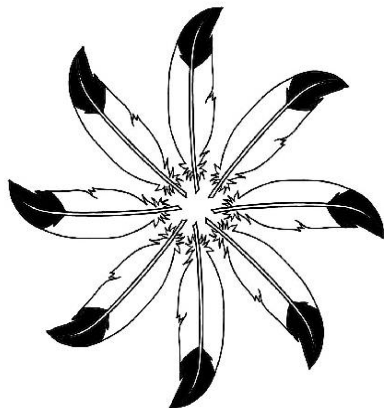
Six Nations Palliative Care Shared Care Outreach Team



Canadian Hospice Palliative Care Conference

October 29-November1, 2015

Objectives:

- To understand how health care providers in Six Nations of the Grand River created local palliative care capacity based on a community capacity development model.
- To demonstrate the structure and benefits of implementing shared care teams for First Nations communities.
- To understand the importance of developing and strengthening partnerships with external health care providers and provincially funded resources and services.

Haudensosaunee Philosophy Statement

- Traditional philosophical principles have a crucial relevance to the challenges our people face today. Ohenton Karihwatehkwen or the words that come before all else are a reminder of the place that we as human beings were meant to occupy in relation to all of Creation; a place of balance and respect. Our worldview comes from the Creation Story, the Original Instructions and is expressed in our annual cycle of ceremonies of thanksgiving. Our worldview teaches us that we exist with purpose, with a sacred intent and a duty to uphold the human responsibility to all of Creation. Our core philosophy is simply expressed as one body, one mind, and one heart. In the Haudenosaunee tradition, acceptance comes from a view of the natural order that accepts and celebrates the coexistence of opposites; our purpose is contained in the quest for balance and harmony, and peace is gained by extending the respect, rights, and responsibility of family relations to other peoples. The values are the state of peacefulness, the proper way to maintain peace, and the friendship and trust needed between all things for respect to prevail. In the words that come from the Thanksgiving Address "we must see the cycle of life continue"-and ensure the health and wellness of the people.

CURRENT ISSUES

- The aboriginal population is generally quite private and do not seek medical attention until late in the disease process and then services need to be initiated quickly
- The disease process needs to be communicated in a timely way and must allow the client the right to refuse treatment or consider other Traditional options
- The palliative care team needs to respect cultural beliefs and determine what is important to the client and reassess the plan of care often
- The palliative care team needs to acknowledge the spiritual nature of the process and the importance of symbols and ceremonies and the traditional roles of the family

CURRENT ISSUES (cont.)

- Institutions need to accommodate large Aboriginal families ie move client to a larger room, formulate policies for Aboriginal ceremonies
- Language acquisition for caregivers is important to promote trust and understanding when caring for an individual of Aboriginal culture ie they need to understand what the medical terms mean
- Aboriginal palliative care teams need to include consultants in Traditional ways to provide cultural competency
- Realize that Aboriginal communities are small and close knit and so the paid caregiver may be a family member as well and so self care of the formal caregivers is very important

CURENT ISSUES (cont)

- Assist client as to where they want to be at end of life, either home, hospice or hospital and realize that all families cannot assist in care and provide the care and figure out any payment later (jurisdictional issues and Jordan's principle)
- After care for families is essential and many more resources need to be set up not only for palliative situations but also as it applies to sudden deaths ie suicides and death by accidents
- Cancer Care Ontario states that cancer is on the rise in Aboriginal populations and more are dying from cancer as compared to non-Aboriginals with cancer . Much of the increase is due to the rise in colorectal cancer and lung cancer and smoking is the most important risk factor.

Implications for Development of Palliative Care Program

- 1999-2003 Inception of Six Nations LTC/H&CC and development of in house palliative care committee
- 2005 Involvement in HNHB Hospice Network /Advisory Committee and development of Adhoc Aboriginal Palliative Care Committee with mentoring from Chairman of HNHB Advisory Committee
- 2005 Masters Student Research –Valerie Obrien (Respectful Dying: A First Nations Perspective)

STRATEGIC PLANNING FOR ABORIGINAL PALLIATIVE CARE

- The Local Health Integrated Network of Hamilton,Niagara , Haldimand, Brant (LHIN 4) has the greatest Aboriginal population and so felt that it was important to understand the Aboriginal perspective on palliative care and so convened an Aboriginal Hospice Palliative Care Services Committee in 2005.
- The goal of the committee was “To create a roadmap that describes the steps needed to design and implement an organized , coordinated , integrated delivery of hospice care services within the Aboriginal communities”
- To this end a Strategic Planning Session on Palliative Care was held on December 2,2010 at Six Nations with the purpose to request community and care providers input to establish priorities in care provision and to strengthen the networks that are involved in providing care to Aboriginal clients.

STRATEGIC PLANNING (cont)

- There were 61 participants from both Aboriginal and non Aboriginal agencies and communities.
- The agenda was designed to :
- 1.reflect the culture and traditions of Aboriginal communities
- 2.provide information on current palliative care research , programs and services (through presentations and information booths) and
- 3.provide opportunities for the participants to have discussions and share their thoughts on Aboriginal palliative care considerations and priority actions

Improving End-of-Life Care in First Nations Communities Research Project

- 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

Six Nations Palliative Care Needs Assessment

- In April 2011 – May 2012, an Aboriginal Community Facilitator interviewed and surveyed Six Nations community members about understandings and experiences in providing palliative care; perceived barriers and supports; education and program needs; along with external health care providers input.

Highlights of Needs Assessment Results

- 90% of them had either personally cared for or knew of a family member who had provided care for someone who was dying.
- The majority of survey participants (90%) felt that, if services were available and adequate, community members would choose to die at home.
- 75% of survey respondents felt that talking about death and dying is acceptable in their community.

Receiving Care in the Community: Supports

- familiarity and comfort,
- access to culturally appropriate services
- care could be provided by people you know,
- 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. Visitation can occur at all hours, enabling the person to remain supported.

Barriers

- a lack of knowledge: not knowing what services are available in the community and also regarding what all is involved in the provision of end-of-life care at home,
- lack of preparation for families prior to a loved one coming home,
- the health care system can be difficult to navigate
- caregiving is a 24/7 responsibility, however 24/7 care is not available in the community,
- access to doctors and proper pain management

Program and Services Needed

- Increased access to support services is needed, including access to 24 hour/day care.
- More nurses are needed for respite services.
- A palliative care program within the community that would be inclusive of all health care and social service providers, spiritual and cultural resources, and volunteers.
- A palliative care team to be available 24 hours/day and provide education to family members about caring for a loved one at the end-of-life.
- Culturally sensitive programs, the use of traditional medicine.
- Grief support services are needed in the community, both for family members and for health care providers.

Six Nations Leadership Team

Following the needs assessment, Six Nations developed a Leadership Team, who was responsible for the development, implementation and evaluation of their program.

This team is 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.

Responding to the Needs of the Community: Six Nations Shared Care Outreach Team

What are Outreach Teams?

- Outreach teams are based on an evidence based best-practice model
- Integrated & seamless shared care involves primary care providers forming a partnership of care with expert clinicians
  - Patients continue to see their family physician for routine follow up, test, medications
  - Outreach physician monitors for pain/symptom management
- Teams are defined by population & geography

Why Involve Outreach Teams?

"When people have access to hospice palliative care services, they report fewer symptoms, better quality of life, and greater satisfaction with their care. The health care system reports more appropriate referrals, better use of hospice care, fewer emergency room visits and hospitalization and less use of ineffective intensive interventions in the last days of life."

The Way Forward National Framework, CHPCA 2013

Developing the Six Nations Shared Care Outreach Team

- Shared Care Teams were identified as a priority of the HNHB End-of-Life Network
- In addition, Six Nations was working in partnership with HNHB Palliative and Aboriginal Advisor for the LHIN
- 24/7 care and a formalized palliative care program were identified as a need from the palliative care needs assessment
- Call for a proposals from the HNHB LHIN – Stedman took the lead to submit a proposal for the Brant, Haldimand, Norfolk, Six Nations area for a Shared Care Team

Geographic Area

- In 2012-2013, proposal was approved by HNHB LHIN. Funding went directly to Stedman
  - MOU was signed between Stedman and Six Nations Council.
  - Salary dollars for staff were sent to Six Nations
- In year 1 (2013-2014) the Shared Care Team began with strong mentorship from Stedman
- In Year 2 (2014-2015) the Shared Care Team addressed the needs of Six Nations and statistics doubled.
- Year 3 (2015-2016), the Shared Care Team is currently developing the annual plan

Purpose of the Six Nations Shared Care Outreach Team

To reduce suffering & improve or maintain quality of living and dying

"I have opened my heart more than my heart has ever been opened in my life… I feel that everybody when you are dying or your loved one is dying [is] in a very vulnerable state . I feel like it's a gift from my Creator to help, help walk with these people and help them hopefully have a peaceful journey"

New Staff on Six Nations Outreach team

Eligibility

- Is not limited to cancer diagnosis
- Would you be surprised if this person died within the next 12 months?

- Who is eligible?
  - Patients with a life threatening or chronic illness who could benefit from a palliative care approach
  - Patients can still be seeking curative treatments, but would benefit from pain/symptom management

Referrals to the Six Nations Shared Care Outreach Team

- Intake and processing of all referrals through Stedman Community Hospice- Clinical Navigator.

- Received from all access points
  - Physician-to-physician referrals

- Referrals can also be requested to psychosocial/bereavement clinician
  - Does not need to be followed by outreach physician

- Family physician maintain primary role
  - Routine follow-ups, tests & medications

Team Approach to Service Delivery covering Brant, Six Nations, New Credit, Haldimand, Norfolk

- Shared Care Outreach Team works with
  - 4 other Palliative Care Physicians
  - 3 other Clinical Nurse Specialists
  - 2 other Psychosocial/Bereavement Counsellors

- Close partnership with community agencies
  - Six Nations LTC/HCC
  - Community Care Access Centres (CCAC)
  - Red Cross Care Partners Nursing & Other Community Nursing Agencies
  - Pharmacies & Labs

Palliative Care Physicians

- Consults received from Family MDs or Specialists (Surgeons, Hospitalists, Oncologists, Internal Medicine)
- Collaborates with Family MD, CCAC, Cancer Clinic & Community Nursing Agencies
- Home & Hospice visits with clinical nurse specialist and psychosocial support on as needed basis
- Rotating call for 24 hour coverage of community patients & dedicated palliative beds at local hospital

Clinical Nurse Specialist

- Canadian Hospice Palliative Care Association Certification
- Point of contact between:
  - CCAC & community nurses
  - Patients & families
  - Cancer clinic physicians & Family MDs

Clinical Nurse Specialist with Palliative Care Physician

- Establish & implement treatment plans for pain & symptom management in the home
- Daily home visits independently & with physicians
- Provide clinical support to families & community nurses
- Maintain daily outreach schedule & facilitate bi-weekly team rounds with entire team
- Monthly rotating on-call schedule for troubleshooting & home visits after hours/weekends/holidays

Supportive Care Clinician

- Provides emotional and spiritual care for individuals dealing with a life limiting illness and their families
- Incorporating Culture into Our Approach
- 4 Strings Ceremony
- Assesses, acknowledges and nurtures those who are living with advanced illness and the journey of dying and death
- Respect for all personal, culture, financial, legal, health care and spiritual needs

Supportive Care Clinician

- Spiritual support includes:
  - Emotional suffering
  - Redefining hope
  - Facilitating search for meaning & inner peace
- Emotional support for children and teens
- Legacy Leaving & Memory Making
- Advanced Care Planning
- Funeral/Memorial Service Planning
- Grief, Bereavement and follow-up support

Where We Are Today

- Holly Cowan – completed her specialist certification as a clinical nurse specialist in palliative care
- Sherry Sandy – completed her master’s degree in Social Work
- Dr. Amy Montour – close mentorship relationship with Stedman Hospice physicians, original Aboriginal rep on HNHB Regional Palliative Council
- Building trust in the community
- Building partnerships with community care providers

Outreach Team Referrals 2012

Quarter	Six Nations	New Credit	Hagersville	Caledonia	Cayuga	Nanticoke	Jarvis	Selkirk
1st	4	0	1	1	0	0	0	0
2nd	4	0	1	2	0	0	1	1
3rd	1	0	2	1	0	0	0	0
4th	3	0	5	3	0	0	0	0
Total	**12**	**0**	**9**	**7**	**0**	**0**	**1**	**1**
Total Referrals for 2012	**30** (Shared Care Outreach Team)							

Outreach Team Referrals 2013

Quarter	Six Nations	New Credit	Caledonia	Cayuga	Hagersville	York	Jarvis	Nanticoke	Selkirk
1st	8	0	6	0	3	0	1	1	1
2nd	10	0	4	0	4	0	4	0	0
3rd	7	1	5	2	3	1	1	1	0
4th	3	0	6	3	5	0	0	0	0
Total	**25**	**1**	**15**	**2**	**10**	**1**	**6**	**2**	**1**
Total referrals for 2013	**80** (Shared Care Outreach Team)								

Outreach Team Referrals 2014

Quarter	Six Nations	New Credit	Caledonia	Cayuga	Hagersville	Jarvis	Nanticoke	Selkirk
1st	11	0	4	1	8	1	1	0
2nd	4	0	10	0	2	4	0	0
3rd	5	1	6	1	4	1	1	2
4th	2	0	8	1	3	0	0	0
Total	**22**	**1**	**28**	**3**	**17**	**6**	**2**	**2**
Total referrals in 2014	**81** (Shared Care Outreach Team)							

Setting of Death 2013-2015

Location of deaths for Six Nations/New Credit & Haldimand

- Home – 55
- Hospital - 22
- Hospice – 6

- Six Nations Long-Term Care/Home & Community Care

RECOMMENDATIONS

- As one of the largest Home and Community Care programs working in Aboriginal palliative care we would like to recommend that Palliative Care be included as the ninth essential element within the Home and Community Care mandate.
- We would like to advocate for resources and training to manage the growing need for excellent Palliative Care in Aboriginal Communities.
- We would also like to advocate for an Aboriginal Hospice that would function at the grassroots level and complete the cycle of life for our population

Acknowledgements

Nya:Weh

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