

## End-of-life issues for aboriginal patients

### *A literature review*

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#### ABSTRACT

**OBJECTIVE** To understand some of the cross-cultural issues in providing palliative care to aboriginal patients.

**SOURCES OF INFORMATION** MEDLINE (1966 to 2005), CINAHL, PsycINFO, Google Scholar, and the Aboriginal Health Collection at the University of Manitoba were searched. Studies were selected based on their focus on both general cross-cultural caregiving and, in particular, end-of-life decision making and treatment. Only 39 relevant articles were found, half of which were opinion pieces by experienced nonaboriginal professionals; 14 were qualitative research projects from nursing and anthropologic perspectives.

**MAIN MESSAGE** All patients are unique. Some cultural differences might arise when providing palliative care to aboriginal patients, who value individual respect along with family and community. Involvement of family and community members in decision making around end-of-life issues is common. Aboriginal cultures often have different approaches to telling bad news and maintaining hope for patients. Use of interpreters and various communication styles add to the challenge.

**CONCLUSION** Cultural differences exist between medical caregivers and aboriginal patients. These include different assumptions and expectations about how communication should occur, who should be involved, and the pace of decision making. Aboriginal patients might value indirect communication, use of silence, and sharing information and decision making with family and community members.

#### RÉSUMÉ

**OBJECTIF** Tenir compte des questions interculturelles dans la prestation de soins palliatifs aux patients autochtones.

**SOURCES DE L'INFORMATION** On a consulté MEDLINE (1966 à 2005), CINAHL, PsycINFO, Google Scholar et l'Aboriginal Health Collection de l'Université du Manitoba. On a conservé les études qui portaient sur les soins de santé interculturels généraux et plus particulièrement sur la prise de décision et les traitements en fin de vie. On a repéré seulement 39 études pertinentes, dont la moitié étaient des opinions anecdotiques de professionnels chevronnés non autochtones; 14 étaient des études expérimentales qualitatives du point de vue de l'anthropologie et des soins infirmiers.

**PRINCIPAL MESSAGE** Chaque patient est unique. Certaines différences culturelles risquent d'apparaître lorsqu'on dispense des soins palliatifs à des patients autochtones pour qui la famille, la communauté et le respect de l'individu sont des valeurs importantes. Il est fréquent que la famille et la communauté participent aux prises de décision pour les questions portant sur la fin de vie et les cultures autochtones ont souvent des approches différentes pour communiquer les mauvaises nouvelles et maintenir l'espoir chez les patients. L'utilisation d'interprètes et de modes de communication variés ajoute au défi.

**CONCLUSION** Des différences culturelles existent entre le personnel soignant et les patients autochtones. Mentionnons, entre autres, des croyances et attentes différentes sur la façon de communiquer et ceux qui devraient y participer et sur le rythme de la prise de décision. Le patient autochtones pourrait préférer communiquer indirectement, recourir au silence et partager information et prise de décision avec la famille et les membres de la communauté.

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Terminally ill patients and their family members face difficult decisions. When medical staff members are not of the same cultural background as the patient, communication and decision making take on new challenges.<sup>1</sup> This review was undertaken to see how the published literature could inform care delivery for dying aboriginal patients.

### Data sources

MEDLINE (1966 to 2005), CINAHL, PsycINFO, and Google Scholar were searched using various MeSH headings, including *American Indians; communication barriers; traditional medicine; health knowledge, attitudes, practice; terminally ill; right to die; palliative care; decision making; informed consent; advance directives; and organ transplantation*. The Aboriginal Health Collection at the University of Manitoba Library was also searched.

### Study selection

Three hundred articles were identified in the search. Most of the articles dealt with specific medical problems (eg, diabetes, tuberculosis, HIV), rather than end-of-life issues. Only 39 articles focused on death and dying or relevant cross-cultural medical caregiving.

The studies reviewed varied in size from fewer than 10 subjects to large population surveys. Of the 39 articles used, 15 were review or opinion pieces, and 14 were qualitative studies using interviews or focus groups. Three quantitative studies used observed interactions or surveys. Population surveys included the 1991 Aboriginal Peoples Survey (N=25 122) and the 2003 Ontario First Nations Regional Health Survey (N=1094). Article characteristics are outlined in **Table 1**.<sup>1-39</sup>

Most papers were written by nonaboriginal authors exploring various aspects of aboriginal beliefs. Relevant papers covered several of the following topics: palliative care and barriers to such care, end-of-life decision making, coping with death in the family or community, organ and tissue donation, and modern and traditional aboriginal health and healing.

### Levels of evidence

**Level I:** At least one properly conducted randomized controlled trial, systematic review, or meta-analysis

**Level II:** Other comparison trials, non-randomized, cohort, case-control, or epidemiologic studies, and preferably more than one study

**Level III:** Expert opinion or consensus statements

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Most research studies were qualitative. Salvalaggio et al and Macaulay suggest that community-based qualitative methodology might be the most appropriate cross-cultural methodology.<sup>23,33,34</sup>

### Synthesis

Many traditional aboriginal perspectives differ from the viewpoints of other Canadians.<sup>27</sup> Authors encountered various attitudes when studying end-of-life issues, demonstrating the variety of beliefs within aboriginal communities. Ellerby et al noted that some aboriginal patients valued the “maintenance of quality of life rather than the exclusive pursuit of a cure” and emphasized that “life is to be preserved and should be pursued whenever meaningful quality can be maintained.”<sup>8</sup> In contrast, Molzahn et al documented that some aboriginal patients believe medical intervention should be minimal and that the Creator determines the time of death.<sup>27</sup> Diversity of beliefs might vary between and within aboriginal communities, owing to differences of “traditional, acculturated or religious perspectives.”<sup>39</sup> While generalizations are often inappropriate, some common themes documented below might be reflected in end-of-life issues.<sup>20,27</sup>

**Respect.** Several commentators identified the importance of family, community, and respectful interpersonal relationships to aboriginal culture.<sup>3,8,13,16</sup> Browne’s in-depth interviews of 5 Cree-Ojibway key informants from northern Manitoba found that actively listening and accepting others’ decisions were important for successful interpersonal relationships.<sup>4</sup> Brant, a Mohawk psychiatrist, identified the concept of non-interference in his opinion article.<sup>3</sup> He suggested that many aboriginals believe that all people are entitled to make their own decisions. This high degree of respect for personal independence means that advising, persuading, or instructing is “undesirable behaviour.”<sup>3</sup>

Elders might be participants in decision making, as they are highly respected in aboriginal communities. They are valued for their wisdom and experience<sup>3</sup> and might be quite knowledgeable about medicinal herbs and spiritual matters.<sup>32</sup> This respect for elders and healers can lead aboriginal patients to accept medical advice from physicians without question, out of respect for their parallel role as healer.<sup>3</sup>

**Traditional perspectives.** Traditional medicine is often assumed to refer to land-based medicines and plants. Hart-Wasekeesikaw, an aboriginal nurse who did a qualitative research study involving interviews with 42 aboriginal patients, suggests it is probably best understood as a set of assumptions concerning the holistic nature of a person.<sup>10</sup> Both physical and emotional health are seen to stem from balance between the mind, the body, and the spirit, as well as strong interpersonal

**Table 1. Articles focusing on end-of-life issues\***

AUTHOR (YEAR)	NO. OF PARTICIPANTS (N)	TYPE OF STUDY	LEVEL OF EVIDENCE	COMMENTS
Benoit et al <sup>2</sup> (2003)	61	Qualitative	II	Focus groups and interviews, Vancouver, BC
Brant <sup>3</sup> (1990)	—	Opinion	—	Overview, Mohawk psychiatrist
Browne <sup>4</sup> (1995)	5	Qualitative	II	Interviews regarding respect, Cree-Ojibway, MB
Browne and Shultis <sup>5</sup> (1995)	15 reserves	Survey	II	Matched aboriginal and nonaboriginal communities regarding services, ON
Callender et al <sup>6</sup> (1997)	40	Qualitative	II	Organ donation, US minorities
Cree Regional Child and Family Services Committee <sup>7</sup> (2000)	—	Participatory research	—	Participatory research, Cree, QC
Ellerby et al <sup>8</sup> (2000)	—	Review	III	Discusses aboriginal values, Ojibway
Garro <sup>9</sup> (1990)	121	Qualitative	II	Ethnographic field work, Anishinaabe, MB
Hart-Wasekeesikaw <sup>10</sup> (1996)	47	Qualitative	II	Ethnographic interviews with cancer patients and their families, MB
Health Canada <sup>11</sup> (2000)	—	Opinion	—	General overview
Hepburn and Reed <sup>12</sup> (1995)	—	Opinion	—	Palliative decision making, United States
Hotson et al <sup>13</sup> (2004)	44	Qualitative	II	Patients and medical personnel, MB
IMPACT <sup>14</sup> (2005)	—	Statistics	II	Death and injury, motor vehicle accident statistics, ON
Iwasaki et al <sup>15</sup> (2005)	26	Qualitative	II	Focus groups, aboriginal and Métis, MB
Jennings <sup>16</sup> (1994)	—	Opinion	III	Discussion of patient autonomy, United States
Kaufert and O'Neil <sup>17</sup> (1989)	—	Qualitative	II	Dying patients in MB and Inuit in NWT
Kaufert and O'Neil <sup>18</sup> (1989)	25	Qualitative	II	Field observation of inpatients regarding giving consent, MB
Kaufert et al <sup>19</sup> (1998)	12	Qualitative	II	Observed conflict behaviour and interviews, MB
Kaufert et al <sup>20</sup> (1999)	12	Qualitative	II	Observation and interviews, Ojibway, Cree, Island Lake
Kaufert <sup>21</sup> (1999)	40	Qualitative	II	Interviews with patients and family about cancer care, MB
Kelly and Brown <sup>22</sup> (2002)	10	Qualitative	II	Grounded-theory interviews of physicians, Canada
Kelly and O'Driscoll <sup>1</sup> (2004)	—	Opinion	III	Clinical palliative care issues
Macaulay <sup>23</sup> (1994)	—	Opinion	III	Ethics guidelines
MacKinnon <sup>24</sup> (2005)	—	Review	—	Political review Romanow
MacMillan et al <sup>25</sup> (2003)	1094	Survey	II	Ontario First Nations Regional Health Survey
McQuay <sup>26</sup> (1995)	—	Opinion	—	Organ donation review, United States
Molzahn et al <sup>27</sup> (2004)	14	Qualitative	II	In-depth interviews, Coast Salish, BC
Newbold <sup>28</sup> (1999)	25 000	Survey	II	Analysis of 1991 Aboriginal Peoples Survey regarding disability care
Paniagua <sup>29</sup> (1994)	—	Opinion	III	Communication guidelines, United States
Preston and Preston <sup>30</sup> (1991)	—	Qualitative	II	25 yrs of ethnography James Bay Cree, QC
Prince and Kelley <sup>31</sup> (2006)	216	Survey and nested qualitative	II	13 northwestern ON communities
Reynolds-Turton <sup>32</sup> (1997)	100	Qualitative	II	Foundational inquiry, US Ojibway and Chippewa
Royal Commission on Aboriginal Peoples <sup>33</sup> (1996)	—	Report	III	Government of Canada report
Salvalaggio et al <sup>34</sup> (2003)	12	Qualitative	II	Interviews with aboriginal patients, Anishinaabe, ON
Sarsfield et al <sup>35</sup> (1988)	—	Opinion	—	Role of community health representatives, MB
Schaeffer et al <sup>36</sup> (1998)	495	Retrospective	II	Organ donation demographics, United States

Table 1 continued...

AUTHOR (YEAR)	NO. OF PARTICIPANTS (N)	TYPE OF STUDY	EVEL OF EVIDENCE	COMMENTS
Smylie et al <sup>37</sup> (2000)	—	Policy statement	III	Society of Obstetricians and Gynaecologists of Canada policy statement
Verble et al <sup>38</sup> (2002)	323	Qualitative	II	Focus groups about organ donation, United States
Westlake Van Winkle <sup>39</sup> (2000)	—	Review	III	American and Alaskan literature review

\*Blank cells indicate that information was not available or not applicable.

relationships.<sup>8,15,24,32</sup> This holistic view means that modern healing practices that focus purely on physical problems are often not immediately accepted by aboriginal patients, particularly elders. They might prefer to be treated by traditional healers, using healing circles, sweet grass, or other spiritual methods. Patients might also wish to involve elders in their care and treatment decisions.<sup>2,8,37</sup> Kaufert and colleagues suggest that access to a traditional healer in a modern hospital is similar to access to a hospital chaplain.<sup>20</sup>

Garro encountered an aboriginal perspective that differentiates between “Anishinaabe sickness” and “white man’s sickness.”<sup>9</sup> Anishinaabe sicknesses can be caused by such things as “onjine” (bad behaviour) or bad medicine, and can only be cured by medicine men, not by modern doctors. White man’s sicknesses, which did not exist until the Anishinaabe people were exposed to white men, require a physician who might be more adept at these treatments.<sup>19</sup>

Not all aboriginal patients want traditional healing.<sup>11,22</sup> During the 44 interviews conducted by Hotson et al in northern Manitoba, “most community informants... did not identify the need for any ‘traditional’ services for those who are dying.”<sup>13</sup> This topic therefore needs to be cautiously explored with aboriginal families, as those from a Christian tradition might take offence.<sup>34</sup>

**Truth-telling.** Jennings, McQuay, Ellerby et al, and Kaufert et al all discuss the concepts of truth-telling and maintenance of hope.<sup>8,16,19,20,26</sup> Relatives of a terminally ill aboriginal patient might not want their loved one to know the seriousness of the medical condition, as positive thinking is thought to promote health. Discussing terminal illnesses or death can cause the patient to die more quickly. For this reason, some aboriginal patients might accept “uncertainty in prognosis or disease progression” more easily than nonaboriginal patients.<sup>8</sup> Ellerby et al and Kaufert et al cite instances where this focus on hope led relatives to protect their sick loved ones by acting as proxy decision makers or by discouraging physicians or interpreters from delivering bad news.<sup>8,19,20</sup>

**Use of interpreters.** Some aboriginal people do not speak English and rely on interpreters in their health care. In 3 studies using observed interactions with follow-up

interviews, Kaufert and colleagues discussed the particular skills interpreters should have.<sup>19,20,21</sup> Owing to differences in values and beliefs surrounding medical care, interpreters require good understanding of patients’ cultures as well as their languages. Kaufert et al and Smylie et al explain the disadvantage of using a family member as an interpreter, despite the apparent convenience.<sup>19,21,37</sup> Individual privacy concerns and end-of-life values might conflict between the patients and their family members. This can lead family member–interpreters to consciously or unconsciously alter the doctor’s message in order to deliver a message that they think their loved one would want to hear.<sup>19,21,37</sup> In addition to invaluable cultural and language interpretation, experienced nonfamily interpreters might have links to traditional healers and other services of interest to patients or their families.<sup>17</sup>

**Trust.** Benoit and colleagues studied 36 aboriginal women living in Vancouver, BC, using participant observation, focus groups, and follow-up interviews.<sup>2</sup> The women liked the informal nature of the services at their urban health centre. They preferred aboriginal staff and wanted more information available in areas of parenting and coping with family illness. They liked the fact that they did not have to give any personal medical information on their first visit. Once they had built trust with the staff, nurses, and physicians, then they could address their specific medical concerns.<sup>8</sup> Kelly and Brown also found this importance of trust in their interviews with 10 Canadian physicians working with aboriginal patients.<sup>22</sup> They learned that it often took years of working in the same community before patients really started to open up and discuss issues.

Similar comments were made in northern Quebec by women involved in a diabetes education program.<sup>7</sup> They thought the group of researchers should have had more understanding of their Cree community before coming to teach them about gestational diabetes. They also thought more local people could have been involved in organizing the project.<sup>7</sup>

**End-of-life decision making.** Many authors said aboriginal patients strongly preferred immediate and extended family members to be involved in medical decision making.<sup>8,13,16,19,20,39</sup> Reviews by Ellerby et al, Brant, Kaufert et al, and Jennings, as well as interviews by Hotson et al

and Kelly and Brown, all demonstrated the centrality of family and community.<sup>3,8,13,16,19,20,22</sup> When it comes to end-of-life decision making, family members of many aboriginal patients attempt to balance keeping their loved ones informed with still allowing them to maintain hope.<sup>20,21</sup>

Several authors mentioned the difficulty obtaining advance directives from aboriginal patients.<sup>12,39</sup> The formal structured approach used by many hospitals might be ineffective with aboriginal patients.<sup>12,18</sup> Hepburn and Reed, as well as Westlake Van Winkle, recommend trying to determine patients' wishes in a less formal manner.<sup>12,39</sup>

Kaufert et al and Kelly and Brown also suggested that language barriers, as well as cultural differences in behaviour, might impede a physician's ability to assess the patient's mental competence to make informed decisions.<sup>20,22</sup>

**Family caregiving.** Newbold reviewed the Aboriginal Peoples Survey of 1991 (N=25 122) and learned that family or friends often care for disabled aboriginal patients, instead of involving external agencies.<sup>28</sup> This might be due to the geographic remoteness of patients, financial barriers, or the personal importance of family. MacMillan et al had similar findings in 2003, analyzing the Ontario First Nations Regional Health Survey (N=1094) compared with the National Population Health Survey (N=4840).<sup>25</sup> It is difficult to tell if this caregiving by family members is by choice or out of necessity.<sup>25</sup> Most aboriginal patients would like to die at home<sup>13</sup> but do not.<sup>31</sup> Aboriginal northern Ontario community members (N=216) cited inadequate resources, training, and time as contributing factors.<sup>31</sup> Aboriginal patients in remote communities more commonly interact with nurses, social workers, and alternative health care providers than they do with family doctors. Aboriginal patients might, therefore, be more comfortable with nonphysician care providers.

**Family involvement with the death of the patient.** In the event patients are incapable of making their final wishes known and a substitute decision maker has not been appointed, health care providers might have to determine which family member acts as spokesperson. Hepburn and Reed found that a spokesperson often emerges without any formal intervention by caregivers.<sup>12</sup>

Some aboriginal people see death as a necessary part of the life cycle and are quite accepting.<sup>12,39</sup> Terminally ill patients might feel that it is very important to say goodbye to loved ones before they pass away.<sup>31</sup> This might relate to their belief in an afterlife and the importance of maintaining relationships with loved ones upon entering the spirit world.<sup>18,30</sup>

Once an aboriginal patient has passed away, there might be additional local cultural considerations. In

aboriginal communities, news that someone has died is usually told simply, directly, and promptly.<sup>30</sup> Views on the handling of the body vary by community and family. The review by Smylie et al presents several belief systems.<sup>37</sup> It might be important for family and community members to be present at the time of death. The patient or family might request that the death take place in the home community. If this is not possible, the family might request to have the body returned to the community soon afterward. The family might ask to be directly involved in the preparation of the body, and some traditions even require that the body not be left alone until after burial or that the body be buried within 24 hours of death.<sup>26,37</sup>

**The process of dying.** Many traditional aboriginal cultures consider death to be very natural. For many aboriginal people, a "good death" is one where they meet death with dignity and composure.<sup>31</sup> Dying this way implies a further experience of an afterlife.<sup>11</sup> Focus groups in 10 northern Ontario communities further defined a "good death" as "during sleep, without pain, in a patient who had received proper care."<sup>31</sup>

There are several accounts of aboriginal patients seeming to know when they will die. This can allow them to prepare themselves both physically and spiritually. Some people die while dressed in particular clothing which family members believe were specifically worn as preparation for their journey. This knowledge allows them to say goodbye to their loved ones, thereby maintaining their important positive relationships.<sup>30</sup>

Most authors point out that dying is a uniquely individual process, and care must be taken to ensure sensitivity toward the specific patient's wishes.

**Organ donation.** Molzahn and associates conducted interviews with 14 members of the Coast Salish people in British Columbia regarding organ donation. They encountered a belief in the existence of spirits within each person: when aboriginal people die, they should be buried with a complete body and soul so that they are prepared for their next life.<sup>27</sup> This concept was also discussed by Kaufert et al in their reviews, and by Verble et al in their study of data collected from routine organ donation meetings (N=323).<sup>18,20,38</sup> Molzahn et al also discussed the concept of spirit transfer: some of the participants believed that part of a donor's spirit might be transferred to the recipient during an organ transplantation.<sup>27</sup>

These body-wholeness and spirit-transfer values might be issues for aboriginal patients contemplating organ donation. Molzahn et al mentioned the large number of aboriginal people awaiting transplantation and the low donation rate. The need for an intact body and complete spirit at burial might be met by performing a cleansing ceremony before the procedure.<sup>27</sup>

Injury is the leading cause of death for aboriginal people, most from motor vehicle accidents.<sup>14</sup> Evidence from United States general population shows that minority ethnicity lowers donation rates across many cultures.<sup>36</sup> Molzahn et al pointed out that many aboriginal people do support organ donation but lack relevant information.<sup>27</sup> In the United States, Callender and colleagues found that a community-based minority research program in Washington, DC, increased organ donation rates over a 17-year period, addressing awareness and “ethnically similar messengers” with “culturally sensitive messages.”<sup>6</sup> Even among the 14 interview participants of Molzahn and colleagues, there was considerable diversity of beliefs, and the authors acknowledged the paucity of Canadian research on barriers to and beliefs about organ donation in aboriginal communities.<sup>27</sup>

**Grieving.** The concept of grieving parallels culturally appropriate care. Aboriginal people express their grief in various ways. Some aboriginal cultures view outward expressions of emotion as inappropriate,<sup>20</sup> and the apparent grieving period is often quite short.<sup>30</sup> Some families hold sharing circles or other ceremonies to help with their emotional pain.<sup>20</sup> A traditional healer is sometimes consulted to help bereaved families spiritually.<sup>26</sup> Additional customs sometimes take place during the year following the death of a family member.<sup>11,30</sup>

**Complications and barriers.** Hotson et al interviewed 44 key informants including community residents, elders, northern physicians, and nurses.<sup>13</sup> They identified some of the challenges to providing a high level of health care: geographic isolation, language barriers, and financial barriers. The remote nature of many reserves means less access to medical procedures and professionals, lack of inpatient facilities, lack of permanent nursing staff, and difficulty accessing medications.<sup>13</sup> Physician turnover and inexperience can also play a role.<sup>28,35</sup> Brown and Shultis found that nonaboriginal communities had more health care services than aboriginal communities of similar size and geographic remoteness.<sup>5</sup>

Physical distance might force patients to leave their families and communities and go to larger cities for medical treatment. Hospitalized patients often feel isolated and lonely without these supports,<sup>8,17,34</sup> compounded by the unfamiliar atmosphere of a distant hospital.<sup>17</sup> One author wondered if a history of “inadequate health care and broken treaties” might contribute to an undercurrent of suspicion of Western caregivers.<sup>39</sup> Doctors’ and aboriginal patients’ communication styles often differ. Aboriginal patients might be comfortable with more silence than Western caregivers are.<sup>11,22,29</sup>

### Discussion

This small literature set gave a consistent, incomplete picture of issues that can arise in dealing with end-of-life

#### EDITOR'S KEY POINTS

- Many aspects of traditional aboriginal perspectives differ from the views of other Canadians. These perspectives might affect decision making and provision of palliative care.
- It is important to note that beliefs regarding end-of-life issues vary within aboriginal communities. The authors caution that the process of dying is uniquely individual. Care must be taken to ensure sensitivity toward patients' specific wishes.

#### POINTS DE REPÈRE DU RÉDACTEUR

- Les façons de voir traditionnelles des Autochtones diffèrent de celles des autres Canadiens à plusieurs égards, ce qui est susceptible d'influencer la prise de décision et la prestation des soins palliatifs.
- Il importe de noter que les croyances concernant les questions de fin de vie diffèrent d'une communauté autochtone à une autre. Les auteurs rappellent que le processus de mourir est éminemment individuel. On doit être particulièrement attentif aux attentes spécifiques des patients.

care for aboriginal patients and their families. Recurrent themes include the creative tension between individual care decisions and family and community values, the mind-body holistic conceptual framework, and geographic isolation and its effects on medical resources.

These themes have implications for communication issues: style and pace of discussions, use of interpreters, and involvement of family and possibly other community members. Cultural beliefs of respect, trust, and spirituality can also factor into end-of-life discussions.

Several electronic and library databases were accessed to find the studies considered in this review. Other excellent small research projects might not have been catalogued and were therefore not reviewed.

This literature review has been a useful starting point for development of a community-based research project in northwest Ontario in partnership with an aboriginal research institute. We hope to explore some of the issues identified in the literature and see how they apply in our region. This could inform development of culturally appropriate tools for stating end-of-life preferences, patient transfer to medical facilities, level of investigations and care, and organ donation. Community-based regional research might remove some barriers to effective communication about these important end-of-life issues.

### Conclusion

Aboriginal patient care might involve unspoken beliefs about end-of-life issues typically unexplored by physicians. These discussions can involve interpreters, family, and other key community members. Family members

as interpreters might not be the best choice in these situations. The interplay of patients' individuality and of community and family concerns presents challenges for caregivers. Generalities might be useful to inform physicians of the potential scope of individual variation in end-of-life discussions, but each patient and family needs to be addressed individually. ❁

### Contributors

**Dr Kelly and Ms Minty contributed to concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.**

### Competing interests

None declared

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