

Naotkamegwanning First Nation

- Maxine Ranville

Peguis First Nation

- Jeroline Smith

Six Nations of the Grand River Territory

- Lori Monture and Ruby Miller

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Kenora Chiefs Advisory, Jocelyne Goretzki

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Research Staff

- Aboriginal Community Facilitators
 - Natalia Collins
 - Tracy Sinclair
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- Aboriginal Research Assistant
 - Melody Wawia
- Aboriginal Graduate Student Trainee
 - Robert Sleeper

Research Plan

- Comparative case study design
- Participatory Action Research
- Community Capacity Development

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.

- Researchers and Aboriginal Community Facilitators will work with each community to conduct a community assessment through a local Project Advisory Committee
- 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 then 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

Delivery of Health Services

“Recognize and accept the federal government role as a direct provider of health care to certain populations under federal responsibility and ensure appropriate programs and funding for these populations, most especially for our First Nations and Inuit peoples.”

Honourable Sharon Carstairs

Raising the Bar: A Roadmap for the Future of Palliative Care in Canada, June 2010

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