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Knowledge, Beliefs, and Behaviors Regarding Organ and Tissue Donation in Selected Tribal College Communities

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Abstract

Background—American Indians and Alaska Natives (AI/ANs) suffer a disproportionate burden of diabetes and kidney failure. For those with chronic kidney disease, transplantation may be the most effective treatment option. However, low rates of organ donation and transplantation are reported for AI/ANs, who face significant barriers in accessing the transplant waiting list. They are also less likely than Whites to consent to become organ donors.

Methods—We partnered with five tribal colleges and universities to conduct focus groups to assess knowledge, cultural beliefs, and behaviors related to organ donation and transplantation among AI/AN college students. Focus group data were used to develop a culturally targeted media campaign and outreach strategy aimed at increasing rates of consent to donate organs.

Results—Community knowledge typically drew from direct family experience with chronic illness. Study findings confirmed that attitudes about organ donation were influenced by cultural beliefs. Nevertheless, many participants supported organ donation even when it conflicted with cultural and spiritual beliefs about keeping the body intact for burial. Participants also expressed mistrust of the local health care system, suggesting that trust issues might interfere with health messaging on this topic.

Conclusion—This is the first study to examine sociocultural beliefs about organ donation among AI/AN college students. Through focus group findings, study staff were better positioned to develop culturally relevant outreach materials. Rising rates of chronic illness among AI/ANs ensure that organ donation and transplantation will be a long-term feature of the health landscape in AI/AN communities. Targeted health messaging must be part of the strategy to reduce donor shortages.

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INTRODUCTION

A major contributor to poorer overall health and shorter life expectancy in American Indian and Alaska Native (AI/AN) communities is the disproportionate burden of chronic illness, including diabetes and kidney disease. Type 2 diabetes is three to eight times more prevalent in AI/ANs than in the U.S. general population, with variation by region and tribe.^{1,2,3} Diabetes is the leading cause of kidney failure, and associated mortality rates are 2.8 times higher for AI/ANs than for any other U.S. racial group.⁴ The prevalence of end-stage renal disease (ESRD), due primarily to advanced kidney failure, is 3.5 times higher among AI/ ANs than Whites.⁵ For people with chronic kidney disease, kidney transplantation may be the most effective treatment option. In particular, among those with ESRD, transplantation increases both quality of life and long-term survival.⁶

Low rates of organ donation and transplantation are reported for AI/ANs. Compared to their White counterparts, AI/ANs are less likely to receive kidney transplants, and they wait twice as long for transplantation.^{7,8} A recent study reported that AI/ANs waited the longest of any racial or ethnic minority population between initiation of renal dialysis and receipt of a deceased donor kidney transplant.⁹ Study investigators also found that AI/ANs experience significant socioeconomic barriers, including poverty, rural residence, and lack of health insurance, to accessing the national transplant waiting list. In addition to these challenges, AI/ANs represent only 0.3% of the donor pool, but 1% of the candidates on the transplant waiting list.¹⁰ Rates of consent for deceased donation in AI/ANs are lower than in the general population. One study reported a deceased donor consent rate of 39% for AI/ANs in the Northern Plains region, compared to 66% for Whites and 34.6% for all racial and ethnic minorities combined.¹¹

Culturally targeted education has the potential to improve organ donation and transplantation rates in minority communities.^{12,13} Given the unique cultural and spiritual beliefs of many AI/ANs, including the importance of keeping the body intact for burial,^{14,15} such education must consider relevant knowledge, beliefs, and behaviors in each AI/AN community. Reaching AI/AN college students is a potentially powerful approach. A recent literature synthesis identified college students as a key target population for education on organ donation, as they are typically open to new knowledge, available in academic environments, and younger and healthier than the general population.¹⁶ While many community colleges and state universities have diverse student bodies, AI/ANs are the most underrepresented minority population in these settings, accounting for approximately 1% of all enrolled students.¹⁷ Fortunately, a network of 38 tribal colleges and universities (TCUs) provides academic training across 75 campuses located in 15 states. Through TCUs, AI/AN college students can more readily be reached for health messaging. TCUs serve students from more than 230 federally recognized tribes, with a combined enrollment of nearly 17,000 students in 2005. Approximately 80% of TCU students are AI/AN.¹⁸

The purpose of this study was to characterize the knowledge, cultural beliefs, and behaviors of AI/AN college students that influence individual-level decisions to become an organ donor. Information was gathered from 10 focus groups conducted at 5 TCUs. Focus group data guided the development of targeted media materials and campaign strategies to increase the number of AI/ANs who consent to become organ donors.

METHOD

Theoretical Framework

This study was reviewed by the University of Washington's Institutional Review Board and determined exempt. The Organ Donor Willingness Model (ODWM)¹⁹ guided focus group

discussions. This model considers individual knowledge, attitudes, beliefs, and behaviors as determinants of willingness to become an organ donor. Knowledge is defined as an acquaintance with the facts and truths around organ donation. Knowledge refers to both medical and non-medical topics and includes familiarity gained from personal experience or statements widely endorsed in the community. Attitude is defined as a predisposition or feeling about organ donation. Attitudes reflect a particular orientation of thought or a general evaluation of organ donation. Beliefs can be characterized both as altruistic statements and as misconceptions or fears about organ donation. As illustrated by the ODWM, attitudes and beliefs are interrelated. The strength of a belief influences a person's overall attitude toward organ donation. Finally, behavior is defined as an action or reaction with respect to willingness to donate organs. Behavior responds to knowledge and is heavily influenced by attitudes.

Focus group questions were derived from ODWM variables. Plans for materials development and outreach were guided by the community-based approach recommended by the Minority Organ Tissue Transplant Education Program (MOTTEP).²⁰ The MOTTEP model engages community stakeholders in planning and delivering programs, builds collaborative partnerships between organizations, and uses various media and communication channels for health messaging.

Selection of Partner Sites

Given the sensitive nature of this research topic and a desire to ensure participant anonymity, TCU staff requested that their institutions not be identified by name. Therefore, this study describes only the general location and selection process for participating sites. During the planning phase, study staff hosted a series of community discussions with TCUs and tribal leadership councils to announce the project and generate community interest. Partner sites were selected according to three criteria: level of interest in becoming a partner, identification of a faculty liaison to coordinate the project, and an established health program to host the project. The five TCUs with which we ultimately partnered represent three distinct geographical regions (Pacific Northwest, Northern Plains, Rocky Mountains), both rural and urban areas, a range of student body sizes (from 535 to 1,167 students), and diverse tribal nations.

Recruitment of Focus Group Participants

To ensure that the project was locally relevant and sustainable, the research team at the University of Washington recruited faculty liaisons at participating TCUs. Each faculty liaison served as the main point of contact throughout the life of the project, and in turn was responsible for hiring students to assist with project coordination. Faculty liaisons also promoted the study and recruited focus group participants. Informational flyers about the focus groups were posted on campus and handed out to students during class. Flyers provided a brief project description, eligibility criteria, focus group date, amount of incentive for participation, and staff contact information. Eligibility criteria were self-identification as AI/AN, age at least 18 years, and affiliation with the local TCU as a student or staff member. Interested participants were asked to telephone or e-mail study staff for a telephone or in-person screening. Once eligibility was determined, study staff enrolled participants.

Focus Group Guide and Procedures

The focus group guide was circulated among AI/AN staff at the University of Washington to assess cultural relevance. An expert consultant with experience on a similar project also provided input. After the initial review, research staff worked closely with the TCU faculty liaisons to ensure that the focus group guide was consistent with local cultural values and

concerns. This extensive cultural consultation helped staff to ensure that sensitive issues, including spiritual beliefs about death, were explored respectfully. The final focus group guide assessed previous knowledge of organ donation and transplantation, perceptions of community need, beliefs about doctors and the health care system in general, beliefs about organ procurement procedures, related spiritual and religious beliefs, willingness to donate organs in the future, and attitudes regarding donation, including the family's role in decision-making.

Focus groups took place in a private room at partner sites between October 2008 and April 2010. Each session was conducted by a trained AI facilitator and lasted approximately 90 minutes. Discussions were audio-recorded and transcribed verbatim.

Analysis

After all focus groups were conducted and transcribed, study staff used a descriptive content analysis approach to analyze the transcripts. Four members of the study staff independently read each transcript several times and extracted specific topics to identify themes within and across the discussions. Categories of knowledge, attitudes, beliefs, and behaviors were used to code themes. There was considerable crossover between attitudes and beliefs in the analysis.

After the independent review and identification of themes, the team met as a group so that individual members could present and discuss their findings. If disagreements about themes arose, transcripts were reviewed and a consensus approach was used to decide whether to include, discard, or rename the theme. This process enabled staff members to agree with, refute, or expand research interpretations, and it substantially improved the analysis of qualitative findings.

RESULTS

Participants

Partner sites requested that we omit detailed demographic data on study participants, so we do not report the age, gender, or tribal affiliation of any participants. All data are presented in the aggregate. Focus groups were generally large, with an average size of 10 participants (99 participants across all groups). Most participants were enrolled as students at the local TCU; some came from the broader community but were affiliated with the TCU (e.g., staff). Table 1 presents the geographic region and number of participants for all focus groups.

Knowledge of Organ Donation and Transplantation

Each focus group began with a discussion of the participants' current knowledge of organ donation and transplantation. In general, participants' knowledge was drawn from direct family experience with chronic illness, such as diabetes or ESRD. For example, those with family members on dialysis or with advanced kidney disease were more knowledgeable of the advantages of organ donation. They expressed an understanding of the medical benefits (greater likelihood of survival) as well as the medical process (referral, donor waiting list). In contrast, many participants who did not have a direct family link to the issue expressed apprehension about organ donation, and were generally less knowledgeable about the medical benefits and process. However, in many cases where knowledge was limited, participants noted that more information was needed, and that the local community was prepared to receive it.

"I have a relative that, um, actually did the kidney transplant. I've heard they can transplant other organs like hearts and stuff. I've never really looked into any of that."

"[T]here's a lot of people on the reservation that do have diabetes and that probably later on in life – with their diabetes – will be on dialysis. So I think it's going to be a big part of our health plan that we have to figure on that becoming a bigger problem."

"I believe it's a problem, because a large amount of community members have diabetes and kidney disease."

"You know, I don't want my children to die, I wouldn't want them to die prematurely. And I believe that this community is ready for the information they are not getting."

Knowledge of the process required to become an organ donor, including registration, also varied across participants. In some cases, people who had already registered felt that the process was too complicated, and that it relied too much on Internet access and computer literacy. In other cases, people felt that they lacked basic information about becoming an organ donor, and therefore did not have a sense of which steps were required to register. In cases where knowledge was limited, participants linked this limitation to geographic factors (e.g., rural, isolated residence) or to the cultural beliefs of a particular community.

"[J]ust because it says on your license doesn't mean that you're going to donate. You fill out a thing – some kind of application to donate."

"Yeah there's not a lot of information in this community about organ donors just for the fact that the religion that most people carry here is, you just don't do it."

"I only knew about it [organ donation] whenever I got my driver's license."

"I have no idea, like I had no idea. I've never really been given information about it, you know, at all."

"[P]eople just have a vague idea of organ donation you know. It's not really advertised."

Pathways to learning about organ donation and transplantation were discussed. Aside from family experience, most participants indicated that televised advertisements, television shows, and movies comprised their main source of information on organ donation. Specific movies or episodes of television series were noted, suggesting that the information was retained because of media exposure.

"I've seen it on TV. They advertise with it. To promote bone marrow ... I've never actually tried to investigate on the reservation what kind of organs they want."

"Yeah, I've seen it on TV. Are you familiar with House, that show?"

"[T]hat movie, *My Sister's Keeper*... whatever this little girl needed, they could get it from her sister and she was pretty much born to donate to her sister – to help keep her sister alive.."

"[T]here was this girl on *Grey's Anatomy* – this young girl ... they just found out she was brain dead ... She couldn't be on life support for too long. She needed to make up her mind."

Beliefs About Organ Donation and Transplantation

Non-biomedical, culturally-based beliefs about organ donation were often attributed to elders or to people described as "traditional." Participants described traditional beliefs as commonly held, but they were not necessarily pervasive among the participants themselves.

"Well most Indians around here believe that Indians should go back to the ground with what they were born with."

"Culturally like they just don't believe in it – like giving their bodies away or anything like that."

"What is yours when you die – because they say that when you come back – so you've got to have everything with you, I guess so you'll have it when you come back."

Beliefs About the Health Care System

Beliefs about the health care system, including physicians, were also similar across sites. In general, participants who expressed mistrust for physicians or the health care system were less likely to report willingness to donate. Mistrust of the health care system or physicians always had a local context and was framed within examples of perceived inadequacies in care, lack of qualified providers, difficulties in accessing quality care, and lack of funding.

"Well, we were just saying how it's more or less IHS doctors here but maybe if it was in [large city named] or any other place I would definitely trust the doctors."

"A lot of the health care we get up here isn't up to standards, I believe, because of the tight budget ..."

Behaviors Related to Organ Donation and Transplantation

Willingness to become an organ donor or to consider donation was similar across groups. For most participants, living donation to a family member or close friend was an acceptable form of organ donation.

"To me [if I ever donated an organ] I think it would have to be a really close person like my kids or something – whatever. Because to me like they're younger. Not necessarily one of the old – I don't think I would. If it was the younger generation, like my kids or something, I would because they have their whole life – if I did that."

"I think it's going to be hard to change a lot of Native American thinking. I think that we'll have to do a lot with the families and you pretty much – when you do need a kidney transplant – you'll have to rely a lot on your family because they are the ones that are more likely to have your blood type and they're going to know you and they all make the decisions if they want to donate. I think you pretty much have to rely on your family. A lot of Native Americans oppose it culturally and then have doubts and aren't educated on it."

"I think, I think that I wouldn't want to be a donor. But I guarantee you, if my brother needed it – and my family knows that. No matter what my beliefs are on me, I'm always willing to put you know, a lot of my family before me."

Participants who did not report a strong affiliation with traditional cultural beliefs were generally more likely to report willingness to donate. In contrast, those with deeply held cultural beliefs (including spiritual beliefs) were less likely to report willingness to donate or to consider donating. When participants expressed apprehension about becoming an organ donor, they sometimes provided a cultural explanation. "I figure, like for me, I don't think I'd be one. But if it was to help like maybe my close kin, I probably could do that – but I wouldn't just donate because my religion is against it."

Some participants recognized that a certain level of personal health was required to be an organ donor, and indicated that their health status would prevent them from donating.

"I don't think I would because ... I know you have to have a certain lifestyle for that – to keep your immune system up and keep healthy. But not everybody can. I sure can't keep healthy."

"Because of my diabetes, I can't donate."

Attitudes Toward Organ Donation and Transplantation

Attitudes about organ donation were discussed mainly in the context of the family's role in health care decisions. In most cases, participants expressed willingness to honor the written or spoken requests of their family members. However, family decisions relied heavily on knowledge of the deceased person's desire to donate. In cases where the deceased did not specify, or where approval was uncertain, most participants agreed that they would be unwilling to offer their family member's organs because of cultural beliefs about the body and spirit.

"[W]hen my brother passed away –you know he was perfectly healthy and everything, and when the doctors asked if we wanted to donate his organs we said no. I think that if you want to be an organ donor you should fill out the application and make it aware to your parents that you're going to be an organ donor."

"[W]hat if they didn't sign anything? They just left it unsigned. They didn't say yes or no. I think the family should be allowed to do whatever they want with those organs. But I think the right thing to do would be to donate those organs."

DISCUSSION

Findings from the 10 focus groups conducted with AI/AN college students and community members provide unique cultural perspectives on geographically diverse populations. Results informed our subsequent development of educational materials and messages aimed at the participating communities.

A key finding from the focus groups was that community knowledge of organ donation and transplantation was influenced by direct family experience with chronic illness, including diabetes and kidney disease. Building on similar research,¹⁵ the present study shows that close, personal experience with chronic disease is the primary source of knowledge about donation. Several participants had family members on renal dialysis, and many reported the loss of a family member to factors related to diabetes and chronic kidney disease. The extent of poor health conditions in a given tribal community was acknowledged as a variable associated with levels of general knowledge about organ donation and transplantation, such that communities with poorer health were more knowledgeable about donation.

Information on the channels through which focus group participants consumed health messages was also a key result of the study, one that informed our campaign strategy for educational materials. Participants cited mass media, primarily television programming, as the principal source of their knowledge about organ donation and transplantation. The driver's license registry was another commonly cited institution through which educational messages could be provided and decisions about serving as an organ donor could be made and recorded.

Study findings confirmed that attitudes about organ donation and transplantation are influenced by cultural beliefs. Nevertheless, many participants acknowledged that cultural transitions were under way, in light of the burden of kidney disease in their communities. Research with diverse tribes has consistently found that traditional beliefs about the body remaining intact for burial are in conflict with the reality of diabetes in the community and with the need for organ donation.¹⁵ Most participants were supportive of organ donation and willing to donate to a family member, concurring that traditional beliefs have their place, but may not be relevant to this issue.

Issues related to mistrust of the local health care system were also raised. Some participants were concerned that the local health care system was inadequate. They expressed a lack of trust stemming from high turnover of providers and the resulting lack of a consistent primary care provider. This mistrust must be considered in future health communication campaigns in tribal communities, along with an understanding of the extent to which information offered by providers is valued by community members.

Outreach to increase knowledge and awareness of the need for AI/AN organ donors was welcomed by participants. These outreach efforts should include acknowledgement of the prevalence of type 2 diabetes and ESRD. Participants could personally identify with the need for organ donation because they knew people in their communities who were waiting for a kidney or who had already received a kidney transplant. Nevertheless, the disparity between the substantial need for kidney donation and the low rates of consent among potential AI/AN donors is alarming. Donation from a member of one's own tribe is especially desirable, because similarities in genetic background increase the probability of human leukocyte antigen matching and improve rates of graft survival.²¹

Limitations

All focus group research has limited generalizability, so the findings reported here cannot be applied beyond the communities where this study took place. Potential selection bias is another key limitation, since focus group participants obviously had an interest in organ donation and transplantation. Despite these limitations, the use of volunteer focus groups remains a relevant methodology for collecting in-depth information that is rarely possible to obtain through other approaches.

Because we were unable to collect or report detailed demographic information on participants, we cannot identify possible differences due to age or gender. Tribal college communities include faculty and staff as well as students and their immediate and extended families, potentially offering a rich source of demographic variables. While we cannot provide demographic details, we can nevertheless affirm that the focus groups were generally representative of the broader community context of each tribal college. As a result, we are confident that these focus group data have been beneficial in developing health messaging for wide consumption in each community.

Conclusions

This study makes a significant contribution to existing research on organ donation, since it is the first to explore sociocultural beliefs on donation in AI/AN communities by focusing specifically on AI/AN college students. As such, it provides the first clear picture of the intersection between culture and knowledge within this broad and relatively unstudied demographic segment, for which organ donation is an increasingly critical public health issue.

This study also provides insight into intragroup differences in AI/AN communities, revealing the tension between traditional concepts of health and healing and the demands of

Finally, an understanding of the cultural variables that influence decisions to become an organ donor will result not only in more appropriate health messaging but also in more uptake of new knowledge and attitudes. Organ donation by AI/ANs remains disproportionate to the significant and growing need for donation in AI/AN communities. Increasing rates of diabetes, chronic kidney disease, and ESRD ensure that organ transplantation will be a long-term feature of the health landscape in these communities. Targeting health messaging to college students in tribal communities must be part of any comprehensive strategy to reduce donor shortages.

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Table 1

Focus Groups by Region and Number of Participants

Tribal College Region	# Participants
Pacific Northwest	8
Pacific Northwest	16
Northern Plains	10
Northern Plains	9
Northern Plains	6
Northern Plains	16
Rocky Mountain	9
Rocky Mountain	13
Rocky Mountain	7
Rocky Mountain	5
Total Participants	99