



Knowledge and Attitudes of Canadian First Nations People Toward Organ Donation and Transplantation: A Quantitative and Qualitative Analysis

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Background: Organ donation and transplantation rates are low for aboriginal people in Canada, despite a high demand.

Study Design: An explanatory mixed-methods design was used to describe knowledge of and preferences for organ donation and transplantation among First Nations people and identify factors that may influence these preferences.

Setting & Participants: We recruited on- and off-reservation First Nations adults.

Methodology: A 45-item survey was administered to 198 participants, of whom 21 were assessed further with a qualitative interview using a multiple case study approach.

Analytical Approach: In an iterative process, themes were identified from qualitative data using critical realism as the theoretical framework. Critical realism is an approach that describes the interface between natural and social worlds to explain human behavior.

Results: Although 83% of participants were in favor of transplantation, only 38% were willing to donate their organs after death, 44% had not thought about organ donation, and 14% did not believe it was important. Only 18.7% of participants reported that their cultural beliefs influenced their views on organ donation and transplantation. In the multivariable analysis, the only factors associated with willingness to donate organs were higher education and considering organ donation important. Four themes emerged from qualitative data: importance of traditional beliefs, recognition of need due to the epidemic of diabetes among Canadian aboriginal people, reconciliation between traditional beliefs and need, and general apathy in the community.

Limitations: Cultural, socioeconomic, and political diversity exist between and within aboriginal groups. Findings may not be generalizable to other aboriginal communities.

Conclusions: Willingness to donate organs was lower in these First Nations participants compared to the general population. Education to address knowledge deficits, emphasize the negative impact of organ failure on the community, and contextualize organ donation within the older traditional native beliefs to help First Nations people understand how organ donation may be integrated into native spirituality likely is required to increase donation rates.

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INDEX WORDS: Aboriginal; First Nations; Canada; indigenous communities; transplantation; organ donation; native spirituality; diabetes; end-stage renal disease; qualitative; survey; mixed methods.

Organ donation and transplantation rates are low for aboriginal people in Canada despite a high demand.¹ Demand is driven in large part by the epidemic of diabetes mellitus in Canada's aboriginal communities,² leading to organ failure. This is particularly relevant for individuals with end-stage renal disease (ESRD). Aboriginal people in Canada experience disproportionately high incidence rates of ESRD.^{3,4} Kidney transplantation is the preferred treatment for most patients with chronic kidney failure. Canadian aboriginals often reside in geographically remote locations where dialysis units may be hundreds of kilometers apart. Extended social support networks play a key role in most aboriginal cultures.⁵⁻⁷ Relocation to receive dialysis disrupts social support and adds financial and psychosocial problems.^{8,9} Transplantation may be a preferred treatment for many aboriginal patients with ESRD because it permits them to remain in their own communities. However, aboriginal people have markedly lower rates of organ donation and transplantation than nonaboriginal

people¹⁰⁻¹² that cannot be explained by referral rates or geographic location.^{10,12-14} Based on the relatively little research available regarding low organ donation and transplantation rates in Aboriginal cultures, influencing factors appear to include limited knowledge about transplantation as well as cultural beliefs^{5,11,15-18} and mistrust of the health care system.¹⁹

Understanding factors affecting aboriginal people's knowledge of and interest in organ donation and transplantation in order to develop health

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policies and strategies to optimize transplantation rates in aboriginal patients while respecting cultural beliefs and preferences is crucial. The purpose of this study was to describe knowledge and attitudes toward organ donation and transplantation among First Nations people and explore beliefs that influence their decisions about organ donation and transplantation.

METHODS

Study Design

This mixed-methods study used a sequential explanatory design consisting of a quantitative followed by a qualitative phase.²⁰ The qualitative data helped explore and elaborate on the quantitative survey results in the first phase. The rationale for this approach was to provide a more comprehensive understanding by noting trends and generalizations from the survey, as well as in-depth knowledge of participants' perspectives.

Participants

Participants were recruited from the general population of First Nations people in Alberta, including on- and off-reservation members. They were consecutively approached from on-reservation community centers and community functions and from medical outpatient clinics at the University of Alberta Hospital between March 2008 and December 2011. Participants were 18 years or older and had no physical or mental conditions that would make survey or interview-based data collection inappropriate. Ethics approval was obtained from the University of Alberta Research Ethics Board.

To ensure that participant selection and information gathering were appropriate and culturally sensitive, the study was coordinated and interviews were conducted by a First Nations member (S.N.D.). She is fluent in Cree, which allowed for recruitment of participants along the continuum of acculturation; has competency in biomedical terminology and aboriginal concepts of health; and has been trained in qualitative interviewing.

Data Collection and Analysis

Quantitative

After providing verbal informed consent, participants completed a 45-item survey assessing knowledge and attitudes about organ donation and transplantation. Survey questions have been validated in the Canadian general public^{17,21,22} and were formatted in English at a grade-6 Flesch-Kincaid readability level. It was administered by the study coordinator, who was able to translate for individuals who were unable to read English or preferred to have it administered in Cree.

Statistical analyses were performed using SPSS, version 20 (IBM). Results were expressed as mean \pm standard deviation for continuous variables and percentage for categorical variables. In univariate and multivariable analyses, the primary outcomes of interest were self-reported willingness to donate organs after death and to donate one kidney while alive. $P < 0.05$ was considered for statistical significance in the final models. Independent variables significant at $P < 0.2$ in univariate analyses were selected and fit into multivariable models. This included age, education, having a living will, considering donation personally important, and having signed an organ donor card. Negative binomial distribution regression models were developed to compute prevalence ratios. This allowed for the variance to be adjusted independently from the mean, given the mean was not equal to the variance in our data set.²³

Qualitative

In the second qualitative phase, we used a multiple case study approach²⁴ to help explain the significant factors from the survey associated with participants' attitudes toward organ transplantation and donation. For this phase, we purposefully selected participants based on their survey responses. This included those who thought that traditional cultural beliefs were and were not significant in explaining preferences for organ donation and transplantation and those who were and were not willing to donate organs. We used in-depth face-to-face interviews and the interviewer's reflection notes as data sources. Interviews were conducted using a semi-structured interview guide, occurred at the participant's home or an alternative place of their choosing, and ranged from 40 minutes to 2 hours in length. Although not sought, 5 participants involved their spouses in the interview. Reasons for their presence were not explicitly asked. Questions were not directed to the spouses, but they were free to add to the conversation at the discretion of the study participant. There were no differences in themes when spouses were involved. All interviews were audio recorded, transcribed verbatim, and anonymized. Transcripts were reviewed against the audio recording and field notes by the interviewer/study coordinator to provide necessary translations and ensure accuracy. In an iterative process, codes were assigned to data in several coding cycles. As patterns emerged, these codes were categorized to identify concepts that were then grouped into themes. Data were coded manually with word-processing software. Data collection occurred concurrently with analysis to allow for refinement of the interview schedule and clarification of emerging themes. Repeat interviews were conducted with 3 participants for clarification. Recruitment was continued until saturation of the data was achieved.

The theoretical framework for data analysis was based on critical realism. Critical realism views human behavior as being influenced by the complex interaction between individual values, experiences, beliefs, and knowledge and structural factors such as physical environment and social and cultural norms.^{25,26} This approach has been used extensively to examine ethnicity and evaluate social and health programs²⁷⁻²⁹ and allowed for exploration of the relationship between participants' beliefs and their attitudes toward organ donation and transplantation.

RESULTS

Of 235 approached potential participants, 198 (84%) responded to the survey (Table 1). Attitudes toward organ donation and transplantation are presented in Table 2. Most participants either had not thought about donation (44.4%) or did not believe it was important (13.8%) and <50% of participants reported a willingness to donate either their organs or those of a loved one after death. Interestingly, more participants were willing to donate their loved ones' organs (48%) compared with their own (37.9%). Conversely, most participants would accept an organ transplant if needed. Reasons not to donate included: "the dead must be left in peace" (32.8%) and one "must enter the spirit world with an intact body" (10.7%). Although these beliefs are thought to be associated with traditional native culture, only 18.7% of participants reported that their religious or cultural beliefs influenced their views on organ donation and transplantation. Participants believed that the most sick and those who had been on the wait list the longest should receive priority for organ

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