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Organ Donation and Transplantation:

A Dialogue with American Indian Healers and Western Health-care Providers

Felicia Schanche Hodge, Patricia Bellanger, and Connie Norman

INTRODUCTION

Surgically replacing organs in the human body has become an acceptable and successful procedure in Western medicine. For a number of decades, using donated blood products for blood transfusions was the treatment of choice for severe blood loss largely due to accidents and anemia. In more recent years, replacing major organs in the human body with those procured from deceased or living donors has become commonplace. Organs (for example, lungs, heart, liver, stomach, intestines, and skin) that are damaged and nonfunctioning due to accidents, burns, and illnesses as a result of type 2 diabetes, cardiovascular disease, and infections can now be replaced by using donated organs in a transplantation procedure that extends lives and improves the quality of lives.

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Disparities exist at the earliest stages in the donor and transplantation process in that American Indians experience a higher prevalence of chronic diseases, which often require organ transplantation, and as a result suffer from high morbidity and mortality. For example, type 2 diabetes has reached epidemic proportions among American Indians with a prevalence of 30 percent or higher, fueling a rise in renal failure and an increased need for kidney transplantation.¹ American Indians are 2.7 times more likely to be diagnosed with diabetes, and they are 6.3 times more likely to develop renal failure than non-Hispanic whites.² Additionally, American Indians are 1.6 times more likely to be obese and 1.3 times more likely to have hypertension than whites, which is detrimental to the cardiovascular system and contributes significantly to organ failure and death.³

Currently, nearly one thousand American Indian candidates are on the transplant waiting list in the United States.⁴ Unfortunately, the number of organ transplantation surgeries performed on American Indians in 2008 fell short by 25 percent of those waiting for a transplant.⁵ Although a matching donor from another racial or ethnic group is possible, rates of transplant success with either a live donation or a donation by a deceased donor may increase when organs are matched between members of the same ethnic background.⁶ The number of American Indians who are currently registered as organ donors in state and national registries remains low, as only 0.4 percent of American Indians have consented to organ donation upon death.⁷ Despite the fact that American Indians are disproportionately in need of donor organs, they are significantly less likely to consent to donation than other racial or ethnic groups.⁸ Consequently, a lack of organs that are compatible matches for American Indian patients can add to long waiting periods for transplantation and contributes to higher death rates.

A better understanding of the barriers, facilitators, and opportunities for organ donation and transplantation is needed for American Indians. This article attempts to fill this gap by reporting on the results of a dialogue between traditional American Indian healers and Western health-care providers regarding the barriers and facilitators to organ donation and transplantation.

BACKGROUND

A two-day symposium workshop focused on raising awareness about organ donation among American Indian communities was held in Minneapolis, Minnesota, in 2005 and was attended by more than 160 American Indian participants and non-Indian health-care providers. The perceptions and viewpoints reported in this manuscript are from a sample of American Indians in

the midwestern region, and perceptions may vary across tribal and regional groups. The goal of the symposium was to engage traditional American Indian healers and Western health-care providers comprised of transplant teams in a dialogue regarding the cultural impact of traditional American Indian beliefs, taboos, and practices regarding organ donation and transplantation. A secondary goal was to advance the education of American Indian communities in order to increase their understanding of the medical techniques involved in transplantation. This information was shared in order to demonstrate that conserving culture could be achieved while participating in donation and transplantation processes, particularly in light of rapidly changing medical procedures that are more amenable to traditional viewpoints.

Four key agenda items were selected for the symposium: identify (1) the cultural constructs and the barriers and facilitators of organ donation and transplantation; (2) the spiritual ramifications for organ donors, transplant recipients, and their families; (3) the role, if any, of the American Indian healer in decision making during surgery and postsurgery recovery; and (4) the relationship between American Indian healers and Western health-care providers to the cultural sensitivities of the American Indian community regarding organ donation and transplantation.

In the first half of the symposium, a presentation was given by Western health-care providers, specifically physicians, nurses, and health-care workers from a transplant team at a major hospital in Minnesota. Information was provided in easy-to-understand language regarding common transplant presurgical and postsurgical procedures. To help foster discussion, questions from the audience were encouraged throughout the presentation, and additional time was given for a question-and-answer session following the presentation. Of note, audience participants asked the speakers to clarify donor recruitment and selection processes, which are often misunderstood and mistrusted by minority populations. The workshop presenters (health-care providers and the transplant team) explained that permission from family members and approvals noted on drivers' licenses are the major methods of identifying deceased potential donors. For living donors, the individual or the parent (or conservator) is required to provide written approval prior to the surgery. Further, it was explained that the donor generally cannot specify who will receive their organ. States differ in donor-list record keeping and protocols.

The second half of the symposium consisted of a presentation given by two groups of traditional American Indian healers who are well respected in their communities and have encountered issues with organ donation and transplantation in their practices. Five American Indian healers came from the Sioux tribes (Rosebud, Oglala, and Standing Rock) of North Dakota and South Dakota, and three Ojibwe healers (Mille Lacs, White Earth, and Fond du Lac)

came from Minnesota. The eight American Indian healers, all male, were older in age (55–70 years). They presented on Sioux and Ojibwe healing practices, beliefs, and stories regarding the giving and receiving of organs.

This symposium was supported by a grant from the Minnesota-based Two Feathers Endowment of The Saint Paul Foundation (previously known as the Diversity Endowment Funds). Grants are made to community-based, nonprofit organizations that reflect the American Indian community's defined needs and allow for every interested donor to participate at any level. The recipient of the grant, the Native American Community Clinic (NACC) of Minnesota, is a community-based nonprofit health-services clinic funded by foundations, donations, and various grants. The event was planned and coordinated by a group representing the NACC, the University of Minnesota, and a transplant team at a major hospital in Minnesota.

METHODS

This project takes an exploratory approach by examining a two-day recorded dialogue in the form of a symposium workshop between traditional American Indian healers and Western health-care providers. The workshop was at an agreed-upon site that workshop planners assessed would be compatible to and accessible by all participants. Institutional Review Board approval was obtained from the University of Minnesota. Participants were recruited by using flyers posted in tribal community centers, in health clinics, and at the University of Minnesota. Attendees were consented by project staff prior to the symposium, and all agreed to be audiorecorded. Participation was explained to be completely voluntary.

Trained research assistants at the University of Minnesota transcribed the recordings verbatim. Professional American Indian researchers who followed grounded theory methodology analyzed the transcripts. Words and phrases were highlighted if related to culture, illness beliefs, healing approaches, taboos, and donation or transplantation, and then they were compared and grouped by similarities. Emerging constructs were categorized into themes with supportive notes that served to provide a broader explanation of the themes. Common themes were listed with a summary of the words and comments made by the workshop participants who contributed to the discussion. The content of the themes was verified by a group of American Indian conference-organizing committee members. These themes then became the explanatory terms for barriers to and facilitators for American Indian organ donation and transplantation.

FINDINGS

The themes emerging from qualitative analysis provide a strong illustration of how American Indian participants perceived barriers, procedures, and the cultural constructs of living and deceased donations and transplantations. Six common themes emerged: the need for knowledge, cultural acceptance, breaking of taboos, retaining the body for the journey into the afterlife, the role of American Indian healers, and spirituality. These themes provide a window into the cultural perspectives and illness beliefs that are barriers to American Indians as transplant recipients or organ donors.

The Need for Knowledge

During the course of the symposium dialogue, Western providers spoke of their interest in the donation and transplantation experiences and barriers faced by American Indians. They acknowledged that they seldom encounter an American Indian donor or transplant patient and expressed a desire to learn more in order to serve the American Indian community better. The American Indian healers shared their experiences of working with American Indian patients who follow traditional tribal customs and beliefs and rely on American Indian healers for decision-making guidance; these patients often concurrently seek medical care from Western health-care providers during illnesses or injury. The American Indian healers pointed out during their presentation that type 2 diabetes is a growing epidemic among American Indians and that kidney or other organs often need to be transplanted in order to save lives. Two American Indian healers revealed that they were recipients of an organ (kidney) that extended their lives and improved their quality of life. Another healer shared that he was on a transplant waiting list. None reported to be consented, deceased, or living organ donors.

Areas of American Indian participant-knowledge gaps included the process of surgery, the protocols for deceased or living donations, the procedure for the return or disposal of human tissue and remains, and postsurgery care. Audience members voiced a common fear of undergoing surgery, describing it as a frightening and an overwhelming experience for most individuals:

I am just too afraid to do that. I could never go in for surgery. I don't know what it takes—what it does to you.

Who do we talk to—where can we get some information?⁹

The participants requested information regarding what constituted a need for transplantation surgery, procedure logistics, treatment expectations, and follow-up care. Audience recommendations to the Western health-care

providers included strengthening communication with patients who need a transplant and involving patients' family members in all aspects of the donor and transplantation process. Identifying the family decision maker, as extended families often relegate important decisions such as surgery to the elders in the family, is an important step. One participant shared:

We don't know what goes on. How do I know when they will take my parts? Who will they talk to?

Another participant voiced a very common concern regarding who would receive the donated organ:

Who says that they can do that? I want to know what I am signing over and when I will have surgery. And who gets the organ—can we say who will be walking around with our kidney?

Individuals who give release of their organ upon their death cannot specify who will be the transplant recipient. The hospital transplant teams maintain a transplant list of individuals and priority is determined by factors that may include compatibility, wait time, severity of condition, organ availability, geographic distance, and provider recommendation. Because donors do not have the ability to determine who will receive their organ during the process of a deceased donation, American Indian donors may feel a loss of control over their decision-making powers to ensure future guardianship of their organ. To American Indians with traditional beliefs, it is important that the organ is maintained in good condition, so that the journey into the next life is ensured and not hampered by a poorly maintained organ.

Cultural Acceptance and Taboos

American Indians may view being an organ donor or organ recipient as taboo or unacceptable based on cultural and spiritual beliefs, thus posing a significant barrier to surgery. Many individuals and family members express concerns regarding the cultural acceptance of organ donation by other members of the community and the fear of breaking tribal taboos, which are at the forefront of their trepidation. Several symposium participants expressed the fear that one would be ignoring and breaking a taboo regarding perceived inappropriate procedures that entail living or deceased donations:

I didn't think we could give our organs away. Our medicine man may not allow it. We don't do that. We don't give our body parts away.

Culturally determined attitudes contributing to the reluctance to participate in the donor and transplant program can be overwhelming for the patient

suffering from chronic illness, the patient's family members, and the health-care provider treating the patient. Understanding the reasons for the taboo and the basis for the unacceptable attitudes toward the surgery is important for the provider and transplant team so they can help to offer the patient appropriate care. One American Indian healer provided the following explanation for why the donation and receipt of an organ would be taboo in American Indian culture:

We were given these bodies by the Great Spirit—and we must take care of all the parts. We cannot throw these parts away, and we cannot abuse them. Our spirit resides in our body.

Another American Indian healer spoke of the cultural taboos but explained his opinion of how the meaning of cultural beliefs did not necessarily negate donation, particularly if it meant helping the American Indian community:

I think that many people do not understand our culture. We honor our culture and our spirit and our body. That does not mean that we cannot “loan” out a part to save the life of a relative. We are caretakers and we are caregivers. Our body parts will always be ours, but they can be given in the spirit of healing.

During the symposium, the need for a center that would be available to answer questions about organ donation and transplantation was readily apparent. Participants agreed that such a center could be placed almost anywhere, as long as it was available by phone or the Internet in order to find out information about how to obtain an organ transplant, be an organ donor, and go about the process in a manner that would be culturally acceptable and appropriate for the family and community.

Retaining the Body for the Journey into the Afterlife

Cultural beliefs regarding the need to enter the afterlife with all body parts intact, and the belief that one's spirit follows these body parts, are barriers to organ donation and transplantation. Participants stated:

How can I go on that journey, that long walk with a missing body part? And if someone has my hand, is it not still my hand?

We are taught that we need to have all our body parts in order to go into the afterlife.

Families of the deceased may require assurance and procedures to return body parts for later burial. There may be special ceremonies to make one whole, cleanse the body, or accept the condition of the body, thus allowing for the afterlife journey. This aspect of organ donation and transplantation is an

extremely important consideration and can be incorporated into an organ-donation program's protocol.

Currently, ceremonies are performed by many tribes for returning veterans of war who seek ceremonies for the loss of body parts. These ceremonies are "cleansing" and "accepting" ceremonies that recognize the loss of a body part and make allowances for the loss. A similar allowance is also often made for American Indian medical students who perform perceived taboo practices during their training, such as touching a dead body; they must undergo "cleansing" periodically so that they can reenter community life.

Role of American Indian Healers

American Indian traditional healers were identified as holding an important role prior to, during, and after organ donation and transplantation. As the need for organs rises in American Indian communities, tribal members seeking information, understanding, and for approval for an organ donation and transplantation often approach American Indian healers. The new role of American Indian healers may include facilitating discussions between the patient and the transplant team, organizing a meeting of the family to discuss the process, and helping to educate the community regarding the process of organ harvesting and transplantation and the cleansing ceremonies afterward. They can provide information to the transplant team regarding the illness beliefs of the patient and perhaps the need for the return of body parts. Participants may be more inclined to donate or receive organs knowing that their healers may conduct a special ceremony for them along with their family members. Healers have a role in providing information, assurances, and healing rites and in clarifying that traditional taboos do not prohibit donations or transplants as long as certain conditions are met (for example, special ceremonies being done before and after the procedure). One healer said:

I myself received a kidney a few years ago. It didn't change me into someone else. I know what the process is, how the surgery takes place . . . how I view the whole situation. We have a role that is forked—we help to heal the spirit and the body and we help talk to and work with those docs, the transplant team so they understand our ways, our need for ceremonies and prayer. I can go with you.

Spirituality

American Indian participants in the symposium perceived life and death through a spiritual spectrum; thus they viewed the process and consequences of organ donation and transplantation as being tied to the spiritual and physical worlds. Non-Indian and Western health-care providers—as a worldview

and as a part of their culture—can better understand American Indian spirituality, which encompasses everyday events and lives. To an American Indian with traditional spiritual beliefs, any illness can be thought of as the result of a bad deed or the end product of poor relations. Within this cultural perspective, the giving and receiving of organs can also result in illness. These cultural constructs and beliefs are important for health-care providers who treat American Indian patients to understand; individuals cannot separate themselves from their spirituality; it is a part of them. Despite differences among Western medicine beliefs regarding the body, providers and patients may find that they can incorporate spirituality into the healing process, whether it is a part of the surgery or a part of the donor process, in order to achieve better outcomes. Thus transplant teams must recognize spirituality as having a significant role in the transplant process.

SUMMARY

American Indian cultures encompass a mixture of traditions, beliefs, and ceremonies that are guided and reinforced by traditional American Indian healers. We discovered that the giving or receiving of an organ is not an easy topic for the Northern Plains community to discuss or agree with due to long-standing taboos, beliefs, and misunderstandings. In this project, a group of Sioux and Ojibwe healers reinforced the cultural views and practices of their people, yet they recognized and discussed the need for modern-day procedures, such as organ donation and transplantation, which are designed to save and prolong life and to improve the quality of life. The view of helping other American Indians by sharing life can be appealing and can provide justification for participating in organ donation and transplantation, thereby reducing disparities in available organs. Three significant pieces of information were shared by the American Indian healers: (1) American Indians are not prohibited from seeking care from Western health-care providers, and American Indian healers will often refer individuals to hospitals or specialists for care; (2) a belief exists that one must have all body parts upon death as a whole body is needed in the afterlife; and (3) although there are many beliefs and taboos among tribes regarding individual behaviors, donation and transplantation may be discussed and approved by tribal-specific American Indian healers, as tribes may hold accepting or cleansing ceremonies.

Views regarding health and healing are very diverse nationwide—even within one region. Within a single tribal culture views can be quite numerous. It is not recommended for health-care providers to assume that they can judge one American Indian patient based on what they have learned about the views

of other American Indian patients. Thus, although the findings of this article cannot be generalized to American Indian tribes in other regions, there are several reports of similar concerns expressed by Navajos and others regarding organ donation and transplantation.¹⁰ This illustrates that there may be more similarity than differences between tribes with regard to the loss of body parts and beliefs of personal responsibility in the procurement and transplantation of organs. Our findings that conflicting cultural views have complicated relationships between health-care providers and Native patients and that cooperation, understanding, and sensitivity can yield great benefits are important for providers to consider.

The dialogue with American Indian healers and Western health-care providers brought new knowledge and understanding in the area of culture, healing ceremonies, taboos, and cultural constructs of illness. Increased understanding of the importance of traditional and Western viewpoints is instrumental not only for physicians and transplant teams but also enables American Indian communities to address important and timely issues regarding the need for organ donation and transplantation. Given the severity of chronic health conditions that have increased morbidity and mortality among the American Indian population, transplantation must be considered and incorporated into options for health care in order to save lives. This two-day gathering also enabled patients and community members to discuss important aspects of illness and to make recommendations for their communities and families with regard to increased involvement in organ-donation and transplantation programs. Culturally sensitive approaches in donation and transplantation requests from donation programs or patients must consider American Indian beliefs and taboos, fears and misinformation, and extended-family preferences in the patient-provider communication. Transplant teams should encourage family discussions of donation and transplantation as part of health-care decision making. Employing the influence of the American Indian healer as an educator and source of support is also very important because healers may serve as an excellent bridge between transplant teams and patients and the patients' families. The health and well-being of American Indians is closely tied to the community's values, illness beliefs, and practices of which the traditional healer has significant influence.

It is clear that the articulation of these themes is a first step toward a better understanding of the donation process, barriers to care, and the immediate needs of the American Indian communities in terms of knowledge, resources, and counseling. A need for better-informed information and education for American Indians and their family members exists, so that they will participate in organ-donation and transplantation programs. Because we observed a lack of information and understanding of American Indian cultures and the impact

on organ donation and transplantation, there is a strong need to provide this information to hospitals, health-care providers, and transplant teams. This is essential, so that providers and the transplant team can better understand the barriers, traditional healing, taboos, cultural beliefs, and illness perceptions held by American Indians. Together, a better-informed donor and recipient, along with an educated transplantation staff, can come together as a team, so that American Indians can fully participate in donation and transplantation programs.

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