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Bridging Conventional Western health care practices with traditional Aboriginal approaches to end of life care: A dialogue between Aboriginal families and health care professionals

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Abstract

Background

End-of-life care is an emerging health care issue for Indigenousl Peoples worldwide. However, Aboriginal peoples (First Nations, Métis, and Inuit) currently face a number of barriers preventing them from receiving necessary care (Lemchuk-Favel & Jock, 2004; Kelly & Minty, 2007). Many of these barriers result from clashes between conventional Western heath care practices and traditional Aboriginal cultures.

Objective: The present study is part of a larger research project exploring pathways to culturally appropriate end-of-life care for Aboriginal families.

Methods: In this research study, Aboriginal families who had experienced the passing on of a loved one in a hospital, as well as non-Aboriginal nurses and social workers who had provided end-of-life care for Aboriginal families were invited to participate in three separate focus groups to discuss their experiences of health care practices at end-of-life.

Results: Research results were analysed using grounded theory methods (Strauss & Corbin, 1998).

Conclusion: The emerging themes identified barriers to culturally appropriate end-of-life care for Aboriginal families as well as solutions for change.

Key words: Aboriginal, cross-cultural awareness, end-of-life.

Introduction

End of life care is an emerging health care issue for Indigenous Peoples worldwide. Canadian statistics show that Aboriginal populations (e.g. First Nations, Métis, Inuit) are continuing to increase and that these populations have both higher mortality rates and higher rates of chronic illness than non-Aboriginal Canadians (Allard, Wilkins & Berthelot, 2004; Fisher, Ross, & MacLean, 2000; Statistics Canada, 2004; Waldram, Herring, & Young, 2000; Young, 1994). Of particular concern is the fact that despite this growing need for health care services amongst Aboriginal peoples, actual utilization of services by Aboriginal peoples is low due to various barriers. While some of these barriers are due to access to services (Lemchuk-Favel & Jock, 2004), barriers also result from clashes between conventional Western heath care practices and traditional Aboriginal cultures.

In general, researchers have found that ethnic minorities experience barriers to health care that involve political, depersonalized ways in which medical services are organized, including depersonalization, policies which block individualized care, and logistical lack of physical space (Fisher et al., 2000; McGrath, 2000; O'Connell, 1996; Shah & Dubeski, 1992; Sherley-Spiers, 1989). Other key areas of concern include discriminatory attitudes and lack of respect for unique cultural differences, as well as lack of staff training in areas of culture and spirituality (Anderson, Waxler-Morrison, Richardson, Herbert, & Murphy, 1990; Browne, 1995; Doka, 1993; Hepburn & Reed, 1995; Kaufert & O'Neill, 1991; Kogan, Blanchette & Masaki, 2000; Smith, 1996). Some major barriers specific to Aboriginal peoples is under-referral and lack of awareness of available services (Fried, 2000; O'Neill, 1994). A "culture clash" between dominant health care expressions of values and beliefs and Aboriginal cultural expressions create additional barriers, e.g., communication difficulties, discrimination, institutional structures which interfere with traditional kinship responsibilities, etc. (Halfe, 1989; Hallenbeck, Goldstein, & Mebane, 1996; Kaufert, Putsch & Lavallee, 1999). McGrath (2000) writes, “A degree of cultural brokerage, in which messages, belief systems and instructions are exchanged between cultural groups, is required" (p. 48). Lack of resources for dialogue between cultures, delayed diagnosis due to social isolation, and lack of health education have also been cited as barriers (Fisher et al., 2000; Fried, 2000; Halfe, 1989; McGrath, 2000).

Additionally, barriers exist regarding clashes between different cultural constructs for death, dying, and grief. Westernized constructs of death view death as an enemy and treat the experience in an institutionalized "hands off" manner (Kubler-Ross, 1975; Morgan, 1995; Schneidman, 1983). Aboriginal constructions of death emphasize family involvement in decision-making, the importance of spiritual factors, and inclusion of community in ceremonies (Brokenleg & Middleton, 1993; Preston & Preston, 1991; Turner-Weeden, 1995). Western constructions of dying are dominated by a focus on biological factors and technology, with curing emphasized over pain relief (Anderson et al., 1990; Braun, Pietsch, & Blanchette, 2000; O'Connor, Meakes, McCarroll-Butler, Gadowsky, & O’Neill, 2001), which differ from traditional Aboriginal epistemology that focuses holistically on dying as making a journey (Baydala, Hampton, Kinunwa, L., Kinunwa, G., Kinunwa, L., 2006; Fisher et al., 2000; Holmes & Holmes, 1995). A concept analysis of grief among different cultural groups found that intrapsychic grief reactions are similar;

however, mourning rituals and appropriate expression of grief differ by culture (Cowles, 1996). Halfe (1989) writes, “What differs between races and cultural groups is not so much the feelings of grief but their forms of expression” (p. 37). Aboriginal constructions of grief encourage acceptance; however, intergenerational grief responses from cumulative losses relating to residential schools issues, etc., have led to PTSD (post traumatic stress) responses from unresolved grief (Bailey, Kral & Dunham, 1999; Kent, 2001; Rando, 1993; RCAP, 1998; Zisook, Chentsova-Dutton, & Schuster, 1998).

Research shows that culturally competent interventions increase Aboriginal participation in health care services (Burhansstipanov, 1999). However, healthcare personnel guidelines for appropriate cross-cultural practice are currently lacking, especially guidelines specific to culturally appropriate end of life care for Aboriginals. Proposed guidelines for overcoming barriers to culturally appropriate health care services involved, changing the structure of the medical system by including cross-cultural policies, staff training to reduce conflict arising from cultural and communication differences, enhancing culturally appropriate resources, and increasing knowledge among ethnic minorities about available services (Anderson et al. 1990; Braun et al., 2000; Browne, 1995; Doka, 1993; Ellerby, McKenzie, McKay, et al., 2000; Fisher et al., 2000; Fried, 2000; Hallenbeck et al. 1996; Hepburn & Reed, 1995; Kaufert & O'Neil, 1991; Nyatanga, 2002: Rosenblatt, 1993). However, specific recommendations concerning best practices to facilitate change are needed. McGrath (2000) writes, “Care is largely derived from culture and needs to be based on knowledge of a specific culture if it is to be effective and relevant” (p. 48).

Culture Defined

Before proceeding further, it is necessary to stop and reflect on what is meant when the term "culture" is used. Defining culture is no easy task, as there are many different conceptualizations of what this concept encompasses. We choose to approach the task of defining culture in a manner which reflects the research team's dedication to community-based production of knowledge (Baydala, Placsko, Hampton, Bourassa, & McKay-McNabb, 2006). Members of the research team contributed their own personal reflections about what culture means to them and several common themes emerged. Shared traditions and relationships with family and friends were seen as an important component of culture by team members. Angelina Baydala, a non-Aboriginal academic, stated, "for me culture is about traditions, the little regular things that happen in the day to day as well as the big ceremonial traditions that we share with friends and family." A similar view of culture as providing a sense of familiarity and comfort was shared by Christina Drost, a non-Aboriginal academic, who stated:

> **"To me culture is the shared customs and meanings that I have with my family and friends that make it so comfortable to be around them. There is just this sense of mutual understanding that makes you realize that this is where you fit."**

Team members related experiences of culture becoming more significant when amidst people who do not share the same culture. Mary Hampton, a non-Aboriginal academic, reflected:

> **"I realized that I come from a "majority, dominant" culture that defines my lifestyle to such an extent that I'm unaware of it. This just means that I "fit into" the mainstream as it's been constructed. … Whenever I spend time as a minority person amongst Aboriginal peoples, I begin to feel the culture I was raised in."**

Culture was also seen as being an important component of personal identity. Carrie Bourassa, an Aboriginal Métis academic, explained how identity and culture are interrelated:

> **"I guess to me culture is my identity. It encompasses my values and morals. Essentially, it defines who I am as a person. For many Aboriginal people when our culture was stripped, it really was our identities that were stripped."**

Kim McKay-McNabb, an Aboriginal academic, also talked about culture and identity being related and discussed how exploring her connection with her First Nations ancestry played a large part in her process of developing culture:

> **"To me culture, as a First Nations woman, emerged from exploring the traditional and cultural aspects of being First Nations through my connection to traditional ceremonies, gatherings, powwows, and having numerous Elders assist me along the way, I can say that culture is a connection to the earth, to all peoples, and acceptance of the First Nations teachings as I navigate the journey to gain a better understanding of my culture… I have developed "culture," which I believe is an individual's identity as a person."**

In addition to conceptualizing culture as something that is developed, culture was also described by team members as something that could change over time. Angelina described culture as "fluid, alive and changeable" and Carrie stated that, "it is ever changing, it is never stagnant. You grow with and through your culture."

These reflections from our research team are similar in many ways to definitions of culture put forth in the academic literature. Shwedder (1984) talks about "culture as shared meaning systems.." (p.1) LeVine (1984) also subscribes to this collectivist notion of culture and states that, "culture represents a consensus on a wide variety of meanings among members of an interacting community." (p. 68) Berry and Triandis (2006) explain how, although there are many different conceptualizations of what is meant by culture, there are certain common characteristics that most researchers recognize as being part of this concept, “First, culture emerges in an adaptive interaction between humans and environments. Second, culture consists of shared elements. Third, culture is transmitted across time periods and generations.” (p. 50).

In summary, culture is a concept that refers to shared meanings and traditions between people relating to one another, personal identity, personal ancestry; and is something that is dynamic and evolves over time. This discussion of the concept of culture is ended with reflections from Elder Betty McKenna, an Aboriginal Elder who has provided us with guidance throughout this research process,

“Culture is my language, my ancestors, the faith I have in the sun, moon, water, wind, fire, and mother earth. Culture is all my relations and the actions of my everyday living with all my relations. My spiritual connection and knowledge transfer from and to all things. This tells me I have been. I am. And I will be.”

Current Study Background

The present study is part of a larger research project exploring pathways to culturally appropriate end of life care for Aboriginal families. For a more in-depth review of the overall research project details, refer to Baydala, Placsko et al., (2006). Our research takes a participatory action research approach, which emphasizes working respectfully with community members towards a co-construction of knowledge and community action (Mertens, 1998). Furthermore, our research involves the convergence of three cultures (the university, the health region, and Aboriginal families) to produce mutual understanding. We invited Aboriginal families who had experienced the passing of a loved one in a hospital, as well as nurses and social workers who had provided end of life care for Aboriginal families, to participate in focus groups. In these groups they then discussed their experiences of health care practices at end-of-life, in order to further assist in identifying existing barriers to culturally appropriate end-of-life care for Aboriginal families, as well as to suggest possible solutions to these barriers..

Methods

Grounded Theory

The qualitative method we chose for data collection and analysis were grounded theory methods as described by Strauss and Corbin (1998). However, since our site for data collection was limited to one selected Canadian prairie city and reflects the cultural diversity of this area (i.e., primarily Cree, Saulteaux and Metis Aboriginal communities), we also used the model of "case study research" described by Eisenhardt (1989). We proposed generating a theory of cross-cultural delivery of end of life care from the collection of focus group data within two local hospitals.

Ethics

We obtained ethics approval from the Research Ethics Board at the University of Regina and the Regina Qu'Appelle Health Region Research Ethics Board, before proceeding with this research. Our research team recognized the importance of ethical and respectful research when working with the Aboriginal community and approached this research from a perspective of conducting research *with*, *by*, and *for* Aboriginal peoples, as opposed to research *on* or *about* Aboriginal peoples (Baydala, Placsko et al., 2006; CIHR, 2007). Although the individual families who participated in this research may not have benefited directly, this research would benefit the Aboriginal community as a whole because it was being used to identify changes that were needed for current health care practices, as well as assisted in the development of additional resources for Aboriginal families facing end-of-life.

Participants

Participants for the three focus groups were recruited through snowball sampling. All participants were recruited from the only two hospitals in our designated Canadian prairie city. One of the hospitals offered palliative care services as well as a Native Health Service unit that was given responsibility for assisting Aboriginal families who access health care in either hospital. Social workers at Native Health Services served as community partners in the research and assisted with recruitment and facilitation of the focus groups.

The first focus group consisted of 11 Aboriginal family members who had experienced the passing of a loved one/family member in a hospital in the past 12 months. These 11 research participants included eight females and three males, with an age range of 29 – 61. These Aboriginal individuals received an invitation from the receptionist at a local Native Health Services location to participate in this research focus group. After reviewing and signing informed consent forms, participants filled out a demographic form. They varied in terms of Aboriginal ancestry (e.g. Cree, Saulteaux) and spiritual beliefs (e.g. Christianity, traditional Aboriginal spirituality). When describing the death of their loved one(s), participants stated that the deceased persons' ages at death ranged from 19-75. Participants' relationships to the deceased included son/daughter, spouse, sibling, and parent. Seven of the deaths were categorized by the participants as "sudden" (two identified multiple losses) and 6 were "long-term."

Participants for the subsequent two focus groups, with nurses and social workers respectively, were recruited by invitation; the researchers identified those health care providers working specifically with patients at end-of-life, either in acute or chronic settings. Our decision to recruit nurses and social workers rather than physicians was supported by previous work done by the research team that determined that these front line service providers had the most contact with Aboriginal family members and were willing to participate in a focus group (Baydala, et al., 2006).

The second focus group consisted of five non-Aboriginal female nurses who had experience providing end of life care to Aboriginal families. They ranged in age from 44-54 and had 20-30+ years in health care. Only two had previously received cross-cultural training, yet all stated that culture is important to health care; one stated she studied Native Studies.

The third focus group consisted of five social workers: two female Aboriginal, two female non-Aboriginal and one male non-Aboriginal social worker. All had experience providing end of life care to Aboriginal families; three of these had received cross-cultural training and all stated that cultulre is important to health care.

Procedures

All focus group participants were provided with an explanation of the purpose of the research and informed them of what their participation would entail prior to commencing the study. Participants then provided their consent either in written form, or if they were not comfortable providing written consent, they provided consent verbally. The initial Aboriginal families' focus group was conducted in the local Native Health Services facility gathering room and was guided by an Aboriginal Elder from the community, as well as facilitators from the research team. After gathering, the first focus group began with an opening prayer, then the intention of the focus group was stated, and family members were invited to share their experiences. The discussion then proceeded around the circle in order to give everyone a chance to share. The focus group ended with a closing prayer. These procedures are culturally appropriate for Aboriginal gatherings (Waldram, 1997). Lunch was provided to them prior to the focus group and gifts were provided as a token of gratitude to participants. Transportation and childcare were also provided at that time. The second and third focus groups conducted with the nurses, and then with the social workers, each proceeded in the form of an open discussion with non-Aboriginal academic facilitators ensuring that each participant had an opportunity to speak. Lunch and gifts were also provided. All three focus groups' discussions were recorded and transcribed verbatim.

Data Analysis

Focus group transcripts were analysed jointly by two of the authors using a grounded theory approach (Strauss & Corbin, 1998) to identify common themes both within and across groups. Three levels of coding were used to generate the final thematic formulation: open, axial, and selective coding (Strauss & Corbin, 1998). Emergent themes from each of the focus groups were circulated among members of the research team to ensure collective agreement on the thematic formulation. Results were used to develop a theory of Aboriginal families' needs for end-of-life care as well as health care providers' needs for providing culturally appropriate end-of-life care, grounded in the expressed concerns and recommendations of focus group participants. We framed our findings as a "dialogue" between the three groups since data convergence was found during analysis, with participants describing similarities in both barriers and solutions to appropriate end-of-life care with Aboriginal families (Eisenhardt, 1989; Coffey, Holbrok & Atkinson, 1996; Kumar, Stern & Anderson, 1993; Mays, 1995).

Results

A number of common themes emerged across each of the three focus groups primarily relating to four areas: [1] communication, [2] cross-cultural awareness needs [3] systemic/policy issues impacting culturally appropriate end-of-life care, and [4] importance of available support. We have chosen to present these themes in the manner of a dialogue between (a) Aboriginal families, (b) nurses, and (c) social workers. We have done this by listing each of the four common themes that were identified as issues across the groups, followed by each group's discussion and feedback about that theme.

Communication

All three focus groups discussed difficulties in communication between Aboriginal families and heath care providers. Along with identifying specific problems with communication, a number of recommendations for ways to better facilitate communication between Aboriginal families and heath care providers were identified.

a) Aboriginal Families

Language. One aspect of communication identified as an important issue by Aboriginal family members was the use of language. Language use by non-Aboriginal health care providers when discussing death was perceived as culturally insensitive. Family members suggested that using language reflecting the conceptualization of dying as a journey, such as “passing on,” might be more appropriate than using terms such as “dead” or “dying.” The use of technical medical language when referring to a loved one was also seen as being culturally insensitive and showing a lack of compassion for family members. One family member who had experienced being in the hospital with his son who was facing end-of-life discussed how the doctor used medical terms about the son that were perceived as being insensitive given the circumstances, “I knew my son had lost his voice and was losing his strength but the doctor was telling me that he was brain dead, he doesn’t understand.” Telling family members that their son could not understand them was seen as harmful when the family was trying to provide him with comforting words as he passed on and was not respectful of their belief that their son was with them and could hear them until the very end, “they hear right to the very end and just keep talking and talking and talking to them because that gives them the comfort too that, you know, that you’re there.” In circumstances such as these, heath care providers are being asked to try to find ways to talk about death that are culturally sensitive and respect Aboriginal families’ traditions and beliefs around the end-of-life.

Caregivers’ lack of compassion. Another concern identified by Aboriginal family members was the perceived lack of compassion from health care providers. While some family members had had positive experiences with hospital staff who were seen as being considerate and compassionate, others related experiences where heath care providers interacted with family members in a way that was perceived as being impersonal. Family members stressed that health care providers need to recognize the importance of the care they are providing for both the person facing end of life, as well as family members who were there to be with their loved one. Elder Ken Goodwill, an Aboriginal Elder who provided his guidance through facilitating the focus group with Aboriginal families reflected,

> **"They must understand that trauma and the worry that goes with family members who have to deal with a loved one laying on that bed in intensive care. And then you have some nurse tell you that you can't be there or whatever because we're very busy. The last thing that family person wants to hear is how busy a person is and we need their understanding, compassion, whatever it takes to make that person, that family member as comfortable as possible. It only takes one or two exceptions to make it even more difficult for family members."**

Opportunities to communicate concerns and share experiences with health care providers and policy makers.

One solution identified for increasing communication between Aboriginal families and health care providers involved creating opportunities for health care recipients and family members to communicate their concerns together and share their experiences with health care providers and policy makers. Speaking to health care providers and policy makers about what Aboriginals found helpful or not helpful could assist in creating health care practices that are more culturally appropriate and respectful. This would not only improve services for Aboriginal families, but could also benefit non-Aboriginal family members, and better the profession as a whole.

b) Nurses

Barriers. The nurses in another focus group identified a number of barriers to communication between nurses and Aboriginal family members. Differences in language use and terminology surrounding death was seen as one issue and nurses expressed that they felt that they had a lack of knowledge regarding culturally appropriate language to use when speaking to Aboriginal families. Differences in communication styles were also seen as a barrier, including differences in the expression and release of emotions, the use of eye contact, and lack of direct questioning, as these differences tended to leave health care providers feeling either uncomfortable or unsure of how to interact with Aboriginal families. Discomfort and uncertainty experienced by both nurses and family members was also seen as prohibiting effective communication between these groups. As one nurse reflected "the biggest gap I see on our floor is that the families don't feel comfortable enough asking us and we don't know where to start to ask them."

Facilitators. The nurses also identified a number of facilitators to better communication with Aboriginal family members. They talked about the importance of being open and honest with family members and letting the family know what is going on with their loved one. Ensuring that doctors took the time to speak to families was stated as something that could be helpful, because family members often were not given the information they needed in order to understand the health status of their loved one. It was suggested that it would be helpful if one family member act as a spokesperson when interacting with health care providers. The nurses also recognized the need for health care providers to be willing to hear what families have to say and to take that time to listen.

c) Social Workers

Barriers. Social workers in the third focus group also discussed different barriers to communication between Aboriginal families and health care providers. Language was identified as a barrier, both in terms of differences in naming death and speaking about the death process, as well as the use of medical language by staff that was difficult for family members to understand. Differences in communication styles was also discussed, particularly the experience that Aboriginal families sometimes communicate in a more passive and non-verbal way and might not be willing to speak to health care providers. The social workers also pointed to power imbalances between Aboriginal families and health care providers as a barrier to effective communication. They discussed how sometimes there is a reluctance among Aboriginal families to question authority and an attitude that the "doctor knows best." On the other hand, sometimes the social workers had experienced power conflicts where Aboriginal individuals resisted listening to and complying with requests from health care providers because they were part of the "dominant, white majority."

Facilitators. A number of facilitators to effective communication were also identified by the social workers including being upfront, and offer clarification about what health care providers have said to the family members to ensure understanding, identifying one family member to act as a contact person and communicating with the family through them, asking questions, and listening. One social worker identified the best approach to communication as:

…"**just by listening and just by asking them more questions if they are bringing issues up that to talk about and to listen to they often will open up and educate me about what it is their family is and what they're looking for and what they're hoping."**

Cross-Cultural Awareness

The importance of cross-cultural awareness for facilitating culturally appropriate end-of-life care and the current lack of adequate knowledge and training in this area was another common theme among all three focus groups. Along with identifying the current deficits in this area, members of each three focus groups identified possible ways to help facilitate increased cross-cultural awareness amongst health care providers.

a) Aboriginal Families

Lack of cross-cultural awareness training. Aboriginal family members identified lack of cross-cultural awareness training for health care providers as being an issue. They suggested that this type of training should be provided to staff on paid time and to be made available for health care providers on all hospital units, especially intensive care and palliative care. Another identified issue was the fact that the current training that was provided was often out of date and no longer relevant to the lives of Aboriginal peoples today. More contemporary training is needed that should include evolving definitions of family and relationships, an understanding of who typically fills the role of primary caregiver, as well as training in language sensitivity. Knowledge about cultural practices, including traditional ceremonies and rituals, was also identified as something that was lacking in hospital settings. Elder Ken Goodwill discussed how this lack of knowledge could be detrimental to families who are facing the passing of a loved one in a hospital setting:

> **"Maybe the hospital staff didn't know what was happening. It seems that their interference made the grief and pain much more difficult to bear for the families because they didn't know what the family needed whether that was smudging or putting tobacco under the pillow or food even."**

Aboriginal family members also identified a lack of awareness of the impact and extent of historical racism and oppression, as well as the higher incidents of traumatic and multiple deaths that are experienced by Aboriginals and the impact that these experiences can have on family members and the Aboriginal community. One family member stated,

"Try to live in our shoes, you wouldn't survive out there… it's hard being Aboriginal, our poverty, there's so much poverty, there's so much diabetes, there's death, we die before we're supposed to. And I don't think that the larger population sees as much as we do."

Taken together, the history of racism and oppression combined with the high rates of traumatic and unexpected deaths, as well as experiencing multiple deaths within one family or community, can lead to a sense of cumulative loss and complicated grief reactions such as post-traumatic stress, alcoholism, and shock. This needs to be addressed in healthcare providers' training so that there is better understanding of the historical context for these experiences, and so staff would be better equipped to know how to provide appropriate care to family members. At the same time, one of the Aboriginal family members stressed the importance of recognizing the strength of Aboriginal peoples and their ability to survive through these circumstances:

"I strongly believe that Native people are survivors. The Creator put us here for a reason and we, our population is growing, and therefore we have to be survivors. And it comes from somewhere. I realize that it comes from within that survival instinct."

It was also identified that along with these concerns that are specific to the lived experiences of Aboriginal peoples, there are concerns that are common to Aboriginal and non-Aboriginal families. There needs to be an increased awareness of what these differences and similarities are and what impact this may have on experiences of end of life care.

Need for Aboriginal people to care professionally for Aboriginal people. In addition to providing cultural awareness training to non-Aboriginal health care providers, another solution for providing culturally appropriate care that was identified is ensuring that there are Aboriginal people available to care professionally for Aboriginal people in health care settings. One Aboriginal family member stated that they would like to see, "a trauma team… of people that are composed of Aboriginal people because they have got the cultural training.” Another family member shared this desire and stated, “What I’d like to see is when someone just passed away, maybe some staff and Native counsellors could come.”

b) Nurses

Cultural differences that impact end of life care. The nurses identified a number of cultural differences that they had experienced when working with Aboriginal populations. These differences included a greater acceptance of death as a natural part of the life cycle, greater involvement of the extended family, staying with the body of their loved one for a longer period of time after they have passed away, and beliefs about the loved one’s spirit lingering after death.

As one nurse commented,

> **“They have a very proud culture - a very in depth one. I do notice that in most of the cases that they remain with their loved one a long time after they’ve passed away which is unique to the Native family more so than any other culture that I’ve seen and very respectful and more accepting of that death process and the different things that may be happening at that time.”**

Although the nurses expressed a desire to gain a better understanding of these differences and to be respectful, there was also awareness that these differences sometimes made hospital staff uncomfortable and at times clashed with routine hospital procedures.

Need for cultural awareness training. The nurses indicated a clear desire to be respectful towards Aboriginal families and felt that greater cultural awareness would facilitate their ability to be more respectful. However, they felt that they currently lacked knowledge about Aboriginal cultures. As one nurse pointed out,

"I mean if Aboriginal people have special things for end of life we've never really been taught anything about them other then that extended family often comes. I mean that's the only thing we've ever been taught and possibly that's not enough."

Some specific training areas that the nurses felt they both wanted and needed more knowledge about included basic information about Aboriginal cultures and spiritually, Aboriginal views about death and dying, views about intervening in the natural cycle of things (i.e. life support), and the significance of specific rituals (e.g. smudging, sweet grass). Suggested approaches to increased cultural staff awareness identified included education days and training seminars for current nurses, classes for nursing students, mentoring new staff, and providing staff with handouts and/or articles with information on the basic beliefs and traditions amongst Aboriginal peoples. The nurses also discussed how it was difficult to generalize across Aboriginal peoples because in their experience, every family is unique. Therefore, health care providers should not assume that every Aboriginal family will hold the same beliefs, interact with staff in the same way, or require the same type of care.

c) Social Workers

Importance of cultural awareness.

The social workers discussed the importance of cultural awareness for the provision of end-of-life care, which they identified as currently lacking. Specific areas that the social workers identified as being important for understanding included cultural/spiritual beliefs and values, specific views surrounding death, and the impact of residential schools. The social workers suggested a number of ways that health care providers could be educated in order to increase cultural awareness such as specific training and workplace preparation, learning through experience, sharing of learning and experience amongst staff, and going to Aboriginals for help in understanding. It was suggested that health care providers could learn directly from Aboriginal families through storytelling. Having Aboriginals talk to health care providers about their experiences whether positive or negative, was seen as being a more effective way of teaching cultural awareness than a manual or a list of dos and don'ts. As one social worker stated:

"…and that's where the education needs to be in terms is the sensitivity to staff. And not just standing up in front of the things saying, "Well you have to do this and you have to do that," it's the storytelling. And what I find really impacts the staff I work is when somebody comes back and tells their story that has the biggest impact rather than me saying something or you saying something, it comes back from listening to the people tell their story."

However, although the social workers expressed a need for more training in this area, they also identified the importance of recognizing that "unless you're part of that culture you're never going to understand it." The social workers also discussed the fact that although you can try to gain an understanding of basic Aboriginal beliefs, you cannot generalize because there is so much diversity both amongst Aboriginal communities and between individual families.

Importance of respect. The social workers also discussed the importance of being respectful in interactions with family members. As one social worker expressed, "I think it's just important to realize is that we are people we are human beings that need respect and dignity." The social workers indicated that the most effective ways of being respectful and expressing this attitude of respect to families include listening, showing interest, showing that you are making an effort, asking questions, being willing to give explanations, being compassionate, being careful not to re-traumatize, being genuine, and connecting with family members. The social workers discussed the main barrier to being respectful and providing culturally appropriate care as being prejudice and fear caused by a lack of understanding and misconceptions about Aboriginals. As one social worker stated, “I keep seeing fear, people feel fear against approaching other people they think are maybe different.”

Systemic Policy Issues

There were a number of aspects of the organization of Western health care system, as well as specific hospital policies that were identified by all three focus groups as barriers to providing culturally appropriate end of life care to Aboriginal families.

a) Aboriginal Families

Home care vs. hospital care. Aboriginal family members identified a number of unhelpful things that occurred in hospitals that did not happen when people were being cared for at home, including interference with the family’s grieving process, ignorance and misunderstanding of what the family needed. Once a loved one is moved to the hospital, family members were no longer able to care for them in the way they found most appropriate. One family member reflected, “We couldn’t protect her… the health care system takes that away from you.” Although some family members felt that they could better care for their loved ones at home, many had experiences where hospital policy prevented them from doing so. Possible solutions identified included making efforts to make hospital care more similar to home care by allowing or providing for cultural practices such as smudging and, “giving what people want, that are in their last hours of life,” which might also include being allowed to return home.

Space. Aboriginal family members discussed the importance of loved ones being present at the end of life. This is often a problem given both the lack of space available in most hospital settings (both in the patient's room and in the unit), as well as policies restricting the number of visitors allowed at one time. Elder Ken Goodwill discussed how hospital policy restricting the number of visitors is in conflict with the values many Aboriginals place on being surrounded by family and friends,

"Or how many people they allow in the visiting rooms. Sometimes they allow only one or two. Sometimes it's good to allow lots of people into the room to benefit from their energy. …and in some hospitals there's no room…"

Family members identified a need for a space where they can gather together to support each other, grieve, and heal. One family member stated, "There should be a place where we go, a large room where we could go and be." Often there is no place available for gathering in hospitals and when there is such a space available it is often unknown to family members or inaccessible. One family member reflected on how although the hospital where their loved one passed away did have a space for Aboriginal family members to gather together, they were unaware of this at the time. Had knowledge of this space been made available, this family member says it would have been helpful,

"I was hoping to be with the other family members and I don't know this room existed. I would have liked to have sat, just think and talk and just have coffee with the family and maybe have a pastor come in and talk. …we need to come together with us and talk and cry and cry and talk… "

Another concern that was expressed regarding reactions to large numbers of visitors being present was the tendency for health care providers to give less support to family members. One family member stated, "When it was just the three of us, they checked in… when everybody got there, it was like cruel, they never checked in, or they stopped checking."

Family members stressed that even when many family members are present, support from health care providers is still needed.

Eligibility for palliative care services. Another concern that was addressed by Aboriginal families was policy regarding eligibility for palliative care services. There was a specific concern about the fact that there are no palliative care services for patients who are in the intensive care unit. This was identified as being problematic because people often pass away in intensive care or shortly after they are transferred from intensive care. However, intensive care units are often not set up in a way that allows for family members to gather with their loved ones and prepare for their passing. Elder Goodwill explained,

> **"But I also believe that there's a point where that person in ICU may still need the same treatment… but it's a well known fact that they are coming towards the end of their life. And I think that it's very important that family members who want to visit can do so in a much more private kind of environment. … And with the rules and restrictions in intensive care that can't happen. That can't happen because of the lay out in intensive care, it can't happen because you can't get too many people in there, of course it's going to upset, perhaps, other people in there. Other people that are sick as well. I think there needs to be more privacy offered to the people who are at the end of their life, to allow family members and the children to be present."**

Anonymity of staff due to rotating shifts. Another issue that was identified by Aboriginal families was the problem of staff anonymity due to rotating shifts. When the staff working with one patient was constantly shifting, it made it difficult for family members to form a connection with health care providers in order to feel supported. One family member, reflecting on their experience with a health care provider stated, "10 minutes before her shift was over, she said, 'My shift is over in 10 minutes.' So basically, 'she's not my problem anymore.'" Revolving staff also contributed to the Aboriginal family members' perception of health care providers as being impersonal and showing a lack of compassion.

b) Nurses

Organization of Western health care system. The nurses in the second focus group identified a number of aspects of the organization of the health care system, as well as hospital structure and policy that makes it more difficult to provide culturally appropriate care. Although they recognized the importance of adapting to families' needs, they also stated that it is important that family members realize that they have certain roles to fill and rules to abide by. As one nurse expressed, “Well and I suppose like part of it is what expectations we need to fulfill from our side too. You know as far as the rules and running and the… because it's an institution… you know and you can't get away from that.” Some specific issues that were mentioned in this context included security issues with large numbers of family members and people coming on and off the ward, complaints from other family members, needing to clear rooms out quickly after death to make the bed available for other patients, activity and stress on the unit. Another issue that was brought forth was dealing with medical crisis. As one nurses explained,

> **“And I think you know when we're dealing with people in crisis I think that probably the cultural aspect is pushed aside quite a lot because you ask direct questions more and you need answers succinctly and you would explain from your medical point of view first and then you would have to you know ask the questions and see what they understood and that sort of thing. So it's hard to know if that's the right way or not but…”**

Environment and Space. The nurses gave descriptions of what they considered to be the ideal environment for end-of-life care. They described this ideal environment as being quiet, calm, peaceful, comfortable and that ideally, it should feel like you left the hospital. As one nurse stated, "but you know on our ward we have pagers, we have phones, we have buzzers that ding. I mean there's no peace for one thing so space and peace would go a long way. Space and peace and time". Lack of physical space on their units was identified as being a huge problem in terms of being able to facilitate family members being able to be with their loved ones, especially given the tendency in Aboriginal families for extended family to come to the hospital. The nurses also described how an ideal environment for end-of-life care should include beauty, artwork, windows and music, as well as basic supplies to meet family members' needs (e.g. chairs and tea kettle).

c) Social Workers

Organization of Western health care system. The social workers also discussed how the organization of the health care system, as well as hospital structure and policy, are barriers to providing culturally appropriate care. Some of the specific aspects that were mentioned included the "black and white", task-focused nature of the system, lack of attention to holistic needs of patients and family members, lack of flexibility, busy activity of the units, staff turnover due to shift changes, and dealing with crisis situations. The social workers also discussed how Aboriginal families were often put at a disadvantage because they did not always learn how to navigate this system in the same way that white, middle-class families have. The social workers also discussed lack of physical space as a barrier, both to accommodate extended family as well as space to perform cultural rituals.

Importance of involving the family. The social workers discussed the importance of involving family members as a "critical component of care." As one social worker stated,

> **"I see for you know extended families in Aboriginal families it's like I say it's key for them to be there and to provide that support to that family member to have that time**

to joke, laugh, reminisce, do what you know just to be together that's important you know."

In addition to allowing families to be together and support one another, the social workers also stressed the importance of the staff making connections with family members and building relationships. The social workers discussed how one of their roles as social workers was to assist families in their interactions with other health care providers by empowering them by letting them know what their rights are and making sure they understand what is going on and what is being said to them. They saw part of their role as assisting to "turn that control back to the family."

Importance of Available Support

The importance of support in the form of available resources and staff was addressed by all three focus groups as being essential to facilitating the provision of culturally appropriate and holistic end of life care. Concerns were raised about the current lack of needed support and specific suggestions were provided for types of support that would be most helpful.

a) Aboriginal Families

Spiritual support. Aboriginal families discussed the lack of spirituality in hospital environments and identified the importance of spiritual support availability for both the person facing end-of-life and their family. Also, because of diversity of beliefs amongst Aboriginals, it is important that this spiritual support be available from both a Christian perspective as well as Aboriginal Traditional Spirituality. Possible approaches to providing this support included involving Aboriginal Elders and Christian pastors in end-of-life care and having space available for spiritual practices.

Health care support for survivors. Aboriginal families identified a need for increased support for family members who survive the loss of a loved one. Grief reactions can span months or even years following a loved one passing away and therefore, support needs to be ongoing. This is especially true in cases where concerns such as alcoholism, post-traumatic stress, and other complicated grief reactions are present. Family members talked about how both informational and emotional support would be helpful in this context. Specific information regarding what is needed and/or available for the care of a loved one at the end-of-life, plus information about available support was expressed as being helpful for families. Discussions regarding life support was identified as a specific issue that family members would likely need guidance with. Family members could benefit from assistance in understanding both the physical side of this issue, as well as the potential spiritual impact on the family. Also, family members might not be able to come to a consensus regarding this decision and may need someone to help facilitate this decision making process. The availability of Aboriginal Elders to provide guidance to families was seen as something that could be beneficial during this time. As Elder Ken Goodwill reflected, "if the time comes to deal with that decision… have to make sure that there are other people present, like Elders, that can assist in that decision-making process."

Emotional support for family members was also seen as being crucial. Ensuring sufficient time off of work in order to care for loved ones and to grieve was seen as something that was helpful, although the benefit of being able to return to work when ready, as well as engaging in other activities to keep busy was also identified. Another essential component of emotional support that was identified was being able to gather together with others, to express grief and to support each other. The availability of a grief group where people who have experienced the passing of a loved one could come and share their experiences and receive support from each other and counsellors was seen as something hugely beneficial to family members. One family member, reflecting on their experience sharing in a group stated, “It really does help you know, when you can, when you talk to other people and just get that ear. I think that just being here is medicine, has helped me.” The availability of Aboriginal counsellors to help provide emotional support to family members was also seen as an essential service. As one family member stated, “Some of the best support we got that the family received was in…Native Counselling Services.”

Emotional support was also seen as something that did not begin only after the passing of a loved one. Preparing family members when it was known that their loved one was coming to the end of their life was identified as an important component of support. Family members also discussed how it was beneficial when hospitals encouraged flexibility in the types of support provided and were able to allow for needs that were specific to individual families.

Another issue regarding support for family members that was identified was in regards to family members and friends who are coming to visit from out of town. There is often a problem of expenses and need for a place to stay. Services that help care for out of town visitors and provide needed resources were seen as being beneficial and currently lacking. Access to supportive end-of-life health care services, especially in rural areas was also identified as a problem. It was suggested that healthcare staff education regarding these rural areas be improved concerning services needed or available.

b) Nurses

Lack of resources. The nurses discussed lack of resources as being a huge barrier to being able to provide culturally appropriate care. They identified a real deficit in available staff, which also contributes to time constraints. Lack of adequate staff numbers meant that the staff that were working had limited time available to devote to patients and families. As one nurse stated, “we do not have unfortunately the staffing numbers to aid in communications or facilitating or whatever else.” Therefore, there exists a real need in the health care system for more staff in order to be able to have the resources to provide culturally appropriate care for Aboriginal families. Another resource area that the nurses identified as problematic was after hours resources, including lack of facility space after hours, and lack of afterhours support staff . Often the supports that were available during the day (e.g. Aboriginal services) were closed after hours. The nurses also identified a lack of knowledge about what resources were available and stated, “we should have more justification for what we feel we can offer.”

Valuable resources. The nurses identified a number of resources that they felt would be valuable for assisting them in providing culturally appropriate care, some of which are currently available, some that are currently available but need to be improved, and some which are currently absent. They stated that in order to be most effective, these resources should be designed to be multi-functioning. Valuable resources mentioned included social workers (particularly Aboriginal social workers) to help facilitate communication between nurses and Aboriginal families, Aboriginal services, home care, community resources, and lists of people they can contact for support. Pamphlets or handouts were also seen as being helpful, including handouts of information given to family members with information about available services, as well as handouts for staff that explain some basic cultural issues that you need to be aware of when providing care for Aboriginals. Nurses also stated that having Aboriginal family members speak directly to nurses about their needs would be helpful and would help nurses understand their experiences.

c) Social Workers

Support that is helpful/needed. The social workers also discussed a lack of support staff, especially after hours, as a barrier to providing culturally appropriate care. The social workers identified specific support that would be helpful. Having front-line Aboriginal staff (e.g. Aboriginal services) to work as a liaison between Aboriginal families and health care providers was seen as being an invaluable resource. More access to services was also seen as being important, as often Aboriginals support services were limited after hours. The existence of an in-house Elder to assist and guide both family members and staff was also suggested as a potential valuable resource, as well as having contact lists of Elders for support in the evenings and on weekends. The social workers also played a key supportive role themselves in terms of facilitating communication between other health care providers and family members and saw part of their role as empowering staff by providing them with needed information.

Discussion

The themes that emerged from the three focus groups pointed to some clear barriers experienced by Aboriginal families when a loved one faces end-of-life in a hospital, including difficulties in cross-cultural communication, lack of cross-cultural awareness amongst health care providers, aspects of the current Western health care system organization that made it more difficult to provide culturally appropriate end-of-life care, and the lack of available and flexible support for both Aboriginal families and health care providers. While the nurses and social workers expressed a desire to help provide culturally appropriate end-of-life care, they felt that these barriers made it difficult for them to do so.

I In addition to identifying barriers to culturally appropriate end-of-life care, the Aboriginal family members, nurses, and social workers also identified a number of possible solutions that could serve to reduce or eliminate these barriers. Besides cultural awareness training for health care providers, it is crucial that the quality of relationships developed between individuals and that these relationships be based on basic human values such as respect, kindness, acceptance, honour, courage to share and communication. This communication and cultural understanding are facilitated through respectful relationships. Moreover, as addressed previously, there is an important relational aspect inherent in the concept of culture itself. It seems clear through the experiences expressed by Aboriginal families, nurses, and social workers that one of the most important solutions to barriers to culturally appropriate end-of-life care is the availability of resources to support bridge the two different cultures. An essential, common need that was identified through these focus groups for culturally appropriate end-of-life care was the need for a frontline Aboriginal support person, such as an Elder in residence or Aboriginal social workers or counsellors. This support would be available to: 1) facilitate cross-cultural communication between health care providers and families, 2) help educate health care providers about cultural issues, 3) provide aftercare and continuity of care for families, and 4) provide families with spiritual support.

A Additionally, there is a clear need for more facility space and resources specifically designed to facilitate culturally appropriate end-of-life care for Aboriginal families. Although the need for more culturally appropriate resources is often identified in the literature, there remains a current lack of description as to how this space would look or be used. As part of this overall research project aimed at exploring pathways to culturally appropriate end-of-life care for Aboriginal families, the research team worked with Aboriginal and non-Aboriginal health care providers and Aboriginal Elders to create a logic model to inform the development of an Aboriginal component of the Bereavement Centre in Regina, Saskatchewan (Hampton, Baydala, McKay-McNabb, Nutini, Lynn, & Drost, 2008). Logic models serve as a framework for the planning, implementation and evaluation of new programs and address specific categories such as program goals, population of interest, short and long term objectives, short and long term indicators, strategies, activities, process indicators, and available resources. We used the logic model format to address specific needs for the development of an Aboriginal component of the Bereavement Centre that would be useful to community members and would provide culturally appropriate care. This project was part of our research team's vision to help provide solutions for facilitating culturally appropriate end-of-life for Aboriginal families

Another important solution to overcoming barriers to culturally appropriate end of life care is the development of specific health care policies that accommodate the holistic needs of Aboriginal families. These policies need to be flexible in order to allow cultural practices to occur in health care settings. Additionally, efforts need to be made to make families aware of where culturally appropriate services are available, which can be addressed through networking families and community services.

Increased cultural awareness amongst health care providers was also indentified as an important need. In order to facilitate sensitivity amongst health care providers to issues of culture, our research team produced two videos in which Aboriginal Elders and community members spoke about their experiences and regarding needs at the end-of-life. One video was produced for Aboriginal families (Hampton, Baydala, Bourassa, McNabb, Placsko, Goodwill, & McKenna, 2006) and another video was produced to target health care providers in order to facilitate increased understanding of cultural differences (Hampton, Baydala, Bourassa, McNabb, Placsko, & Goodwill, 2005). Our research team is also in the process of developing several new videos that address cultural diversity and target specific audiences such as students in the health sciences, for Aboriginal children who have experienced the loss of a caregiver, as well as addressing issues of multiple losses and complicated grief.

Conclusion

Through the inclusion of front-line Aboriginal support workers, cross-cultural awareness training for health care providers, and policy and resources aimed directly at facilitating culturally appropriate end of life care, Aboriginal culture would be more fully integrated into community health services (i.e., emergency medical care, palliative care, grief support, mental health services, etc.). It is clear that there are many benefits to the convergence of culture and community, such as increased utilization of necessary health care. As Kleinman and Benson (2006) state, “Cultural factors are crucial to diagnosis, treatment, and care. They shape health-related beliefs, behaviors, and values.” (p. 1673)

Our research aims to bridge the cultures of the university, the culture of Westernized health care, and Aboriginal cultures, in order to identify Aboriginal families’ needs for end-of-life care as well as for health care providers’ needs for providing culturally appropriate end-of-life care. In order to produce respectful research, it was important to approach the research from a place of care. This required developing trust and building relationships with community members, a process that requires respect, patience, and time. As identified previously, an important component of culture is shared meanings and traditions between people relating to one another in every day life. Thus, in order to ensure that research progressed in a respectful and culturally appropriate manner we sought to come together with community members to share experiences (e.g. gathering together, eating together, talking together) and to create mutual understandings. It is only through this forging of relationships that we can work towards the bridging of cultures within communities, a process necessary for eliminating current barriers to culturally appropriate end-of-life care for Aboriginal families.

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