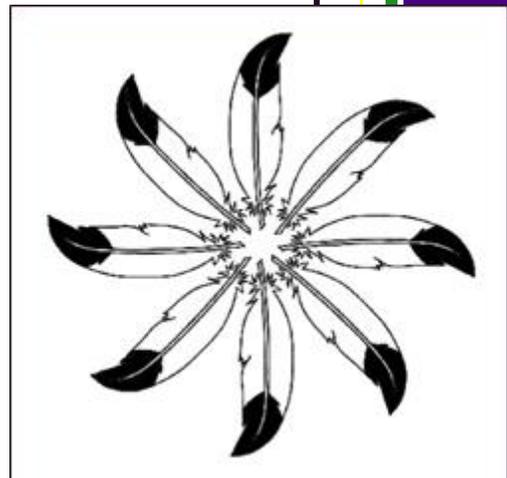


Detailing the Evolution of Palliative Care: Creating a Timeline



Purpose

The evolution of community based palliative care in First Nations communities is poorly documented in the literature. The five-year CIHR grant titled “Improving End-of-Life Care in First Nations Communities: Generating a Theory of Change to Guide Program and Policy Development”, is seeking to improve end-of-life care for First Nations communities. Through the methodology of participatory action research (PAR), four First Nations communities are partners in this project. Each of the four communities is unique in their culture, history, location and experiences in end-of-life care.

The Canadian Constitution Act prescribes responsibility for the affairs of Indians on reserves to the federal government. As a result, the federal government provides funding for health care services to Indians on reserve through a variety of transfer agreements and programs. The administration of health services is left to the local First Nations community, creating a wide variation in how services are administered between different communities. Within these communities, although locally administered, planning for First Nations health care is contingent on federal health funding priorities. As a result, palliative care services are not essentially funded services for First Nations communities according to Health Canada policy. Thus, while First Nations community health teams may be providing palliative services to their members, there is no standard for palliative care service provision for First Nations communities across Canada. The result is a number of piecemeal services that come together to create unique systems of end-of-life care in each First Nations community.

Given that there is no standardized measure of the provision of palliative care services in each of the four communities, the purpose of this research is to establish baseline data that details the historical development, current status, and future outlook of palliative care programming in each of the communities under the scope of the CIHR.

Objective

The main objective is to develop a time-line detailing the evolution of palliative care programming. Using five guiding themes to develop a time-line, specific objectives that this report will identify in each of the four First Nations Communities are: 1) Milestones (when key policy and practice events occurred), 2) Context (names and mandates of agencies and departments involved), 3) Concerns (established concerns and changes to programs over time), 4) Policies and Practices (relevant policies), 5) Outcomes (the impact of policies and practices over time). Each of these areas will be examined in greater detail with more specific questions and will create baseline data for comparing the status of palliative care programming in the four partner communities.

Methods

The overall purpose is to establish baseline data on the development and provision of palliative care services in each of the four communities. To achieve this we will employ a qualitative comparative case study design. The case study design is suited for answering “how” and “why” of an ongoing phenomenon while keeping community context relevant. Given the localized nature of service provision throughout the partner communities, the comparative case study design is applicable. The explorative nature of this research is well suited for qualitative methods.

To collect data, we will employ a key informant approach, utilizing the local Community Facilitator in each of the communities. The Community Facilitator will work with the lead contact and project advisory committee in each community to identify key informants and literature pertinent to the research question. Data collection methods will include key informant interviews with community members who have expertise in palliative care policy, administration, advocacy, and decision making, as well as a review of grey literature.

Data collection will occur in a two stage process: 1) The facilitator will work with key informants to identify grey literature that is relevant to the research question; 2) The facilitator will employ interviews with key informants to obtain information to support and fill in the gaps of the grey literature. Each facilitator will have a standardized series of specific questions to guide the research. The questions will seek to identify: The historical development of palliative care programming, the current status of palliative care programming, and future considerations for palliative care programming. Each community facilitator will thematically analyze the data using the five guiding objectives. The Aboriginal research assistant based at CERAH will synthesize the four completed analyses. Validation of the synthesis will occur through peer review by the community facilitators.

Implications/Outcomes

The research seeks to provide baseline data on the provision of palliative care services in First Nations communities. With the First Nations Inuit Health Branch identifying palliative care services as supportive services, and not essentially funded, the provision of these services is left to the discretion of the specific First Nation community, with the result often being that palliative services are provided only if funding is remaining after essential services are funded. In reality, First Nations health services are stretching their resources to provide palliative services to sick and dying community members, resulting in services being provided in a piecemeal fashion through various departments

and agencies. In addition, palliative services are not provided equally to all First Nations people in all communities across Canada. Regardless of whether services are available, people will get ill in their communities, and also will want to return to their communities to die. Palliative care services are an essential need in First Nations.

The primary outcome of this research is to inform health policy on how to better serve palliative care needs in First Nations communities by identifying gaps and overlaps in service provision, and to display the need for essentially funded palliative services. Additionally, this data will create baseline information that will allow our research and others to measure the development and progress of palliative care in First Nations over five years, and to compare and contrast this to the historical development of care in the communities.

Areas of Investigation

Based on the five objectives stated for developing a timeline, each of the following areas will be examined in greater detail, and will create baseline data for comparing the status of palliative care programming in the four partner communities. Community facilitators should be able to detail each of these areas following the review of literature and interviews with key informants.

Identify:

1. The historical development of palliative care programming
 - a. Identify how end-of-life care historically has been provided
 - b. Detail the development of the home and community care program
 - c. Identify key stakeholders (leaders and partnerships)
2. The current status of palliative care programming
 - a. What is the current availability of palliative services and programs within the community
 - b. Identify the funding and administrative structure of palliative services
 - c. Identify key stakeholders currently advancing the palliative care agenda
 - d. Examine community knowledge of palliative care
 - e. Identify the administrative structure of palliative services
 - f. Identify current partnerships in providing palliative services
3. Future considerations for palliative care programming
 - a. Examine current vision for palliative care in the community.

Investigation Questions (Interviews and Literature Review)

These questions are to be used as a guide to help answer specific details when examining grey literature (reports, documents, pamphlets, minutes, etc), and also as interview questions where grey literature does not contain the required information.

Historical Development of Palliative Care:

Historical Provision of End-of-Life Care

1. Prior to the home and community care program, how was the EOL care provided in the community?
2. Where did funding for the programs come from?
3. Who was involved (both formal and informal)?

Leadership in Palliative Care

1. Who are the key people who have helped to develop palliative/ EOL care in the community?
2. What have they done to advance the Palliative care agenda?

Home and Community Care

1. How did the home and community care program come to exist?
2. Who initiated the HCC program?
3. What services were initially provided?

Partnerships

1. When and how did partnerships become established between the local community and outside agencies?

2. What is the time line of agencies becoming involved in PC in the community?
3. Who initiated this process?

Current State of Palliative Care in the Community:

Delivery of Services (Agencies, who, what, when, how)

1. What palliative care/ EOL services are currently provided in your community? Who delivers these services?
2. What palliative care services are deemed essential in your agency/program?
3. What are the eligibility requirements for palliative care?
4. How does an individual access PC services?
5. What other supportive services are provided?
6. Who are your PC services targeted for?

Funding

1. Who provides funding for palliative care services? Does the First Nation band directly receive the funding? If so, from where? Are external agencies funded to provide PC services? Are there service overlaps/ gaps?
2. Why does your community administer its own PC program? Why does your community not administer its own PC services (i.e. Dilico provides services to FWFN)
3. How many dollars are currently allocated to funding palliative care? Home and community care?
4. What are the resources/ assets/ equipment available? What is planned for future wants/needs in relation to PC equipment funding (wish list)? Future plans.

Advancing the Agenda

1. How did your community become involved in this project?
2. Who in your community has worked to advance palliative care in the community? How? Why?
3. What committees are established in the community that relate to EOL care/ PC? Who sits on these committees? How is the PC agenda advanced through these committees?
4. If you want to advance Palliative care in your community, how do you go about doing this? Who are the decision makers? Who has access to funding? Who do you need to gain support from to advance palliative care? Are these key stakeholders aware of PC? Is it on the agenda in the community? Why, Why not?
5. Why does your community need palliative care? What events have led your community to developing palliative care programs?

Community Knowledge

1. What do you feel the community awareness of PC is?
2. Has any education on PC been provided?
3. How do individuals access PC information?
4. What does your health staff know about PC? Have they received any special training? If so what, when, and from where?
5. Who has received PC training in the community? Who needs PC education?
6. List any health/ EOL education that has been/ is available to the community.

Program Accountability

1. Is there currently a PC program established? If so who manages it, and how are activities documented?

2. Does your community provide PC services through alternative programs (i.e. funding is not dedicated to PC, but support can be obtained from the HCC program)?
3. How are PC/ EOL care experiences documented?
4. How does documenting PC effect funding provided for your program?

Partnerships

1. What organizations are you currently partnered with to provide service?
2. What is the decision making structure with your partners?
3. How did these relationships develop?
4. How did an agency external to your community (i.e. Dilico) become the primary home care provider for your community?
5. Why does your community administer its own home care program?
6. What resources can be accessed through your partners? Please list.

The Future of Palliative Care:

1. What are your goals for the community in terms of being involved in this project?
2. Where do you see palliative care in this community in 5, 10 years?