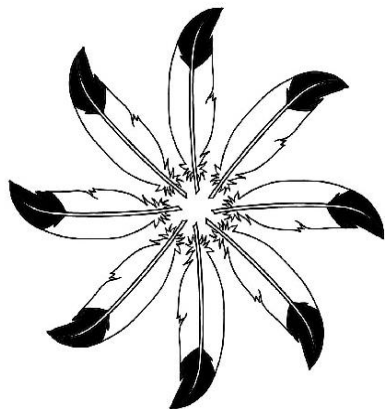


Improving End-of-Life Care in First Nations Communities:



The Power to Choose:
**Developing First Nations' community
palliative care programs**

Conflict of Interest Declaration: Nothing to Disclose

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**Title of Presentation: The Power to Choose:
Developing First Nations community palliative care
programs**

**We have no financial or personal
relationships to disclose**

Acknowledgements



Fort William First Nation



Peguis First Nation



Objectives

- Demonstrate the strengths and capacities within First Nations communities
- Share FN community driven strategies to improve palliative care
- Demonstrate linkages and partnerships with health care providers and policy makers that can support and empower First Nation communities to develop palliative home care

Overview of Research Project

- Project is funded for 5 years (2010-2015) by CIHR
- CERAH, Lakehead University is host organization
- 4 First Nations communities are partners in this project:
 - Fort William First Nation
 - Naotkamegwanning First Nation
 - Peguis First Nation
 - Six Nations of the Grand River Territory

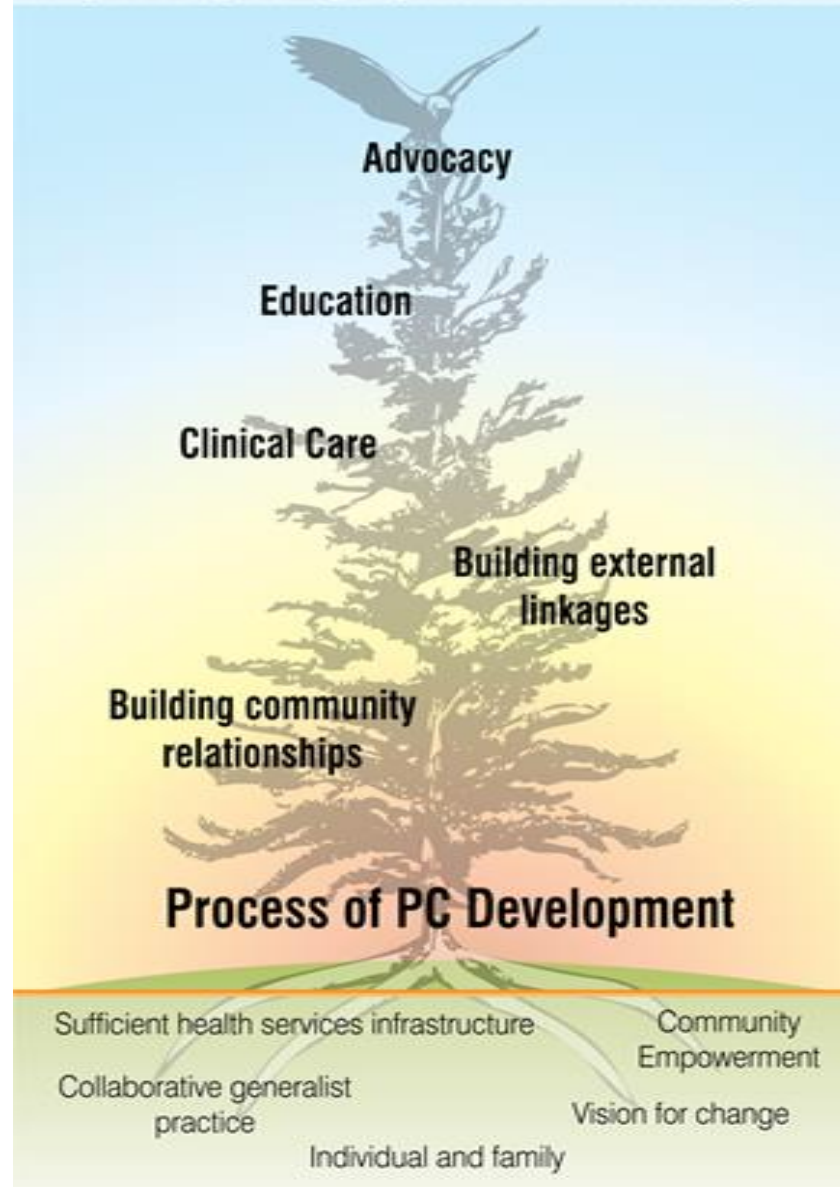
First Nations Communities:



Phases of the Research Project

- Researchers and Aboriginal Community Facilitators worked in each community to conduct a community needs assessment through a local Project Advisory Committee
- Based on the data collected, specific strategies were identified by each First Nation community and are being implemented by the community over five years
- These strategies are being evaluated for effectiveness in contributing to the overall change process in developing a local palliative care program
- The research informed strategies contribute to a “tool kit” for developing local community capacity to provide palliative/comfort care in First Nations communities

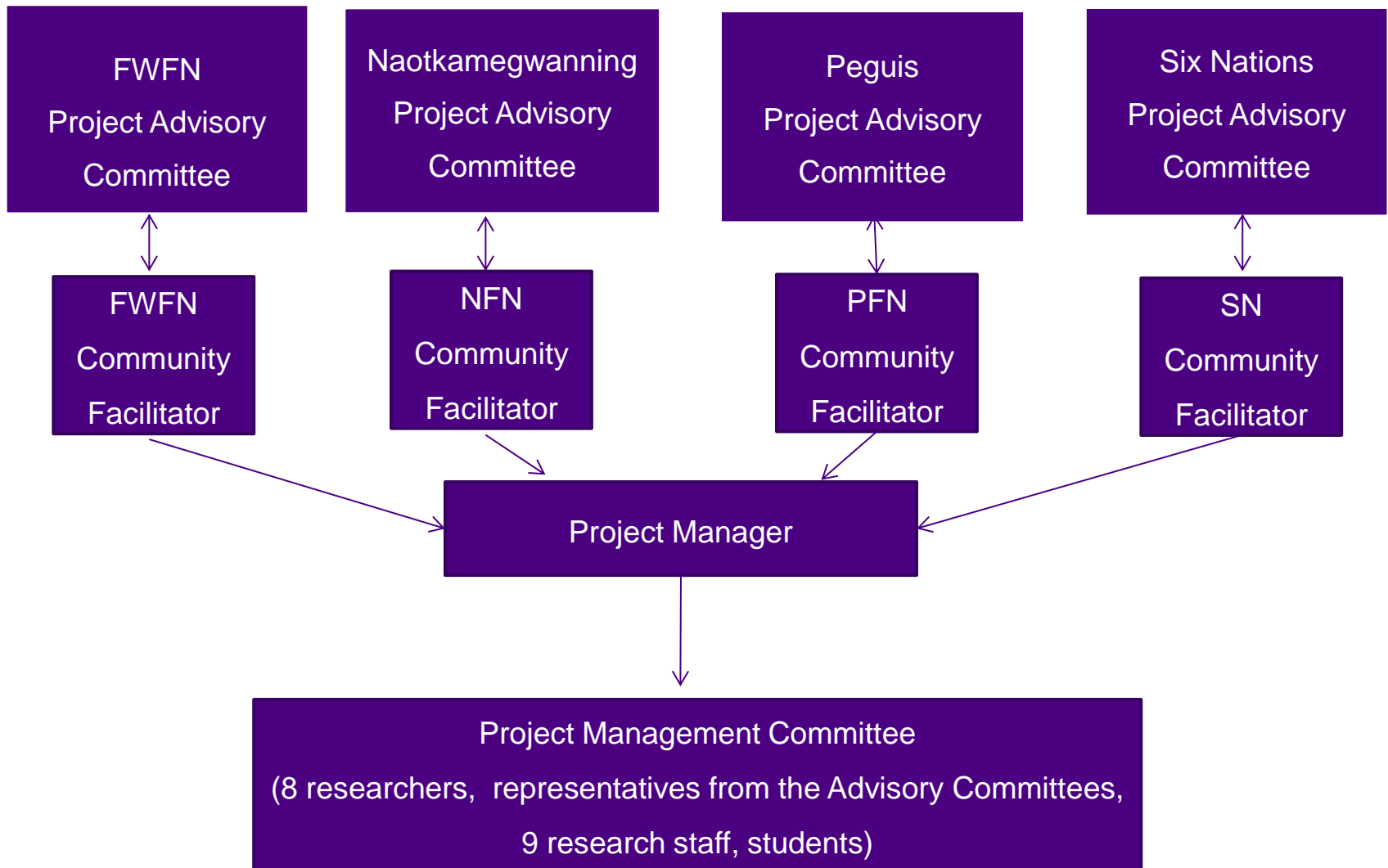
MODEL FOR ABORIGINAL PALLIATIVE CARE



The Power to Choose Video

<http://www.eolfn.lakeheadu.ca/>

Community Control & Ownership



Community Leadership Team

Each First Nations community has developed a Leadership Team, who is responsible for the development, implementation and evaluation of their program.

These teams are focusing on four areas:

- 1) Identifying common issues/concerns and coming up with solutions
- 2) Promoting educational opportunities for care providers
- 3) Increasing public awareness of the availability of palliative care in community; and
- 4) Developing a care pathway and other protocols for clinical teams.

Fort William First Nation



Benefits of Providing Palliative Home Care

Advantages of remaining in the community:

- familiarity and comfort, care could be provided by people you know
- access to culturally appropriate services, including Traditional Healers
- transportation would not be an issue
- dying at home can help to retain one's dignity until the end-of-life
- having frequent access to family, friends and community members

Barriers to Providing Palliative Home Care

- Policy and Funding issues
 - No formalized PC program is funded under HCC
 - Limited overall funding and flexibility in budgets
 - Dilico is HCC provider/stigma of child welfare barrier
- Lack of Infrastructure
 - Overall lack of human resources and services in FWFN
- Lack of PC education and training
 - prevents community members, specifically the elderly, from making informed decisions
 - Paid caregivers lack training in providing PC
- Health system & Clinical challenges
 - Lack of access to pain management/safe medication storage
 - Poor integration of services
 - Poor communication amongst service providers; issue of multiple different consents

Capacity Development Opportunities

- building on preexisting programming
- collaboration with community partners
- community designed and driven programming
- education and training
- a volunteer program

Fort William FN Initiatives

- Journey Mapping Workshop
- Strengthening partnership with Dilico (H&CC provider)
- Community Awareness Sessions (6 sessions with help of community partners: Cancer Centre, CCAC, CERAH, Hospice Northwest)
- Improving Communication and Discharge Planning (TBRHSC, CCAC, & Dilico)
- Community ACP sessions & resource development
- Grief & Bereavement Workshop (winter 2015)

Naotkamegwanning First Nation



Barriers to Providing Palliative Home Care

- Policy and Funding issues
 - Palliative care is not funded as an essential service through the FN Home and Community Care program
- Overall Lack of Infrastructure/Services in the community
 - Lack of essential services for homes such as heat and working appliances
 - Lack of medical equipment
 - Lack of transportation
- Lack of Available Social Network/Family Support
 - Not having family members who are able to assist with caregiving responsibilities, or a lack of family support.
- Lack of PC education and training
 - Lack of trained staff; lack of knowledge related to pain management
- Health system & Clinical challenges
 - Doctors not allowing patients to come home
 - External health care providers stated that the cultural traditions surrounding discussing death and dying are a hurdle in providing quality care on-reserve.

Benefits of Palliative Home Care

Advantages of remaining in the community:

- Access to culturally appropriate services and care
- Familiarity and comfort
- Able to be near to family and friends, less stressful on family
- Economic advantage as costs associated with travel would be avoided
- Transportation would not be an issue
- Community comes together to offer support in times of illness and was described as a naturally emerging process of caring for one another

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Capacity Development Opportunities

Opportunities to further develop or enhance palliative care programming:

- Creating care options
- Collaboration with community partners
- Community designed and driven programming
- Education and training
- Human resources

Naotkamegwanning FN Initiatives

- Wiisokotaatiwin Program
 - Proposal for LHIN pilot funding was successful
- Cultural Competency Curriculum
- Telemedicine (pilot in collaboration with CCO & SJCG)
- Journey Mapping (3 workshops, 24 HCP)
- Advocacy – Federal & Provincial Members of Parliament

Developing PC in FN communities

- Requires a bottom up capacity development approach to developing programs and services
- Requires acknowledging that dying is not a medical event, but a social event that happens in family and community
- Requires adopting a palliative approach that integrates into primary care and chronic disease management including frailty
- Two-eyed Seeing
- Importance of establishing and maintaining strong partnerships with key stakeholders

Regional Partnerships

- First Nations & Inuit Health Branch (FNIHB)
- Chiefs of Ontario (COO)
- Local Health Integration Network (LHIN)
- NW End-of-life Care Network
- CCAC
- SJCG Hospice Telemedicine
- Wesway (Respite Care)
- Hospice Northwest (Volunteer Visiting)
- Kenora/Rainy River Hospice Volunteers
- Thunder Bay Regional Cancer Centre
- Waassegiizig Nanaandawe'Iyewigamig (WNHAC)
- Lake of the Woods District Hospital
- TBRHSC & Regional Cancer Centre
- Dilico

FNIHB Regional Office/Nurse Advisor Role

- Promoting good working relationships with other programs/agencies and jurisdictions e.g. Province
- Providing program support e.g. distribution of relevant documents/resources
- Program expertise
- Coordination of training and continuing education activities for all program elements
- Data and information collection/report preparation
- Program evaluation/monitoring caseload trends

Developing Palliative Care Services

FNIHCC Program Elements

Essential Services

- Structured client assessment
- Managed care
- Home care nursing
- Home support (personal care and assisted living)
- In-home respite
- Established linkages
- Medical supplies and equipment
- Record keeping & data collection

Supportive Services

- May be implemented when essential services are being delivered
- Based on community needs and priorities
- Must be done within existing funding allocation

Needs assessment guidance

Planning for service delivery

Evaluation of implementation

Establishing linkages/facilitating communication

Adapted from: FNIHCC Program Criteria (2000)

NWO End-of-Life Care Network

- One of 14 Networks across the Province
- St. Joseph's Care Group is the Host Agency
- Provides the leadership and “common voice” to facilitate the ongoing development of a comprehensive & coordinated system of palliative & end-of-life care



Regional Planning

- **2012-14:** North West LHIN, St. Joseph's Care Group, and End-of-Life Care Network partner to develop a Regional Palliative Care Plan for the North West LHIN
- **Goal:** To develop a comprehensive plan to mobilize, strengthen, and reorient the health care system to improve access to safe, comprehensive, and high quality palliative care for all residents of Northwestern Ontario.



System Transformation

End-of-Life Care Network

transitions to



Regional Palliative Care Program

Regional Palliative Care Program

- Provides the leadership & structure to advance standardization, education, **coordination**, and continuous quality improvement
- Supports **collaboration & capacity building** at the community level
- Identifies regional service gaps, strengths, and priorities
- Monitors, evaluates, and reports on system performance
- **Collaborates with First Nations communities and organizations to improve access to culturally appropriate palliative care & support for their members**

EOLFN Research Outcomes

- New Guidelines for Policy/Decision Makers and Practitioners
- Four examples of First Nations Palliative Care Programs, including evaluation of process and outcomes
- New Tools and Resources for Program development and Delivery
- Increased collaboration between Federal and Provincial health services
- Advocacy for Gaps in Service (resources, medication, equipment, funding for palliative care through H&CC, LHIN)
- Created Palliative Care in First Nations Communities Stakeholder Alliance (FN communities, health care providers, provincial and federal decision makers, and researchers)

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