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

Using “Journey Mapping” to Improve Access to Palliative Home Care by Integrating Health Services Across Jurisdictions

OACCAC Conference May 28, 2015
Background

• This initiative is part of a 5 year (2010-2015) CIHR funded research project “Improving End-of-Life Care in First Nations Communities” (EOLFN)

• The overall goal of this project is to improve end-of-life care in four First Nations communities by developing local palliative care programs and teams, and

• Create a workbook for developing palliative care programs in First Nations communities that can be shared nationally
First Nations Community Partners

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

www.mapsofworld.com
Naotkamegwanning First Nation

• Naotkamegwanning is located in North Western Ontario in the heart of the Treaty #3 Territory

• The nearest urban center Kenora (approx. 15,000 people) is 96 km north of NFN

• The community has year-round road access and also has an ice road in winter

• There are 712 community members living in the community
Cultural Identity

- NFN is one of the very few communities that have been able to keep their Anishinaabe cultural practices and beliefs strong and vibrant
- 48% of the population are able to speak Ojibway
- Many of the people of NFN continue a connection with the land and maintain a lifestyle that includes fishing, hunting & harvesting of wild rice
- The importance of passing on teachings, language and cultural practices are evident in their delivery of programs and services within the community
- Community cultural context strongly impacts the way death and dying is viewed and discussed in the community
Health System Barriers at EOL

- Communication and language barriers
- Lack of cultural safety and competency (hospital culture)
- Inadequate hospital discharge planning
- Health system lacks understanding of FNIHB & NIHB policies and procedures
- Lack of timely access to medication and equipment in FN community
- Lack of support for client choice to die at home
- Lack of palliative home care services in FN communities
The palliative care journey map is a process flowchart accompanied by a narrative that illustrates a typical client’s progression through the health care system.

The map encompasses medical and psychosocial supports and highlights care options in various settings such as home, hospital and long term care.

It illustrates the “current state” interaction with services and providers and the desired “future state” of care.
Naotkamegwanning First Nation

Experience with

“Journey Mapping”
Step 1

Focus is work in the community.

Educate and engage the community
Leadership Team

• Maxine Crow took the lead in establishing a palliative care program in the community.

• A leadership team was then developed to identify the vision and took responsibility of developing the program.

• These people are local community members from various health care programs, local service providers, Elders, members of leadership, and invested community members.
Assessing Community Readiness

- Leadership team then met several times as a group to complete the EOLFN “assessing community readiness charts”
- These charts focus on five areas:
  - Assessment of local health infrastructure & palliative care services
  - Where are palliative care services being provided?
  - Assessing Community Strengths
  - Assessing & Prioritizing Gaps in Services and Challenges to Overcome
  - Plan for Action
Table 1: Assessment of local health infrastructure & palliative care services

<table>
<thead>
<tr>
<th>Name of Agency/Provider</th>
<th>What services do they provide?</th>
<th>How can they be accessed?</th>
<th>Do they have a representative on the team?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Where are palliative care services being provided?

<table>
<thead>
<tr>
<th>Location of services</th>
<th>List of services that are provided here</th>
<th>Any gaps?</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the client’s home</td>
<td>e.g. homemaking, nursing, spiritual care, volunteer visits</td>
<td></td>
</tr>
<tr>
<td>In the community</td>
<td>e.g. support groups, education/information sessions</td>
<td></td>
</tr>
<tr>
<td>In the hospital / clinic</td>
<td>e.g. interprofessional case conferencing, pain &amp; symptom management</td>
<td></td>
</tr>
<tr>
<td>In long-term care</td>
<td>e.g. pain &amp; symptom management, volunteer visits, spiritual care</td>
<td></td>
</tr>
<tr>
<td>Outside the community</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3: Assessing Community Strengths

<table>
<thead>
<tr>
<th></th>
<th>Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community Characteristics</strong></td>
<td>e.g. closeknittedness, level of volunteerism</td>
</tr>
<tr>
<td><strong>Service/Care Provider Characteristics</strong></td>
<td>e.g. existing relationships, knowledge, skills, experience</td>
</tr>
<tr>
<td><strong>Type/Quality/Accessibility/Delivery of Services</strong></td>
<td></td>
</tr>
</tbody>
</table>
Think about the gaps in service and challenges that your community faces. Identify which gaps are the most important for your team to address (e.g. what gaps do we need to work on filling right away?). Next, identify which challenges will be most important for your team/community to overcome in order for you to “succeed”.

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gaps in Service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Challenges to Overcome</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4: Assessing & Prioritizing Gaps in Services and Challenges to Overcome
Table 5: Plan for Action

Think about your long-term vision and what you will need to do to see it realized. Make a list of all of the goals that you need to be working on in order to transform your vision into reality. To keep from being overwhelmed, start out by listing 2 or 3 short-term goals that are both specific and achievable.

<table>
<thead>
<tr>
<th>Goal</th>
<th>Actions That Need to Be Taken to Achieve Goal</th>
<th>Timeline</th>
<th>Who is Responsible?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Step 2

Engaging Regional Partners and Establishing a Stakeholder Working Group
Educating and Engaging Regional Stakeholders

• After completing the five charts, the leadership team (LT) then engaged with all the external health care providers (HCP) that currently provide service or have the potential to provide service for care of a client in their community.

• The LT then invited all of the external HCP to attend a workshop with the intention of engaging with them to provide better quality care for their clients and understand each others roles.
At the workshop, the following occurred:
1) First the LT discussed with the group their vision and intent
2) They then presented the EOLFN “assessing community readiness charts” and engaged the providers in validating and enhancing them
3) Next, they took the group through the series of steps to discuss what is happening today with a client who is seriously ill (Current State)
   ▪ Each step, was then described in detail answering the “who, what, when, where, how and why”.
For each step, they also asked the group to think about and discuss these four questions for each step:

- What is working well?
- Where do things go wrong?
- Where are the gaps and unmet needs?
- What are your solutions and ideas?

This was all documented on the “Documenting the Current State” chart.
# Documenting the Current State

<table>
<thead>
<tr>
<th>Steps</th>
<th>What is already in place</th>
<th>What is working well?</th>
<th>Where do things go wrong?</th>
<th>Gaps and unmet needs?</th>
<th>Solutions and ideas?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How and where client is identified</strong></td>
<td>Points of entry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Program criteria</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>How/where is client referred</strong></td>
<td></td>
<td>Community referral</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>process</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Is there a comprehensive assessment?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Where/who?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Is there a case conference and development of care plan?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Where/who?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Who provides services?</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Steps</td>
<td>What is already in place</td>
<td>What is working well?</td>
<td>Where do things go wrong?</td>
<td>Gaps and unmet needs?</td>
<td>Solutions and ideas?</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------</td>
<td>------------------------</td>
<td>---------------------------</td>
<td>-----------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>How are services Coordinated?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does the client have the choice to die at home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Who provides follow-up and bereavement support?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case closure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Homework after the meeting

- The leadership team then created a report summarizing the steps and the four questions/responses and send it to everyone that was at the workshop
- The external health care providers were asked to discuss the report internally within their organizations
- The leadership team then drafted out the future desired state from the community perspective
Step 3
Creating and Implementing Naotkamegwanning’s Vision for the New Care Pathway
• The LT then scheduled a second workshop in order to create the vision for the new care pathway using the care path template.

• The LT presented the future desired state from community perspective (9 step care pathway) and then got the providers to discuss and see how these steps be implemented.

• Review the gaps and barriers and discuss how the ideas and solutions could be implemented.
• The group then began to develop an action plan for steps 1-5 and identify the external care providers and their roles.

• Outcome is a diagram of the future state and a draft workplan that identified what each person/organization needs to do.
## Steps 1-5 with external care partners

<table>
<thead>
<tr>
<th>Steps 1-5</th>
<th>What is already in place</th>
<th>Key process and consent</th>
<th>What needs to be accomplished/implemented</th>
<th>Decisions to be made</th>
<th>Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Client is Identified</strong></td>
<td>Points of entry Program criteria</td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Client is Referred</strong></td>
<td>Community referral process</td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Comprehensive Assessment</strong></td>
<td></td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Case Conference and Creation of a Care Plan</strong></td>
<td></td>
<td>Information sharing (who is in the Circle of Care)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Coordinated Health Care Deliver</strong></td>
<td></td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Homework following the workshop

- The leadership team created a second report summarizing the action plan and sent it to everyone that was at the workshop.

- The external health care providers were asked to discuss the report internally within their organizations.

- The leadership team then began to develop their action plan for steps 6-9 internally as a community.
## Steps 6-9 with internal care partners

<table>
<thead>
<tr>
<th>Steps 6-9</th>
<th>What is already in place</th>
<th>Key process and consent</th>
<th>What needs to be accomplished/implemented</th>
<th>Decisions to be made</th>
<th>Stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning for Passing</td>
<td>Points of entry Program criteria</td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client has Passed</td>
<td>Community referral process</td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow-up and Bereavement Support</td>
<td></td>
<td>Information sharing (what and to whom)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case Closure</td>
<td></td>
<td>Information sharing (who is in the Circle of Care)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Individual Meetings

- The LT set-up individual meetings either in person or on the telephone with each major stakeholder to discuss their role.
- The action plan was used as a guide to facilitate this discussion and also formalized the relationship.
- Following this discussion, the action plan was revised and agreed upon.
- A representative from the LT was responsible for updating and revising the action plan.
Formalizing the Program

• The leadership team in collaboration with the external partners develop the First Nations program guidelines which includes:
  ▫ eligibility criteria and referral process
  ▫ mission and vision statement of the program
  ▫ care pathway
  ▫ list of specific services
  ▫ contact information
Implementing the Care Pathway

- Client identification
- Case conferencing
- Client assessment tools and processes
- Education and support for family and health care providers
- Communication and coordination
- Respite care and volunteer program
Plan for Follow-up and Evaluation

- Living document

- Revisit/revise the care pathway after providing care to two residents that have passed.

- Ongoing plan for evaluation and quality improvement
Lessons Learned

• The importance of developing strong partnerships with external care providers—developing the care path requires a real commitment of time and resources from these providers

• The importance of making certain that communication lines between all parties are open

• The importance of ensuring that the community feels that they maintain ownership of the process

• The importance of ensuring that the care path is culturally appropriate and inclusive of traditional practices and beliefs
North West CCAC’s Involvement in the Journey Mapping Process
Individual Meeting following the Creation of the Journey Map

- Duplication of Service: Initial discussions occurred around the confusion that providing PC services by CCAC would be a duplication of service. After some discussion, this was resolved. CCAC supported the Wiisokotaatiwin program to get funding from the LHIN for a pilot project.

- Wiisokotaatiwin Program Information Guidelines - when creating the guidelines, CCAC was asked to review and provide feedback on care path upon completion.
• Wiisokotaatiwin Program Launch/Creating Awareness - CCAC was asked if there could be a dedicated contact in Kenora for the program. This was a strategy to ensure that key people knew the program is available. CCAC committed to informing staff about program.

• Cultural sensitivity training - Appropriate CCAC staff were asked to attend cultural sensitivity training in community.

• Client Referral – CCAC was asked to add Wiisokotaatiwin program to referral forms.
• Case conference – CCAC was asked to be a part of the case conference and circle of care

• Creation of care plan - Written care plan is created, copy is made for circle of care. This process needed to be discussed and agreed upon by CCAC. The circle of care needed to be modified and consent processes also modified

• Coordinated health care delivery – CCAC was asked to provide information regarding the PCA pump use in the community as well as equipment needs.
NWCCAC Role in this Project

• Planning
• Participated in journey mapping.
• Assigned a coordinator and manager for the clinical process mapping exercises.
• Involved the PPSMP
• Assisted with planning a budget for service provision
• Sharing our knowledge about supplies and equipment
• Assigned a coordinator to attend case conference planning meetings (hospital and community)
Discussion Questions

• Is this journey mapping exercise something that would work in your region?

• What other strategies are in place across Ontario in working with First Nations communities?

• Is there any interest in doing an environmental scan of CCACs to see what they all are doing and what is working well?
Acknowledgements

Fort William First Nation

Peguis First Nation

Canadian Institutes of Health Research

Lakehead University
Contact Information

Maxine Crow
Community Care Coordinator
Naotkamegwanning Community Lead and Facilitator
Phone (807) 226-2864
Email: mcrow@lakeheadu.ca

Kathryn Hughes
Director, Community Care
North West CCAC (Thunder Bay)
Phone: (807) 346-3298
Kathryn.Hughes@nw.ccac-ont.ca

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

www.eolfn.lakeheadu.ca