

Developing Culturally Appropriate Advance Care Planning Resources for First Nations Communities

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Background

Improving End-of-Life Care in First Nations (EOLFN) Communities project needs assessment (2010-11) revealed that **86%** of Aboriginal respondents would prefer to die at home if palliative care services were available in their community. Few people had engaged in end-of-life discussions with their family and health care providers, but saw these discussions as important. The need for culturally appropriate advance care planning (ACP) resources to facilitate discussions was identified.



ACP is one important component of a First Nations palliative care program. ACP can prevent or lessen family conflict, guide family members in health care decisions, and enable community members to be treated with dignity and respect.

Goal and Outcome of the ACP Project

The Canadian Hospice Palliative Care Association, the Way Forward, Quality End-of-Life Care Coalition of Canada, and EOLFN project collaborated to develop and evaluate **culturally appropriate** educational resources that could be used to create awareness of ACP in First Nation communities (June-Dec 2014).

- 5 New ACP Resources Were created for use by FN communities:
- 2 Pamphlets and a Poster
- A presentation and facilitator's guide for conducting an ACP community awareness session
- An Instructional video on the process of having an ACP conversation, including a conversation guide.



Methodology

A series of focus groups were held to evaluate the cultural appropriateness of existing Canadian ACP resources (CHPCA poster, pamphlets and video). Participants included 45 adults who lived in two Ontario First Nations (FN) communities.

Thematic analysis of the focus group data was conducted to identify participants' perceptions of the content and presentation formats most appropriate for the new resources.

The research team then developed new print and video resource material based on these findings.

Draft print resources were then taken back to the 2 FN communities to evaluate during meetings and focus groups. Revisions were made.

The print resources were evaluated for content, presentation, usability and national applicability by 25 FN health care providers from seven provinces/territories during the National Home Care Conference (November 2014).

Results

Existing Canadian ACP resources were not culturally appropriate for many FN people. The content, format and education methods used to promote ACP among FN people need to be culturally appropriate. For example, strategies such as the use of storytelling are important for creating interest and awareness. Five new culturally appropriate print and video resources offer FN communities flexible options to promote ACP.

Strategies for Culturally Appropriate ACP Education

- Creating a comfortable social environment is crucial to engage participation
- Avoid use of words considered "aggressive", eg. SPEAK UP
- Using pictures of Aboriginal models and nature is important
- Use simple, consistent and humanistic language; medical and legal terms vary by province/territory and can alienate FN people
- Recognize that every community will have different views, beliefs and customs on death and dying
- The primary goal is to inform First Nations people of their choices and rights, and to empower them to discuss these choices
- With FN people, emphasize the benefits of ACP for their families and communities rather than focusing on individual benefits only.

Dissemination

The EOLFN project and the Way Forward will share the developed resources with First Nations communities across Canada. There will be no cost to the resources and print material can be adapted for local use. Check www.eolfn.lakeheadu.ca for further information.

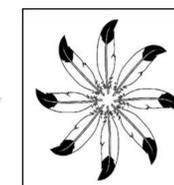
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