

Happenings

Seven Years of Completing the Circle: End-of-Life Care With Aboriginal Families

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Cross-cultural end-of-life health care is described in the literature as a dynamic new direction for research and treatment (Field, Maher, & Webb, 2002; Searight & Gafford, 2005). A recent review of the Canadian literature suggests that there are distinct cultural differences with respect to Aboriginal families (Kelly & Minty, 2007). Over the last 7 years, culturally appropriate end-of-life care with Aboriginal families in the Canadian province of Saskatchewan has been the focus of our research team at the University of Regina. We have learned a great deal about ways in which Aboriginal families are poorly served at end of life by the health-care system and ways in which they could be better served.

Our interdisciplinary team is composed of both Aboriginal and non-Aboriginal academic researchers, Aboriginal guiding Elders, and health-care providers who direct palliative services in our health region and/or services offered at a freestanding bereavement centre in our region. Together we have been able to create space for Aboriginal Elders and community members to speak about culturally appropriate end-of-life care for Aboriginal families.

What Is the Problem?

End-of-life health care is a high-priority international research topic among First Nations peoples due to their growing populations, higher mortality rates, and types of death (Kelly & Minty, 2007). For example, in Saskatchewan the Aboriginal population was estimated to be 14% of the total population in 2001 and is projected to reach 21% by 2017. Although older people in First Nations make up only 3% to 5% of Canada's population, as compared to 11% in the non-Aboriginal popu-

lation, mortality rates among Aboriginal Canadians of all ages are four to five times those for the non-Aboriginal population (Ross, Fisher, & MacLean, 2000). In Canada in 2001, Potential Years of Life Lost (PYLL), a measure of mortality, was approximately 3.5 times higher for Aboriginal peoples than for the non-Aboriginal population (Allard, Wilkins, & Berthelot, 2004). The main contributing factor in the increased PYLL among Aboriginal peoples is “injuries,” which include accidents, suicides, and homicides. The higher mortality rate and growing chronic illness rates (including HIV/AIDS) among Aboriginal peoples suggest a need for culturally appropriate end-of-life health care (WalDRAM, Herring, & Young, 2000).

Nurses and social workers have expressed a desire to provide culturally appropriate end-of-life health care for Aboriginal families and individuals, but there are formidable barriers in the health-care system. These barriers include difficulties with cross-cultural communication, lack of cross-cultural awareness, organizational barriers within the Western health-care-delivery system, and lack of flexible support (Hampton, Baydala, Drost, & McKay-McNabb, 2009). Thus existing services are underutilized, even in the face of higher mortality rates in the growing indigenous populations.

Description of Our Research

The goal of our research team has been to raise awareness about appropriate Aboriginal end-of-life health care among non-Aboriginal health-care providers. We have produced multiple videos featuring Aboriginal Elders speaking about end of life. Two of these are being widely disseminated: a short video and accompanying PowerPoint presentation for non-Aboriginal health-care providers, and a longer video documenting traditional end-of-life protocol for Aboriginal families (see, for example, <http://uregina.ca/hamptoma/>). These videos have been well received by health regions, Aboriginal health-care agencies, academic institutions in seven provinces/territories, and more than 75 audiences. Video has proved to be a powerful medium for conveying narratives of Aboriginal Elders and community members to a wide audience.

We have used an “organic” method of video production, identifying knowledgeable Aboriginal Elders at pow-wows. We ask the Elders what messages they would like to convey to health-care providers. This method differs from the didactic, scripted approach to cross-cultural education. Our method is congruent with our goal of raising awareness about traditional cultural beliefs and protocol using traditional Aboriginal ways of knowing and teaching. One of our participating Elders recently passed away; his family requested copies of the completed video and the original

interview videotape so that his words could guide them as they honoured his journey. Thanks to the credibility and hard work of our diverse, collaborative research team, we are establishing trust among Aboriginal Elders and communities by proceeding in a culturally appropriate and thus ethical manner (Baydala, Hampton, Kinunwa, Kinunwa, & Kinunwa, 2006; Baydala Placsko, Hampton, Bourassa, & McKay-McNabb, 2006). We are still receiving offers from Aboriginal Elders to share their stories and knowledge with us.

Our research program adheres to research guidelines proposed by the Canadian Institutes for Health Research (CIHR) (2010) and Ownership, Control, Access, and Possession, or OCAP (Schnarch, 2004). We open “ethical space,” as suggested by Ermine, Sinclair, and Jeffery (2004), for cross-cultural dialogic inquiry (Hampton et al., 2009). Elders Goodwill and McKenna have guided us on every step of our research journey. We have selected our materials following traditional Aboriginal protocol using prayer and asking for the guidance of Elders. For example, PowerPoint images such as sweet grass used in our education modules have been sanctioned for public use by a group of Elders in our region. Elder Goodwill wrote and recorded the narratives introducing two of our videos and recorded a “farewell song” for another of our videos. These gifts are given by Aboriginal Elders for public consumption in faith and trust. We have followed and will continue to follow Aboriginal protocol as indicated by our guiding Elders and tri-council ethical guidelines (CIHR, 2010).

Knowledge exchange is a fundamental aspect of our research program. We have responded to recent calls for a “cultural shift” in the field of knowledge translation (CIHR, 2008) by using an Indigenous Knowledge System dissemination strategy (Smylie et al., 2004). A significant barrier to accessing appropriate end-of-life services is under-referral by physicians to such services; we expect that increasing knowledge and awareness among non-Aboriginal health-care providers will lead to increased referral. We have chosen video methods of data collection and video production as a means of exchanging knowledge between cultural groups. Wass (2004) reports that the health-care curriculum gives inadequate attention to death, dying, and bereavement. The presentation of educational materials to health-care providers is expected to enhance awareness of the unique bereavement needs of Aboriginal families.

Using videos, PowerPoint presentations, and discussions led by co-presenters, we have provided awareness training to cancer clinics, Alzheimer’s societies, palliative care groups, university classes, and nurses-in-training. As we increase the volume of our material and expand our network, our capacity to offer cross-cultural educational support also increases. The regional bereavement centre serves as a space from which

to disseminate our material and as a central location from which Aboriginal families can access information for integrated dissemination. Our work is published in peer-reviewed journals, including the *Journal of Palliative Care*, the *Canadian Journal of Nursing Informatics*, *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, and *The Humanistic Psychologist*. Further research products are posted on our Web site and we continue to present our videos to multiple audiences. Videos can be purchased for a cost-recovery fee of \$25 by contacting Mary.Hampton@uregina.ca and a description of our work can be found at <http://www.uregina.ca/hamptoma/>.

The Next Steps

In the future we intend to connect nationally and internationally with researchers working with First Nations peoples to understand and represent their language and cultural practices at end of life. Furthermore, we are interested in doing action with First Nations, by, for example, bringing palliative care to First Nations, as Dr. Mary Lou Kelley and colleagues are doing (Prince & Kelley, 2006).

Along with these developments, we hope to extend our research to include cross-cultural bereavement care. Research on utilization of services suggests that most Aboriginal individuals receive end-of-life health care in acute-care settings due to traumatic deaths as a result of accidents, suicides, and homicides (Castellano, 2000). These traumatic deaths can lead to complicated grief reactions in survivors. Furthermore, a chronic illness such as diabetes can lead to amputations that result in grief reactions (Allard et al., 2004). We hope to extend our work into the area of assisting bereaved Aboriginal families by offering and documenting culturally appropriate bereavement services in urban and reserve settings.

We have found a desire among health-care providers to achieve greater understanding and a desire among Aboriginal Elders to communicate meanings of bereavement and information about proper protocol when relating to Aboriginal individuals and families who are grieving. While researchers have come to realize that the poor health status of Aboriginal peoples cannot be attributed only to low socio-economic status or individual life decisions, it remains difficult to incorporate the reality of historic stressors and intergenerational trauma into present-day theories of health care. Our research team proposes to generate a model of bereavement care that integrates these realities.

According to the cross-cultural theoretical framework proposed by Berry, Poortinga, Segall, and Dasen (1992), cultural values must be respected and practices must be uniquely adapted if ethnic minorities are to have confidence in the care provided to them (Nyatanga, 2002). We

believe that “cross-cultural” is a more appropriate conceptual framework for bereavement work than “intercultural” or “multicultural,” since we are attempting to promote understanding *across* or *between* cultural groups (non-Aboriginal and Aboriginal). We intend to focus on the possibilities afforded by dialogue between cultures rather than on “cultural competence.” “Cultural competence” is understood in the literature as requiring more than technical skill; it is “an orientation that becomes part of the practitioner’s sense of self” (Kleinman & Benson, 2006). The term “culturally appropriate” (respectful, relevant to a specific culture) describes the type of bereavement care that we envisage (Burhansstipanov, 1999).

To meet the guidelines for overcoming barriers to appropriate bereavement care, we will have to address the unique causes of grief in Aboriginal cultures and to provide culturally appropriate bereavement care by including cross-cultural policies in our health-care system (Nyatanga, 2002; Ross et al., 2000).

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