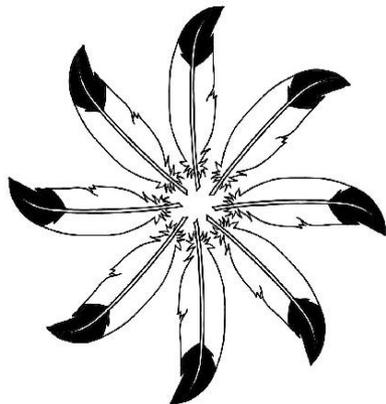


# Developing and Delivering A Community Caregiver Volunteer Program to Improve End-of-Life Care in Fort William First Nation



Presented by:

Luanne Maki, Natalia Collins, & Margie Bannon

# Conflict of Interest Declaration: Nothing to Disclose

**Presenters:** Luanne Maki, Natalia Collins, & Margie Bannon

**Title of Presentation:** Developing and delivering a community caregiver palliative care awareness program to improve end-of-life care in Fort William First Nation

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

# Learning Objectives

- Describe an approach for creating knowledge and awareness of Palliative Care in a First Nation Community.
- Introduce palliative care topics and a format for delivering PC public awareness sessions to a First Nation Community.
- Share lessons learned for developing a community caregiver awareness and hospice volunteer program in a First Nation Community

# 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

# Research Goal

- To improve end-of-life care in four First Nations communities through ***developing local palliative care programs and teams***
- To create a ***tool kit for developing palliative care*** programs in First Nations communities that can be shared nationally

# Key Principles

- Definition of Need and Solution (relevant to Context and Culture)
- Community Capacity Development – Highly localized not regionally generalized
- Cultural Competence and Safety
- Local Control and Ownership
- Partnerships between Provincial & Federal funded service(s)/providers
- One size does not fit all (diversity of culture and context)
- Two-eyed Seeing (the best of both Traditional and Western Knowledge)

# Phases of the Research Project

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

# Fort William FN Initiatives

- Strengthening partnership with Dilico
- **Partnership with Hospice Northwest to create Fort William Hospice Volunteer program**
- Improving Discharge and Discharge Planning
- Community ACP sessions

# Fort William First Nation

- *“If that was me, what would I do? ... I wouldn't want to be alone. When my grandmother was passing, I stayed there right around the clock because I did not want her to die alone, And that's most important. That they don't go by themselves.”* **(Community Member)**

# The Need for Local Hospice Palliative Care Volunteers

- Palliative Care training for volunteers identified as a need by FWFN during community needs assessment.
- FWFN health fair; community members showed interest in receiving training.
- HNW Volunteer Program was willing to collaborate with community to assist with training volunteers (MOU)

# Developing the Curriculum:

FWFN Community Lead and Facilitator

- Reviewed 4 HPC volunteer training curriculums:
  - Hospice Northwest Volunteer training manual.
  - Human Resources and Skill development National Hospice PC training manual.
  - Hospice Association of Ontario: Visiting Volunteer Training Manual
  - CHPCA: A Training Program and Toolkit
- Selected the topics to be covered (relevance to community members)
- Determined how the training would be delivered
- Selected the resources that would be included in the training

# Organizing the Sessions

- Contacted the FWFN individuals who expressed interest in taking the training
- Contacted local palliative experts to deliver topics
- Determined a time that was based on feed back from the potential participants.
- Created poster and announcement
- Advertised locally through Health Center, word of mouth, and community Face book page
- Delivered 5 community awareness sessions in FWFN

# Caregiver Volunteer Sessions: Palliative Care Topics

- Sensitive communication
- Supporting grief and loss
- Supporting the family
- Pain & Symptom management
- Ethical issues and dilemmas
- Practical care (delivered in 2 parts)
- Available PC resources: FWFN and Thunder Bay

# Format

- Series open and closed by Elder (smudging and prayers)
- Small group learning style; circle with tables/chairs
- Held in familiar community space, FWFN
- Provided food
- Interactive; very informal (low technology)
  - Focus on story telling (in person/video); sharing personal stories
- Variable schedule: 1 full day, 2X ½ days, 4 early evening sessions
- Facilitators provided participants print material to take home (brochures, manuals) and modeled/discussed how to use these materials to guide conversations with others
  - Print material chosen carefully to be culturally appropriate, accurate, free of charge and easy to access for future use.
- Group documented a list of emerging ideas for the future volunteer program on a flip chart (for use later by Community facilitator)
- Participants encouraged to attend all 6 sessions but welcome to attend those they could (attendance at all sessions not a criteria)
- Series of 6 sessions ended with a feast: All presenters and participants invited to attend

# Successes of the community caregiver volunteer program?

- FWFN now has 3 individuals who are trained and interested in PC volunteer opportunities
- Participants met and discussed PC issues/questions with community experts (physicians, nurses, social workers, PSW) –reducing barriers to future communication
- Resources selected that would be useful and beneficial to a caregiver volunteer, eg. brochures and comfort care bag
- Discussed how to introduce a caregiver volunteer to a community member who could benefit from caregiver volunteer visit.
- Strengthened relationship with Hospice Northwest Volunteer Visiting program (future collaboration/advice)
- Identified issues/lessons about beginning a volunteer program at FWFN

# Future challenges for a caregiver volunteer program?

- What should the name of the program be?
- Who is coordinating the program?
- How is the program funded?
- Having community leads available later to put the training into practice
- Scheduling of training sessions
- No lived experience of what a FWFN volunteer would actually do in the community? How would it be similar/different to HNW or other urban models?

# Lessons learned

- Identified community interest in attending the volunteer training did not match the actual uptake (attendance low; not all participants committed to multiple sessions)
  - What are the factors?
- Shift to providing Community Awareness sessions to prepare community for future formal volunteer training

# Suggested Next Steps

- Embed PC public awareness into opportunities that naturally exist in the community (meetings)
- Newsletter
- Consistent Reminders
- Modules can be used to deliver future sessions
- Decision to be made where the Volunteer program can be situated
- For those community members interested in a formalized volunteer services connect with HNW

# **Sharing the Caregiver Volunteer Training Experience**

# References

- Human Resources and Skill Development (2009). A National Hospice Palliative Care Training Manual and Distance Education Toolkit for Volunteers in Canada.
- Canadian Hospice Palliative Care Association (2011). Hospice Palliative Care Volunteer Training Program and Toolkit.
- Hospice Association of Ontario(2002). Visiting Volunteer Training Manual.
- Hospice Northwest Volunteer Training Manual

# Acknowledgements



Fort William First Nation



Peguis First Nation



Anishinabek Family Care



# Contact Information

Dr. Mary Lou Kelley  
Principle Investigator  
Phone (807) 766-7270  
Email [mlkelley@lakeheadu.ca](mailto:mlkelley@lakeheadu.ca)

Holly Prince  
Project Manager, Co-Investigator  
Phone (807) 766-7274  
Email: [hprince@lakeheadu.ca](mailto:hprince@lakeheadu.ca)

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