

Résumé

Croyances autochtones et dons d'organes : Points de vue de certains Salish du littoral

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De très nombreux autochtones sont en attente d'une transplantation et l'on a constaté chez les peuples autochtones une réticence à accepter le prélèvement d'organe. Cette étude explore les valeurs et les croyances liées au don d'organes chez les Salish du littoral qui vivent en Colombie-Britannique, au Canada. Des entrevues ont été menées auprès de 14 personnes (8 femmes et 6 hommes) dont l'âge variait de 25 à 63 ans. Les sujets contextuels abordés étaient : le manque de confiance, la vie dans les communautés autochtones et les tensions entre les positions contemporaines et traditionnelles. Les sujets relatifs à la mort étaient : l'acceptation du destin, les habitudes et rituels liés à la mort et la plénitude du corps. Les sujets relatifs au don d'organes étaient : l'attitude voulant que « l'on n'en parle pas », le voyage de l'esprit, et l'entraide. Il y avait une grande diversité de croyances parmi les participants, ce qui montre que les croyances d'un Autochtone ne reflètent pas nécessairement celles d'une communauté autochtone en particulier.

Mots clés : don d'organe, transplantation, croyances ethnoculturelles, culture

Aboriginal Beliefs About Organ Donation: Some Coast Salish Viewpoints

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A large number of Aboriginal people await transplantation, and reluctance to donate organs has been noted among Aboriginal people. The purpose of this study was to explore the values and beliefs regarding organ donation of Coast Salish people living in British Columbia, Canada. Interviews were held with 14 people (8 women and 6 men) ranging in age from 25 to 63 years. Contextual themes were: lack of trust, life in Aboriginal communities, and tension between contemporary and traditional perspectives. Themes pertaining to death and dying were: acceptance of fate, death routines/rituals, and body wholeness. Themes pertaining to organ donation were: “we don’t talk about it,” transfer of spirit, and helping others. There was considerable diversity in beliefs among participants, which suggests that the beliefs held by an individual Aboriginal person should not be assumed to reflect those of any specific Aboriginal community.

Keywords: organ donation, transplantation, ethnocultural beliefs, culture

While transplantation is not always viewed positively, and some people have concerns about disproportionate allocation of scarce health-care resources to the procedure, research shows that transplantation improves the quality of life of many individuals with end-stage organ failure (Molzahn, 1991). A shortage of organs means that many people die waiting for transplantation and that many people wait a number of years while using costly and less effective medical therapies such as dialysis.

Members of Aboriginal and other non-white ethnocultural communities tend to wait significantly longer for transplants than their white counterparts. Some of the difference in waiting times has been attributed to biological differences in tissue types and blood groups that make it more difficult to find a suitable donor in some ethnic groups than in others (Plawecki, Freiberg, & Plawecki, 1989; Verble et al., 2002). A scarcity of donors from Aboriginal communities contributes to longer waiting times for this population.

In Canada, approximately 4% of the population is identified as Aboriginal; nearly one million people in Canada self-identified with one or more Aboriginal groups in the 2001 Census (Statistics Canada, 2004).

Aboriginal communities are quite diverse. Because of the different traditions and spiritual beliefs among various Native groups, we decided to focus on one First Nation, the Coast Salish people who inhabit the southern part of Vancouver Island and the west coast of the Lower Mainland.

The Coast Salish Nation is geographically located in western British Columbia, Canada, and the northwestern United States. The term Coast Salish is used to describe a number of peoples, including Klahoose, Homalco, Sliammon, Sechelth, Squamish, Halq'emeylem, Ostlq'emeylem, Hul'qumi'num, Pentlatch, and Straits. Each of these communities consists of several bands (Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000).

Although there have been some American and British studies on ethnocultural barriers to organ donation, there has been no Canadian research in this area. It is an area that is particularly important for nurses, who are frequently in a position to discuss the possibility of organ donation with families. Knowledge of values and beliefs regarding organ donation can be helpful to nurses and physicians in raising the topic with families in culturally appropriate ways.

The objective of this study was to explore the values and beliefs of Coast Salish people regarding organ donation.

Literature Review

The number of organs available for transplantation falls far short of the demand. Numerous reasons have been proposed for the limited number of organ donations from deceased persons, including fewer accidental deaths, public perceptions regarding organ donation, professional attitudes, the knowledge of health professionals regarding organ donation, donor identification and request processes, lack of family consent for organ donation, and ethnocultural considerations (Molzahn, Starzomski, & McCormick, 2003).

Numerous studies have been conducted to examine the factors that influence decisions regarding organ donation. Some of the research pertains to demographic correlates such as age, gender, class, and level of education. Specifically, it has been found that people who sign organ-donor cards tend to be relatively affluent, educated, and young (the 35–44-year-old age group is more likely to donate than both younger and older age groups) (Cleveland & Johnson, 1970; Frauman & Miles, 1987; Gallup Poll, 1993).

Ethnocultural Beliefs About Organ Donation

Most of the literature on organ donation in ethnocultural communities encompasses diverse people who may or may not share values, beliefs,

practices, or traditions. However, there has been little research that captures the diversity of perspectives within and between communities.

Considerable attention has been given to organ donation in the African-American population in the United States (Callender et al., 1991; Callender, Burston, Yeager, & Miles, 1997). A lack of public awareness about transplantation in the black population, distrust of health providers, and religious beliefs have been found to be barriers to organ donation (Plawecki et al., 1989).

There is some reluctance to donate organs upon death in Chinese communities (Evers, Lewis, & Schaeffer, 1999). In Hong Kong, 37% to 83% of respondents to a survey (using hypothetical cases) indicated willingness to donate (Yong, Cheng, & Ho, 2000). Among nurses working in a teaching hospital in Hong Kong, more than half were undecided about their commitment to organ donation (Boey, 2001). Greater receptiveness was found among younger and better-educated respondents (Yong et al.). Younger and unmarried nurses were more likely to commit to posthumous organ donation than older and single nurses (Boey). Individuals were more willing to donate their own kidneys than to allow the organs of a deceased relative to be donated. Half of the Hong Kong respondents over 60 years of age were opposed to donating organs of next of kin (Yong et al.).

Similarly, Lam and McCulloch (2000), in a US study with 122 Chinese-American church attendees, found that only 23% of the participants would be willing to sign an organ donor card and only 4.9% currently carried organ donor cards. While 45.1% said they would donate their organs to strangers, 84.4% would donate to a distant relative and 95.9% would donate to a close relative.

Wheeler, O'Friel, and Cheung (1994) examined barriers to organ donation among Asian Americans. They used focus groups to collect data from Japanese, Chinese, and Filipino participants in Hawaii. Participants expressed the view that a body should remain intact to the grave, as it would reunite with the spirit in the afterlife. Chinese participants believed that the dead should be buried in their finest clothing and jewellery, and that no part of the body should be missing. Filipinos viewed both cremation and organ donation as destruction of the corpse, which was contrary to their cultural beliefs. These Asian Americans were concerned about lack of respect during handling of the body after death, and did not wish to be party to the desecration of a family member's remains (Wheeler & Cheung, 1996).

Religion and Organ Donation

In addition to the cultural influences on beliefs about organ donation, religion may also have an influence. Although leaders of most organized

religions support organ donation (United Network for Organ Sharing [UNOS], 1995), surveys of general populations have found that one in six people report that, for them, religion is a barrier to organ donation (Enviro-nics Research Group, 2001). Buddhists, Muslims, and Hindus are not prohibited from donating organs and most believe that organ donation is a personal decision (UNOS).

Recent studies in the United Kingdom with people of South Asian origin have found that culture and religion play a much smaller part in decisions about organ donation than originally thought. Randhawa (1998) conducted focus groups and individual interviews, and found that participants expressed a desire to be aware of the religious stances so as to make a more informed decision. Similarly, Exley, Sim, Reid, Jackson, and West (1996) found that barriers to transplantation in the Sikh community seemed to have more to do with lack of knowledge about organ donation than with cultural or religious factors.

Organ Donation in Aboriginal Communities

Aboriginal people in Canada show a disproportionately high incidence of end-stage renal disease, with an eight-fold increase in the number of people on dialysis between 1980 and 2000 (Dyck, 2001). Data are not routinely collected regarding the number of Aboriginal people on dialysis or awaiting transplantation, but with the rising prevalence of diabetes and its complications among Aboriginal people the need for transplantation will only continue to increase. Tonelli et al. (2004) found that Aboriginal patients from Alberta, Saskatchewan, and Manitoba were less than half as likely as other patients to receive a renal transplant after commencing dialysis, even after adjustment for diabetes, other comorbid conditions, residence location, and socio-economic status. The reasons for this discrepancy are not clear. While anecdotal reports from Canadian organ-donation programs/transplant services suggest that the rates of organ donation are very low in Canadian Aboriginal populations, further exploration is warranted.

In relation to Aboriginal perceptions about organ donation, Wheeler and Cheung (1996) report that Native American attitudes towards organ donation are generally positive. However, the rate of organ donation is low. Lee (1996) reports that Native Americans donate 10.5 organs per million population, compared to 27.5 for Caucasians. Blagg et al. (1992) found that less than 50% of Northwest Native Americans would consent to organ donation without a clear directive from the deceased. Several reasons were given for reluctance to donate organs, including: never thought about it, didn't know, had concern about donating unhealthy organs, and wanted to maintain the body intact. It was important to members of this group that family be involved in decisions about organ

retrieval (Blagg et al.). As with other groups, Native Americans without a high-school education were less willing to consent to donation than those with a high-school education.

In these communities there may be less concern about living kidney donation than donation from deceased persons. In a study with 846 Native Americans (Danielson, Lapree, Odland, & Steffans, 1998), 81% of respondents indicated that they would be willing to be live kidney donors for family members. The factors influencing their willingness to do so included knowing someone with diabetes, belief that a transplant could offer a normal life, and comfort in donating to someone of their own culture. In contrast, only 54% of respondents indicated that they would be willing to donate upon their death.

In summary, there has been little research pertaining to ethnocultural beliefs about organ donation and no previous Canadian research addressing the perceptions of Aboriginal people pertaining to organ donation. In this study, we undertook to develop some understanding of the values and beliefs of Coast Salish people related to organ donation, in order to generate more questions and eventually equip nurses to provide more appropriate care.

Method/Design

The approach for the study was naturalistic inquiry (Lincoln & Guba, 1985), which is based on an underlying belief that there are multiple perceptions of reality and that individuals construct understandings of reality in interaction with others. Naturalistic inquiry takes place in naturally occurring environments, with no manipulation of individuals or situations.

The research process, including identification of participants, data collection, and data analysis, was guided by the input of an Aboriginal advisory committee consisting of three Aboriginal leaders familiar with research issues. They included a former Coast Salish chief with graduate education, an Aboriginal physician practising in the region, and a scholar in Native studies. They advised on matters such as selection of participants, appropriateness of the questions, strategies for eliciting the maximum amount of information, data analysis, and validation of the findings.

Sample

Purposive sampling was used to obtain a sample. The sample consisted of adults who were identified as willing and able to express their values and beliefs about organ donation, able to speak English, and willing to participate in the study. Snowball sampling, whereby one participant or

contact person is asked to identify others who have an understanding of or interest in the topic, was also used. The research team received suggestions from members of the advisory committee regarding potential informants. The coordinator then approached these individuals and also asked them about other people knowledgeable about the topic. The coordinator also used his contacts in the Aboriginal community to locate participants.

A total of 14 individuals participated. Approximately five other people who were asked to participate declined because they did not wish to discuss the topic. Eight of the participants were women and six were men. They ranged in age from 25 to 63 years, with a mean age of 39.1 years. Six of the participants lived off-reserve. A variety of occupations and socio-economic levels were represented. One person was disabled. In terms of occupation, they ranged from students to lawyers to band leaders. Participants came from at least seven different Coast Salish bands.

Data Collection

The individual interviews were conducted at a time and location convenient for the participant and for the research coordinator. The research coordinator was a male Aboriginal graduate student. He conducted all the interviews and participated in data analysis. Each participant was interviewed at least once. The interviews lasted approximately 60 to 90 minutes. They began with broad general questions regarding experience with the health-care system and then became more focused (see Table 1 for guiding questions). This approach was taken because organ donation was deemed to be a sensitive topic and we wanted to start with a neutral question. All interviews were audiotaped and transcribed. Follow-up interviews were held with two participants, who reviewed the transcripts and themes that emerged from the data.

Data Analysis

A constant comparative method of data analysis was used (Glaser & Strauss, 1967), with each piece of data being compared with every other piece in a search for similarities and differences. Since the approach used was naturalistic inquiry (rather than grounded theory), no attempt was made to develop a theory or relate themes to one another. The data from each interview were reviewed and the investigators examined the data for themes or categories. Saturation was reached after approximately 10 interviews.

Coding of transcripts and data analysis were facilitated by use of the N5 software package. All co-investigators and the research coordinator participated in the data analysis. Summaries of findings were reviewed with members of the advisory committee and minor clarifications made

Table 1 *Guiding Questions*

Can you tell me a bit about some of your experiences interacting with health-care professionals and the health-care system?
Do you or have you known anyone waiting for an organ transplant?
Can you tell me about your general reaction to transplantation?
Are there any traditional/spiritual/cultural beliefs in the Coast Salish culture about organ donation? Can you tell me about them?
What beliefs or values do most people of your culture hold about organ donation?
Can you tell me how decisions about health-care issues get made in your family?
If a family member indicated that they wanted to be an organ donor, how would you respond? Can you tell me why you have that opinion?
How do you think your beliefs and values about organ donation and transplantation compare to other people in your culture?
Have you ever considered becoming an organ donor? Why or why not?

as a result. As well, themes were reviewed by two participants, who agreed that the findings represented their perceptions. Other participants were not available to review the findings within the time frame requested.

Rigour

The criteria for rigour in qualitative research have been discussed in various ways, using language different from that used in quantitative research. *Credibility* refers to measures that increase the likelihood that credible findings will be produced. In this study, credibility was established by having participants review parts of the data analysis during the research process; two participants and members of the advisory group reviewed and commented on the analysis. *Confirmability* refers to the process of determining the extent to which the description and/or interpretation will serve to illuminate the issue being studied. In this study, participants were asked whether they considered the research analysis to be a true representation of their perceptions and experiences; the participants and advisory committee members agreed that it did. *Auditability* is another hallmark of rigour. In this study, an audit trail (Guba & Lincoln, 1994) was maintained to record the context and background of the study, the rationale for all methodologic decisions, the evolution of the findings, and the researchers' orientation to the problem.

Ethical Considerations

Participation was voluntary and no remuneration was offered. Approval for the study was obtained from the university's Research Ethics Review Committee. Each participant signed a consent form that outlined the purpose of the study and procedures to be used and also assured confidentiality; the participants were told that no individual names would be used in any report on the study and codes would be used as identifiers in the transcripts. Approval was not sought from any band, community, or nation, because we were interested in the perspectives of individual Aboriginal people rather than the official position of any specific community.

Findings

A number of themes emerged relating to two broad categories: importance of context, and values and beliefs.

Importance of Context

Importance of context included life in Aboriginal communities, contemporary and traditional perspectives, and lack of trust. These are each described below.

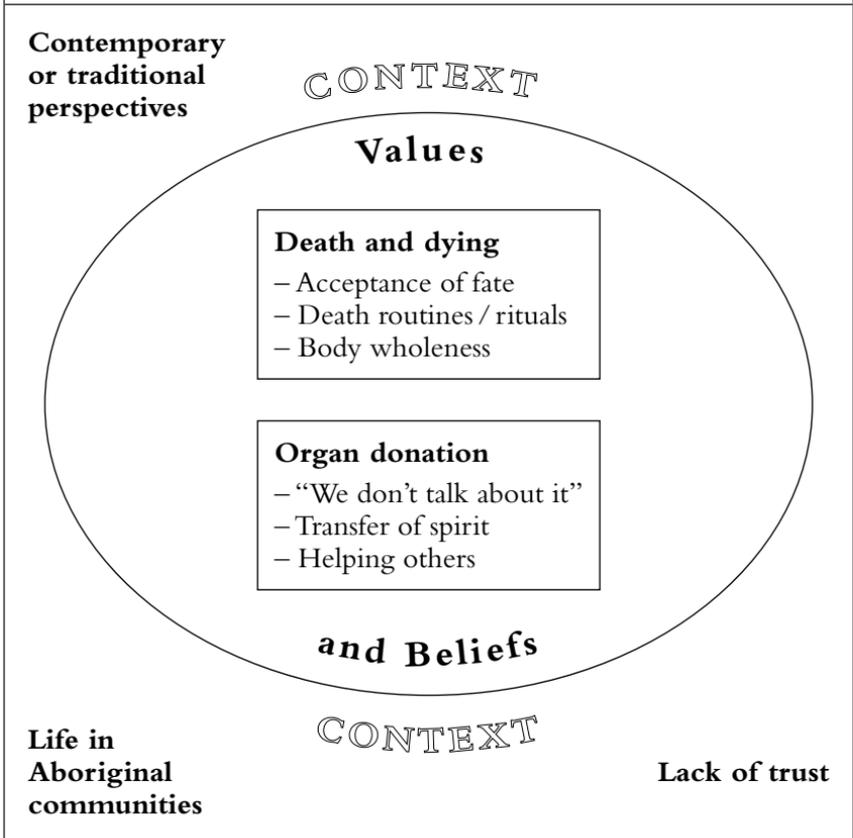
Life in Aboriginal communities. Many participants discussed the context of life in Aboriginal communities in Canada as a backdrop for their responses. For example, one woman who was very supportive of organ donation said:

I think at this point in our lives, in our Native communities, our spirits are in pretty bad shape... You know, if you don't have a good spirit, your body's going to react, you know, your mind and your body reacts to what you're feeling inside.

Frustration with issues pertaining to the jurisdiction over health care between provincial, federal, and First Nations governments was evident. The participants said it was often difficult to obtain necessary medications or other treatment. There were numerous concerns raised about the quality of health services, and numerous examples given of discrimination and racism experienced in the course of accessing health care.

The participants explained that the Coast Salish Nation comprises many communities and perspectives: "each one of our bands, their teachings are different." A woman who had lived in several different communities noted that "in the Chilliwack area," in contrast to other Coast Salish communities, "it's seen as, yeah, if you can help someone out you can do it, and it would be accepted." Similarly, it was reported that means of communicating about organ donation would vary from one commu-

Figure 1 *Themes Arising from Research*



nity to the next. It was also noted that family routines or protocols contributed significantly to values and beliefs. One participant said: "Family law...that's the basis of everything...that's traditional law." Hence, the context for the findings was not only structural and political issues in Canada but also specific differences among Coast Salish communities and families.

As a relatively new technology, organ donation and transplantation had not received a great deal of attention by the participants. None were familiar with British Columbia's organ donor registry. One participant noted that the communities were not accustomed to considering complex scientific issues such as organ donation and transplantation. Nevertheless, there may have been more awareness about it in the region where the study was undertaken than in other Aboriginal communities, because a Coast Salish athlete had developed lymphoma requiring a bone

marrow transplant. This had resulted in numerous community meetings and much media attention. The case of this young man, who subsequently died, certainly raised awareness about the need for bone marrow, and possibly transplantation more generally.

Contemporary and traditional perspectives. While most of the participants spoke of organ donation as a matter of personal choice, some framed the issue in terms of contemporary as opposed to traditional thinking. The participants frequently commented that young adults were likely to feel positively about organ donation but elderly people would “still have some difficulty with it.” One person said: “Every generation seems to be getting more laid back about our ways and stuff.” Another characterized the different views of organ donation as “contemporary,” “traditional,” and “contemporary traditional”:

I think that for someone who's a traditionalist, no, it wouldn't be a dilemma [to donate an organ] because it's, no, this is the way it is and that's what I do. For someone who's a contemporary, they would probably have different values and beliefs...they grow outside the culture, not learning the values and beliefs... I think the individual that would have the problem would be someone who's more a traditionalist contemporary, contemporary traditionalist, they would have more of a dilemma as to what they wanted to do.

Lack of trust. The data show an evident lack of trust regarding health-care professionals and the health-care system. One person said: “There's definitely trust issues and, basically, I see my people as empiricists. They don't believe it until they see it.” Another noted: “I might not be ready to die and they take it anyways. There's no trust there.” A person who indicated a willingness to be a living donor said:

But there's just some fear, some anger somewhere. And I don't know if it's rational. I would...feel much better knowing who it [the organ recipient] was than just a general thing, because I don't think I trust the system enough.

There was also some evidence of a lack of trust in government. For example, in relation to the establishment of an organ donor registry, one person said that the registry should have “Aboriginal people in charge of it...cause it couldn't be the Department of Indian Affairs.”

Values and Beliefs

The participants discussed a number of values related to death and dying. These included: acceptance of fate, death routines/rituals, and body wholeness. In relation to organ donation, a number of values and beliefs

emerged, including “we don’t talk about it,” transfer of spirit, and helping others.

Acceptance of fate. A number of participants expressed the view that medical interventions should be limited:

The elders are saying no, the culture that they grew up with...you die when the Creator thinks it’s time for you to die, not to extend a person’s life simply because of their age, or, you know, because there is a chance to do so.

Then there’s another part of just thinking how much medical intervention is necessary before you accept what your challenges are.

The thinking with regard to organ donation must surely be influenced by such beliefs about death and the need for transplantation.

Death routines/rituals. Some of the participants spoke of the protocols and procedures that were observed following death:

Spiritually, after someone is gone, then our people would say it would be really wrong to touch that person after, after death I guess. So if someone was approached that way, we need a part of your relative that’s gone, that would be a real no-no I guess.

It appeared that each family had its own traditional death ritual. While many of the participants did not discuss specific rituals, because they considered these private and specific to their family, one participant stated:

Basically when, for example, a relative passes away, his family has to go through a traditional ritual, put on a kerchief, wearing sunglasses and having somebody look after them and protect them. Because they have to follow a set protocol and this may be different for different families, but I’m speaking in general terms...picking out the similarities that usually exist... And when that body is in the longhouse, they have somebody looking after the body. And there’s...a spiritual, cyclical content, and after 4 days the funeral happens. And with that in mind, 4 is...very sacred in context. You know, after 4 days you have to be going for baths for days, spiritual bathing. And taking away from that kind of tradition by wanting to put the body elsewhere or use it for something else...that kind of infringes on those people’s beliefs and values.

Other participants similarly noted that there were “routines” to be followed before and after death and that the organ-donation process could interfere with these.

Body wholeness. The concept of preserving body wholeness was emphasized by most participants. One participant summarized the

importance of body wholeness in light of the spiritual journey to the afterworld:

But when it comes to a burial, our people would like to have a whole body, organs intact. Everything. So that a person has a complete soul, body, when they go to, you know, travel on to the rest of their journey. And when they are buried in the cemetery their journey is complete. Their bodies full. There is nothing missing. If they want to be buried and their eyes are missing or their ears are missing or something, it will disturb their journey. And it will bring a lot of hardship to the family or a lot of hardship to the community. It will bring bad things for a while, until the spirits are satisfied that what we did, they sort of have been satisfied that we have sort of paid a price for bringing bad spirits into a place that is very sacred. So it's kind of a rough-doing, organ donation.

“We don’t talk about it.” There was no question that people did not normally talk about organ donation. One person said: “That is something that, you know, we never talk about with elders.” Some of the participants were reluctant to share their beliefs about organ donation. One person explained:

It's sort of too complex to, to really sort of even get into during an interview. And, you know, even...if I were to share an aspect of it with you, you'd be missing the other pieces that went with it so you'd only get, you know, a part of the story.

Others felt they had no right to discuss the subject:

And for some things it's not appropriate for me to be talking about because...it's not my right to talk about them... Someone who has that gift, it's more appropriate for them to be talking about it.

A third reason for not sharing information was that “it’s not appropriate to be sharing outside the culture and it’s also not appropriate to share outside the family, some of the teachings.” The participants were assured that they did not have to respond to the questions and could withdraw at any time. None chose to withdraw but it appeared that several chose not to share this personal information.

Transfer of spirit. Some participants seemed to be concerned that the spirit of one person might be transferred to another during the course of transplantation. One participant said:

It's like we're vessels. Like we're vessels of our spirit, our body is our vessel. So, would I be bringing someone else's spirit to the body part that I have in me?

Some of those who were supportive of organ donation noted that it might be appropriate to do a cleansing ceremony to address this concern.

Helping others. While most of the participants had concerns about organ donation and transplantation, a few were very supportive, primarily because they viewed it as a way to help family members and community members. One person stated, “We always help our own people.” Another said:

I think that if you can save someone's life, then I would support anyone making that decision. I personally would make the decision, although I would respect also my family's wishes.

Some of the participants indicated that they would feel more comfortable donating an organ if they knew the recipient. Certainly, there was a willingness to make a living donation in the case of a family member. However, it was suggested that even then some “psychological/spiritual preparation” might be required.

Discussion

Family and community were important elements of the context for this study. It was evident that extended families were important to the participants and that family members were consulted on all significant decisions. Although some of the participants regarded organ donation as a personal decision, talking over such issues with family members was emphasized as a cultural practice throughout the interviews. In Coast Salish culture, families are intimately involved in routines and rituals relating to death. Miller and Pylypa (1995) point out that Coast Salish families act collectively in the provision of child and elder care as well as in ceremonial functions. Family members provide one another with food, equipment, financial assistance, transportation, and advice. On the other hand, there was also a sense that the family and community would respect the decisions of individuals on personal matters such as organ donation.

The lack of trust found in this study has been noted previously (Miller & Pylypa, 1995; Royal Commission on Aboriginal Peoples, 1996). “The problem of gaining the trust of community members is repeatedly cited in the Swinomish project's publication...and Lewis noted that among Coast Salish peoples, there is a prevalent distrust of all who are not close kin” (Miller & Pylypa, p. 22). Lack of trust in health professionals in particular and mainstream society in general likely influences attitudes about organ donation. Lack of trust has been associated with the structural barriers to access to care, such as language barriers and lack of cultural competence on the part of health-care providers.

Individual as well as systemic discrimination have been found in health-care institutions (Ellerby et al., 2000). Although these structural factors were not the focus of the present study, they certainly influence life in Aboriginal communities and have relevance for the lack of trust cited by the participants.

While some of the participants supported organ donation, it was apparent that they had little information on the procedure for doing so. None of the participants was familiar with the current organ-donor registration system in British Columbia; a registry established in 1997 is the only legally recognized way to register for organ donation (British Columbia Transplant Society, 2004). Of the 4 million people in the province, only about 475,000 have registered, so the lack of awareness goes beyond the Coast Salish community. However, the participants showed greater awareness of the bone marrow registry. This suggests that it may be beneficial to link public education about organ donation to the specific transplantation needs of the Aboriginal community.

It was apparent that many of the values and beliefs of the participants were congruent with traditional Aboriginal values and beliefs. The participants' discussions of body wholeness reflect Kan's (1989) observation, with regard to the Tlinglit culture, that "human remains had to be maintained whole so as to ensure proper rebirth and well-being of the deceased's new incarnation" (p. 127). On the other hand, they also conveyed a sense that the family and community would respect the decisions of individuals on such personal matters.

While the participants displayed a lack of awareness about organ donation, many of their comments indicated that they were cautious about the concept. It was apparent that those holding traditional values would have serious concerns about organ donation. According to traditional Aboriginal beliefs, for one to enter the spirit world after death, one's body must remain whole (Danielson et al., 1998; Evers et al., 1999). Some participants viewed organ transplantation as the transference of one person's spirit to another person (Danielson et al.). Such beliefs are inconsistent with the process of organ donation. A significant subset of participants spoke about the importance of helping others, particularly members of their own community. There appeared to be a contradiction between traditional beliefs about body wholeness and transfer of spirit on the one hand, and the notion of doing good on the other. Participants who were supportive of organ donation suggested cleansing ceremonies to address certain concerns. However, this would likely be insufficient to allay serious concerns. The participants exhibited a wide range of perspectives on the subject, and the beliefs of elders and traditional members of the community may differ from those of young people and individuals with a contemporary outlook.

The attitudes and beliefs of Coast Salish individuals may vary significantly from the position, formal or informal, of the Coast Salish community to which they belong. The participants who were supportive of organ donation cited the importance of helping members of their community. This might be a point to emphasize in community health educational programs. Also, the targeting of organ donation *within* the Aboriginal community might serve to reduce suspicion. However, the ethical implications of such a strategy would have to be considered.

Implications for Nursing Practice, Education, and Research

Nurses can play a key role both in educating patients and families and in respecting their beliefs and wishes regarding organ donation. The purpose of this study was not to alter values and beliefs but, rather, to better understand them in order to influence the organ-donation process so as to make it more culturally sensitive and ensure that people who are interested and willing to donate organs have the opportunity to do so. An attempt should be made to accommodate rituals and cultural practices pertaining to the death of organ donors. These practices are likely to be different for each family. Concerns about body wholeness and transfer of spirit must be respected. Nurses who are knowledgeable about these values and beliefs will be in a better position to respect patients' wishes and address their concerns about organ donation.

In terms of educating the Aboriginal community about organ donation, the results of this study suggest that Aboriginal leaders should be made aware, in meaningful and sensitive ways, of the shortage of organs for Aboriginal people. Given the many challenges facing Aboriginal communities, the issue may not become a priority until a community member develops end-stage organ failure.

Future research might include participatory action approaches whereby researchers and community members work in partnership to address mutual research objectives. It would also be interesting to explore the possibility of involving Aboriginal nurses in education about organ donation and in the donor-request process. This strategy has been effective in the African-American community. Ethnographic studies with Aboriginal families facing organ donation could elicit further details about values and beliefs with regard to organ donation, but ethnography is an intrusive method and is often viewed with suspicion by Aboriginal communities; it would therefore need to be conducted in a participatory manner.

The views of the participants in this study do not necessarily represent the views of Coast Salish people in general or, indeed, those of their own Coast Salish communities. Hence, the findings are not generalizable to other Coast Salish people or to Aboriginal peoples elsewhere. Given

the sensitive nature of the subject and the reluctance of some of the participants to fully disclose their cultural beliefs, it is unlikely that the findings are comprehensive and complete. Furthermore, decisions regarding organ donation are influenced by many factors — in addition to ethno-cultural beliefs — all of which may not have been elicited in this study.

Conclusions

This study has shown that people with traditional Aboriginal beliefs stress body wholeness and are apprehensive about the transfer of the spirit from the organ donor to the recipient. However, it has also shown that Aboriginal people are concerned with doing good for others. While the participants expressed a range of opinions about organ donation, they indicated considerable lack of knowledge about the organ-donation process. These findings raise issues that nurses should consider when requesting organ donation and when planning public education programs around organ donation.

References

- Blagg, C. R., Helgerson, S. D., Warren, C. W., Keendenton, K., Seely, M., Peterson, L., et al. (1992). Awareness and attitudes of Northwest Native Americans regarding organ donation and transplantation. *Clinical Transplantation*, *46*, 436–442.
- Boey, K. W. (2001). A cross-validation study of nurses' attitudes and commitment to organ donation in Hong Kong. *International Journal of Nursing Studies*, *39*, 95–104.
- British Columbia Transplant Society. (2004). *Organ donor registry*. Retrieved April 5, 2004, from <http://www.transplant.bc.ca/>
- Callender, C., Burston, B., Yeager, C., & Miles, P. (1997). A national minority transplant program for increasing donation rates. *Transplantation Proceedings*, *29*, 1482–1483.
- Callender, C. O., Hall, L. E., Yeager, C. L., Barber, J. B., Dunston, G. M., & Pinn-Wiggins, V. W. (1991). Organ donation and blacks: A critical frontier. *New England Journal of Medicine*, *325*, 442–444.
- Cleveland, S. E., & Johnson, D. L. (1970). Motivation and readiness of potential human tissue donors and nondonors. *Psychosomatic Medicine*, *32*, 225–231.
- Danielson, B. L., Lapree, A. J., Odland, M. D., & Steffans, E. K. (1998). Attitudes and beliefs concerning organ donation among Native Americans in the upper Midwest. *Journal of Transplant Coordination*, *8*, 153–156.
- Dyck, R. F. (2001). Mechanisms of renal disease in indigenous populations: Influences at work in Canadian indigenous peoples. *Nephrology*, *6*, 3–7.
- Ellerby, J. H., McKenzie, J., McKay, S., Gariepy, G. J., & Kaufert, J. M. (2000). Bioethics for clinicians: Aboriginal cultures. *Canadian Medical Association Journal*, *163*, 845–850.

- Enviro-nics Research Group. (2001). *Organ and tissue donations: Canadian public awareness, knowledge and attitudes*. Toronto: Author.
- Evers, K. A., Lewis, D. D., & Schaeffer, M. J. (1999). Cultural diversity: Sociological and cultural factors affecting consent for organ donation. *Critical Care Nurse, 19*(4), 57–61.
- Exley, C., Sim, J., Reid, N., Jackson, S., & West, N. (1996). Attitudes and beliefs within the Sikh community regarding organ donation: A pilot study. *Social Science and Medicine, 43*, 23–28.
- Frauman, A. C., & Miles, M. S. (1987). Parental willingness to donate the organs of a child. *American Nephrology Nurses Association Journal, 14*, 401–404.
- Gallup Poll. (1993). *Attitudes and opinions of the American public toward organ transplants/organ donation*. Princeton, NJ: Gallup Organization.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Guba, E., & Lincoln, Y. (1994). Competing paradigms in qualitative research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–118). Thousand Oaks, CA: Sage.
- Kan, S. (1989). *Symbolic immortality: The Tlinglit potlatch of the 19th century*. Washington: Smithsonian Institution Press.
- Lam, W. A., & McCullough, L. B. (2000). Influence of religious and spiritual values on the willingness of Chinese-Americans to donate organs for transplantation. *Clinical Transplantation, 14*, 449–456.
- Lee, S. M. K. (1996). End-stage renal disease in Asian-Americans. *Nephrology News and Issues, 6*, 13–14.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Miller, B. G., & Pylypa, J. (1995). The dilemma of mental health paraprofessionals at home. *American Indian and Alaska Native Mental Health Research, 6*(2), 13–33.
- Molzahn, A. E. (1991). Quality of life after organ transplantation. *Journal of Advanced Nursing, 16*, 1042–1047.
- Molzahn, A. E., Starzomski, R., & McCormick, J. (2003). The supply of organs for transplantation: Issues and challenges. *Nephrology Nursing Journal, 30*, 17–26.
- Plawecki, H. M., Freiberg, G., & Plawecki, J. A. (1989). Increasing organ donation in the black community. *American Nephrology Nurses Association Journal, 16*, 321–324.
- Randhawa, G. (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton, UK. *Nephrology Dialysis Transplantation, 13*, 1949–1954.
- Royal Commission on Aboriginal Peoples. (1996). *People to people, Nation to nation: Report of the Royal Commission on Aboriginal Peoples*. Ottawa: Author.
- Statistics Canada. (2004). *Population and demography*. Retrieved November 9, 2004, from <http://www.statcan.ca/english/Pgdb/popula.htm#firnat>.
- Tonelli, M., Hemmelgarn, B., Manns, B., Pylypchuk, G., Bohm, C., Yeates, K., et al. (2004). Death and renal transplantation among Aboriginal people undergoing dialysis. *Canadian Medical Association Journal, 171*, 577–582.
- United Network for Organ Sharing. (1995). *Organ and tissue donation: A reference guide for clergy*. Richmond, VA: Author.

- Verble, M., Bowen, G. R., Kay, N., Mitoff, J., Shafer, T. J., & Worth, J. (2002). A multiethnic study of the relationship between fears and concerns and organ donation rates. *Progress in Transplantation, 12*, 185–190.
- Wheeler, M. S., & Cheung, A. H. S. (1996). Minority attitudes toward organ donation. *Critical Care Nurse, 16*(1), 30–35.
- Wheeler, M. S., O'Friel, M., & Cheung, A. H. S. (1994). Cultural beliefs of Americans as barriers to organ donation. *Journal of Transplant Coordination, 4*, 146–150.
- Yong, B. H., Cheng, B., & Ho, S. (2000). Refusal of consent for organ donation: From survey to bedside. *Transplantation Proceedings, 32*, 1563.

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