Improving End of Life Care for Aboriginal Families

What is this Project About?
Previous research suggests that cultural barriers can discourage ethnic minority patients from using services based on a palliative care philosophy. Palliative care philosophy promotes the idea of a “good death”, a patient-centred approach to relieving symptoms and meeting the goals of terminally-ill people for their end of life care (Quality End-of-Life Care Coalition, 2004). The research suggests that Aboriginal families in Canada are one culture that particularly needs these services.

Our research project, “Completing the Circle: End of Life Care with Aboriginal Families,” acts on the recommendations in the academic literature for cross-cultural end of life care (Field, Maher & Webb, 2002; Health Canada, 2002; Nyatanga, 2002; O’Neill, 1994). Our research objectives were to:

• Enhance health-care workers’ awareness of Aboriginal families’ end of life care needs.
• Increase awareness of the available end of life care services.
• Increase Aboriginal families’ access to palliative care services.

Our Collaborative Approach
We use the Community Action Research methodology described by Senge and Scharmer (2001). This method promotes a community of practice approach, involving a learning community of practitioners, consultants and researchers working together.

We have developed a strong network of collaborators in the Regina Qu’Appelle Health District in Saskatchewan, including palliative care services, native health services, Elders and other Aboriginal community members and many community-based service agencies. These partners have been involved in designing curriculum, videos and fact sheets, and serve as strong proponents of this project.

Our Activities: Developing Videos and Fact Sheets
For Health-Care Providers
To educate health-care providers about culturally appropriate end of life care for Aboriginal families, we interviewed Saskatchewan Elders, asking them to share their experiences and beliefs about death and dying in the Aboriginal world. Research assistants on this project were graduate students from the First Nations University of Canada and from surrounding First Nations.

The research assistants travelled to powwows throughout southern Saskatchewan to ask Elders what messages they would like to share with health-care providers. We then produced a curriculum package: a 23-minute video, PowerPoint presentation, and lecture

To increase Aboriginal families’ awareness of end of life services, we produced the 53-minute video Completing the Circle: Healing Messages About End of Life Spoken to Aboriginal Families. This video contains messages from Elders to help families deal with end of life care for loved ones. We also plan to produce fact sheets on available end of life care services.

Our Successes and Future Plans
We have shown these videos to many health-care providers, prompting changes such as more culturally sensitive protocols for organ transplants. Other audiences, such as cancer researchers and nurses, have also responded positively to our work. We have secured funding from the Canadian Institutes of Health Research to produce four more videos to address concerns such as bereavement issues of Aboriginal children and the multiple losses that Aboriginal communities experience.

Our team of researchers has generated national interest in our successful collaboration with Aboriginal Elders. We launched a national network of Aboriginal end of life care researchers at a meeting in Montreal and are planning an Aboriginal end of life care research workshop (taught by Elders and Dr. Linda Burhansstipanov) in Saskatoon in September 2007.

We also believe that increasing cultural sensitivity around end of life care may be positive for health-care providers and all families, not just Aboriginal ones. For example, research suggests that death anxiety is a prominent aspect of western culture and can have a negative psychological and emotional impact at the end of life (Neimeyer, Behnke & Reiss, 1984; Neimeyer & Van Brunt, 1995). Awareness of Aboriginal beliefs about “completing the circle” (that the end of life is a natural part of the cycle of life) may lessen this anxiety among other cultural groups.

To view the videos: We have posted a link to the trailer and the videos for health-care providers on the SPHERU website at http://www.sphereu.ca/about/sphereu/our-team/mary-hampton-phd/. We also have a Community Psychology Research Team website at http://uregina.ca/hamptoma.

For more information about the presentations or upcoming conference, contact mary.hampton@uregina.ca.

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