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Organ Transplantation and Donation: Why Minority Groups Need More Organs But Donate Less—It's Complex!*

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In this issue of *Critical Care Medicine*, the study by Moore et al (1) evaluated the three largest ethnic/racial groups in the state of New Mexico (NM), comparing age-adjusted rates of organ candidates for transplantation and deceased organ donation. They hypothesized that age-adjusted deceased donation rates would not differ among the study racial/ethnic groups. They reasoned that the relatively larger proportion of Hispanics (48%) and American Indians (10%) in NM compared with other states, combined with provision of at least some of their healthcare experiences by their own racial/ethnic community, would enhance their trust in the medical system to levels similar to levels enjoyed by non-Hispanic whites, leading to similar rates of deceased donation. African Americans compose a very small fraction of the NM population and were not evaluated.

Analyzing data obtained from the statewide organ procurement organization and the National Organ Procurement Transplant Network, they found that although NM American Indians were 2–3 times more likely to be registered candidates for organ transplantation, they consented to deceased donation much less frequently compared with non-Hispanic whites and Hispanics (0.11–0.13). Additionally, American Indians from NM consented to deceased donation significantly less than other U.S. American Indians, whose donation rates are lower than non-Hispanic whites nationally. However, the rates of deceased organ donation for NM Hispanics were similar to NM non-Hispanic whites, especially among those under 40 years, which differs from national data where their rate for decreased donation is lower than non-Hispanic whites (1).

Obviously, the gap between needed organs for transplantation and available donors impacts all U.S. racial groups. Minority groups are often disproportionally affected because frequencies of blood types and human leukocyte antigen allele combinations differ by race. Greater leukocyte antigen

*See also p. 1386.

Key Words: minority; organ donation; poverty; transplantation

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matching is associated with longer renal graft survival, so donors from matched racial backgrounds are often preferable (2). Minorities frequently are overrepresented on transplant candidate wait lists but are less likely to donate. Decreased donor to recipient ratios among minorities often result in prolonged wait list times for minority candidates (3–5).

Many factors affect both development of end-stage organ failure and access to organ transplantation. Likewise, the decision to be an organ donor is also influenced by many complex factors. Irving et al (6) recently summarized these as follows: 1) relational ties; 2) religious beliefs; 3) cultural influences; 4) family influences; 5) body integrity; 6) previous interactions with the healthcare system—medical mistrust, validity of brain death, and fear of early organ retrieval; 7) the individual's knowledge about the organ donation process; and 8) major reservations about the process of donation, even in those who support organ donation.

Although many American Indians in NM have relatives or acquaintances with end-stage renal disease, recognition of potential benefit from transplantation has not translated into increased community deceased donation participation. Positive community experiences with successful transplantation/donation may in fact be sparse related to multiple potential factors. Many American Indians have religious beliefs that the human body must remain intact after death, which is an obvious obstacle to donation. Continued economic and health disparities among American Indians do not build trust in the healthcare system, including fear that organs will preferentially be allocated to wealthy recipients (7). Neurological criteria for death are not always consistent and clear to even U.S. healthcare workers (8) and are even less clear to those with less education and medical sophistication. Even among populations with a generally favorable attitude toward donation, a persistent barrier to deceased donation is the fear that medical providers will not try as hard to save a dying patient if that patient is recognized as a potential organ donor (8). Finally, United Network for Organ Sharing data show that consent to donate is lower when patients were older than 40 years and for all minority groups, which likely reflects both lower knowledge and cultural preferences (9).

Positive attitudes toward organ donation relate directly to higher socioeconomic status (6). A factor not evaluated by Moore et al (1) that likely impedes deceased donation by American Indians is their pervasive poverty in the United States as a whole (27%) and in NM (>30%), with large fractions living with incomes below the federal poverty line (10). It is noteworthy that the donation rate among NM Hispanics was similar to non-Hispanic whites. The importance of financial concerns was highlighted by another study that demonstrated decreased racial disparity when Hispanic donors had private health insurance (11).

Studies that evaluate receipt of transplanted organs find that minority candidates with low income are less likely to receive an organ compared with other candidates (12). Furthermore, disparities in even completing evaluation for medical suitability are documented for women, as well as people of color or low income (13). This initial evaluation to qualify as a candidate typically requires several visits and involves a medical history, physical examination, psychosocial assessment, evaluation and treatment of medical conditions, and laboratory studies.

Some of the concerns surrounding transplantation can be alleviated through education. High school student support for donation increased dramatically following educational programs (14, 15). Use of public media (16) is an effective method to educate communities, and reported donation support increases when minority groups have greater accurate knowledge regarding the donation process. Engagement of family members in discussions regarding donation enhances expression of donation preferences and is reported to increase donation support. Finally, positive community and individual experiences with the donation and transplantation processes increase trust in the medical system.

Improved access to transplantable organs for low-income and minority groups is important. Understanding why these same groups have historically had low participation in deceased organ donation may inform strategies to increase donation, thereby increasing the chances for successful transplantation and improved quality of life.

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C1 Esterase Inhibitor: A Biomarker for Amniotic Fluid Embolism?*

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Amniotic fluid embolism (AFE) is a devastating condition in pregnancy. Its complications including circulatory and respiratory collapse, neurological symptoms, and intravascular coagulation make AFE one of the major causes of maternal mortality in developed countries and are also associated with a significant maternal and neonatal morbidity in the survivors. Recent large population-based studies, case series, and reviews provided data with a broad variation in prevalence and mortality of AFE ranging from 1 of 4,500 to 1 of 80,000 and 5% to 45%, respectively (1–6).

The diagnosis is based on clinical symptoms and essentially one of exclusion or traditionally made at autopsy in fatal cases upon identification of fetal debris in the maternal pulmonary circulation.

The precise diagnosis of AFE is hampered by the limited knowledge of clear pathophysiology leading to this condition. For several decades, amniotic fluid containing squamous cells, vernix, mucin, and lanugo was suspected to make a physical obstruction in the maternal pulmonary circulation as it is reflected by its name; however, the confounding clinical symptoms and several research data question whether this would be the main pathomechanism. Based on the clinical pattern sharing similarities with anaphylactic shock, a completely different theory was suggested as early as 1956 (7). According to this idea, fetal antigens in the amniotic fluid entering to maternal circulation would stimulate endogenous mediators of anaphylaxis (8). Recent data also highlighted the contribution of immune mechanisms including complement activation in AFE (9). Both serum C3 and C4 levels were found lower than normal in AFE patients in case series (10), raising the presence of complement activation. This notion was also supported by low C3a expression in a histological study (11). However, this concept is still to be verified.

Despite that studies of specific fetal antigen (sialyl Tn), zinc coproporphyrin, or insulin-like growth factor binding protein-1 in maternal serum showed promise (6, 9, 12), one of the major problems that make difficult the investigation and early treatment of AFE is the absence of validated biomarkers. Identification of patients at risk or the early recognition of this condition would largely influence clinical decision making.

In this issue of *Critical Care Medicine*, Tamura et al (13) publish their observations on C1 esterase inhibitor (C1INH) as a possible factor in AFE pathophysiology. They hypothesized that functions of C1INH other than the inhibition of C1 esterase activity, that is, the inhibition of FXIIa and kallikrein activities, might be responsible for AFE symptoms such as vasodilatation, hypotension, vascular permeability, and disseminated intravascular coagulopathy–type postpartum hemorrhage. Based on this assumption, the authors measured the C1INH activity in AFE patients. They concluded that low C1INH activity at the onset of symptoms would predict the risk and the outcome of this condition. They found higher C1INH activities in healthy age– and gestational age–matched controls without AFE than in those with AFE (62% vs 30% of the healthy nonpregnant reference values). They measured even lower C1INH activities in subjects with fatal AFE than in those with nonfatal AFE (22% vs 32%). Their results are seemingly supported by two cases when they used fresh frozen plasma (FFP) for AFE. During FFP therapy, C1INH activity normalized in the surviving patient, while it was constantly depressed in the fatal outcome.

Although these results provide some base for enthusiasm, several limitations of the diagnostic suitability of C1INH activity should be considered.

1. No cutoff value supporting the differentiation between different subgroups was provided.
2. The C1INH activity is depressed even in healthy pregnancy and the detection of a further decrease may present methodological challenge.
3. There is no standard validated method for the C1INH activity measurements; hence, each laboratory should establish its own measurement conditions.

*See also p. 1392.

Key Words: amniotic fluid embolism; C1 esterase inhibitor; disseminated intravascular coagulation

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Effects of Ethnicity on Deceased Organ Donation in a Minority-Majority State*

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Objective: To define how ethnicity affects donation rates in New Mexico when compared with the United States. We hypothesized that deceased donation rates in New Mexico would reflect the ethnic rates of the population.

Design: We performed a retrospective review of the Organ Procurement Database for New Mexico from 2009 to June 2012.

Methods: Rates for donors and transplant candidates were calculated relative to 2010 census population estimates by ethnicity for non-Hispanic Whites, Hispanics, and American Indians. Poisson regression analyses were used to test whether United States and New Mexico rates differed. Rates were scaled to 100,000 patient-years for reporting.

Setting: State of New Mexico population compared to United States population.

Subjects: Reported deaths to New Mexico Donor Services and United Network for Organ Sharing from 2009 to 2012.

Interventions: None.

Measurements and Main Results: Non-Hispanic White age-adjusted donor rates per 100,000 patient-years were 2.58 in New Mexico versus 2.60 in the United States, Hispanic donor rates were 1.98 in New Mexico versus 2.03 nationwide, and American Indian donor rates in New Mexico were 0.26 versus 1.23 nationwide (rate ratio = 0.21; 95% CI, 0.05–0.86). American Indians have significantly lower donor rates in New Mexico compared to non-Hispanic Whites (rate ratio = 0.11) and Hispanics (rate ratio = 0.13) and nationally (non-Hispanic Whites: rate ratio = 0.32 and Hispanics: rate ratio = 0.43). Hispanics and non-Hispanic Whites had similar donor rates regardless of geographic strata (Hispanics vs non-Hispanic Whites, New Mexico: 0.83; United States: 0.75). In New Mexico, Hispanic patients were 1.43 times more likely to be listed as transplant candidates than non-Hispanic Whites and American Indians were 3.32 times more likely to be listed than non-Hispanic Whites. In the United States, Hispanic patients were 1.90 times more likely to be listed as transplant candidates than non-Hispanic Whites and American Indians were 1.55 times more likely to be listed than non-Hispanic Whites.

Conclusions: Donor and transplant candidate rates did not show strong differences by geographic strata. These findings suggest that further work is needed to elucidate the causes for ethnic differences in rates of consent and donation, particularly in the American Indian population. (*Crit Care Med* 2014; 42:1386–1391)

Key Words: ethnicity; organ donation; transplant

***See also p. 1546.**

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There are well-documented disparities in minority access to solid organ transplant. The reasons for these limitations in access are multifactorial, but a large contributing factor is relative lack of minority deceased organ donors. This has been an ongoing problem since the development of successful solid organ transplant, with extensive research done to investigate the nature of the problem and potential etiologies. A large cross-sectional interview identified African American race, older age, lower education, lack of insurance, unemployment, comorbid conditions, and religion/spirituality as factors associated with less willingness to donate cadaveric organs (1). Identification of populations with low rates of donation has led to the development of numerous community-based outreach

programs in an attempt to improve minority donation rates. The National Minority Organ Tissue Transplant Education Program (MOTTEP), a nationwide minority outreach program, has been successful in creating models for community outreach programs across the country that have increased minority donation rates (2). However, even with increasing donation rates, the need for organs continues to rise. A review of the Organ Procurement and Transplantation Network and United Network for Organ Sharing data from 1999 to 2008 demonstrated that the number of African American donors increased from 653 to 1,278 between 1999 and 2008, and the number of Hispanic/Latino donors increased from 612 to 1,112 in the same period; however, despite these increases in minority donors, deceased organ donations from minorities have not kept pace with the growing number of minorities on the transplant candidate wait list (3).

Native Americans represent a disproportionately large percentage of candidates on the solid organ transplant wait list, largely due to the increased rates of diabetes and end-stage renal disease in this population (4–7). However, due to reasons that require further investigation, the rate of consent for deceased organ donation is lower than the rate for other races nationally. Previous interviews with Lakota Sioux tribe members in South Dakota regarding deceased organ donation identified several recurring themes (8). Participants were aware of the need for organs due to the rising rates of diabetes but were generally unaware of the organ donation process and expressed mistrust in the local healthcare systems. They also acknowledged the importance of traditional religious beliefs, including the need to be buried with an intact body. Another large survey in the Midwest identified factors that increased the likelihood of deceased organ donation, including having signed a donor card, being approached by a Native American healthcare worker, donation to a family member, the belief that family members will carry out donation wishes, and the belief that it is acceptable to remove organs from the body (9). However, few studies have focused on Southwest Native American tribes.

New Mexico is a minority-majority state (**Fig. 1**) (10). Only 40% of the New Mexico population self-identifies as Caucasian or non-Hispanic White. Forty-six percent identify as Hispanic, and 10% identify as Native American. In comparison, only 1% of the United States general population is Native American, and 17% identify as Hispanic. We hypothesized that deceased organ donor rates would reflect ethnic rates of population, yielding an increased number of Native American donors in New Mexico versus the United States. The reason for this hypothesis is multifactorial. Since Native Americans represent a larger section of the population of New Mexico and have more representation in the local healthcare system, they potentially have more trust in the system, and thus would give permission for deceased organ donation at a higher proportion than other geographic regions in the country.

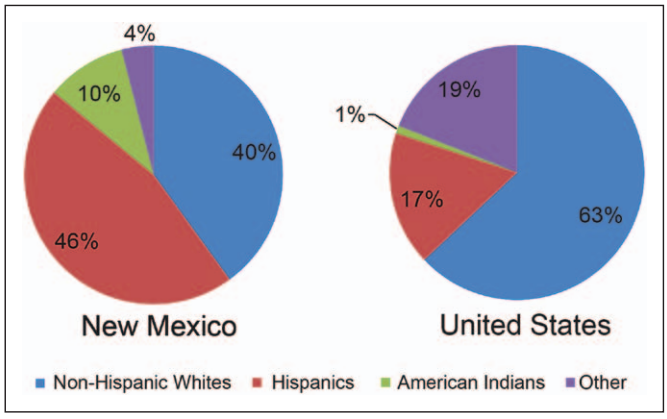

Figure 1. Population demographics for New Mexico and the United States (10).

METHODS

The Organ Procurement and Transplantation Network stratifies donors into racial categories including White, Black, Hispanic, Asian, Pacific Islander, American Indian/Native Alaskan, Multiracial, and other. This study was deemed exempt from institutional review board review by the University of New Mexico Human Research Protections Office. We performed a retrospective review of the Organ Procurement Database for New Mexico from January 2009 to December 2012 compared to the National Organ Procurement Transplant Network January 2009 to June 2012. We collected data on non-Hispanic Whites, Hispanics, and American Indians. Age-adjusted rates for New Mexico donors were calculated relative to the 2010 census population distributions (age < 40 yr and ≥ 40 yr) for American Indians, Hispanics, and non-Hispanic Whites and scaled to 100,000 person-years for reporting (11). Wait list CIs for donor rates and transplant wait lists were calculated using Ulm's method (12). Comparisons of New Mexico and United States rates within race/ethnicity were based on a Poisson model. Rate ratios (RRs) (U.S. referent) and approximate Wald 95% CIs were used to summarize geographic comparisons. Frequencies of New Mexico organ outcomes (donor, consent but not recovered, declined) were tabulated. Factors affecting probability of decline in New Mexico were analyzed by univariate and multivariable unconditional logistic regression analyses. Odds ratios (ORs) and Wald 95% CIs were used to summarize the strength of the association. SAS v9.3 (SAS Institute Inc., Cary, NC) was used to perform calculations.

RESULTS

A total of 27,434 deceased organ donors in the specified time period were identified in the United States. Of these individuals, 18,241 (66%) were non-Hispanic Whites, 3,614 (13%) were Hispanics, and 111 (0.4%) were American Indians. In comparison, there were 170 donors over the specified time period in the state of New Mexico, with 88 (72%) non-Hispanic White, 76 (62%) Hispanic, and 2 (7%) American Indian deceased donors, based on New Mexico Donor Services (NMDS) data. Donor characteristics for New Mexico are shown in **Table 1**. American Indians in New Mexico had a lower donation rate (0.26 per 100,000 person-years) than the overall U.S. rate (1.23 per 100,000 person-years; RR = 0.21; 95% CI, 0.05–0.86)

TABLE 1. New Mexico Deceased Organ Donor Characteristics

Donor Characteristics	All	Non-Hispanic Whites	Hispanics	American Indians
Age—mean (median), yr	38 (38)	44 (46)	33 (29)	25 (25)
Sex (*n*), male, female (% female)	99, 67 (41.2)	46, 42 (47.7)	51, 25 (32.9)	2, 0 (0)
Registered organ donors (*n*)	117	63	51	1

(**Table 2**). There was no difference between New Mexico and U.S. rates for Hispanics (2.03 per 100,000 person-years) or for non-Hispanic Whites (2.58 per 100,000 person-years) (Table 2).

In the United States, a total of 95,059 individual candidates were identified on the kidney transplant wait list in December 2012. Of these individuals, 35,992 were non-Hispanic Whites, 18,149 were Hispanics, and 1,072 were American Indians. In comparison, there were 465 candidates in New Mexico on the kidney transplant wait list in December 2012, with 122 non-Hispanic Whites, 212 Hispanics, and 96 American Indians based on Organ Procurement and Transplant Network data as of January 1, 2013. Number of wait list candidates per 100,000 in **Table 3** is based on typical 2010 candidate wait list numbers for each race/ethnicity in New Mexico. American Indians in New Mexico were 1.37 (95% CI, 1.12, 1.69) times more likely to be on the transplant wait list than American Indians overall (Table 3). Hispanics (RR = 0.60; 95% CI, 0.52–0.69) and non-Hispanic Whites (RR = 0.80; 95% CI, 0.67–0.96) were less likely to be on the transplant wait list in New Mexico.

We conducted univariate and multivariable analyses for New Mexico deceased donors to assess whether the family declining was associated with age, race/ethnicity, and registration status among Hispanics and non-Hispanic Whites. In univariate analyses, age and sex were not associated with odds of declining, but race/ethnicity and registration status were (**Table 4**). Registered candidates were less likely to decline than unregistered candidates. American Indians (OR = 32.0; 95% CI, 9.5–142) and Hispanics (OR = 2.29; 95% CI, 1.17–4.62) were more likely to decline than non-Hispanic Whites. In addition, older Hispanics were more likely to decline than non-Hispanic Whites (continuous age × race/ethnicity interaction, $p = 0.015$). Among non-Hispanic Whites less than 40 years old 13% declined compared to 16% among 40 years old or older (adjusted OR = 1.46; 95% CI, 1.38–6.10), but among younger Hispanics 24% declined compared to 35% of Hispanics 40 years old or older (adjusted OR = 3.13; 95% CI, 1.05–9.94).

DISCUSSION

This study addresses a critical disparity in healthcare: access to solid organ transplant through deceased organ donation. American Indians in the state of New Mexico have a significantly lower deceased organ donor rate when compared to American Indians in the United States overall. This was contrary to our hypothesis, for reasons that will require further investigation. These deceased donation rates are in spite of the significantly higher rate of Native American transplant candidates in New Mexico. Deceased organ donation rates for Hispanics and non-Hispanic Whites were similar to the United States overall, but wait list rates for Hispanics and non-Hispanic Whites in New Mexico were lower than the United States overall.

NMDS is the nonprofit, federally designated transplant donor network serving New Mexico. Organ recovery coordinators and family care coordinators receive extensive cultural training at NMDS. NMDS has one family care coordinator who is half Native American and who is involved whenever possible with Native American donor families. Additionally, Native American transplant recipients speak at donation meetings throughout the state. NMDS also has a presence at The Gathering of Nations each year with educational opportunities for attendees. The Gathering of Nations is one of the largest powwows in the United States. More than 500 tribes from

TABLE 2. National and New Mexico Donor Rate by Race/Ethnicity (per 100,000 Person-Years) 2009–2012

Race/Ethnicity	Geography	Donors (*n*)	Age-Adjusted Donors[a]	95% CI	Rate Ratio	95% CI
American Indian	New Mexico	2	0.26	(0.03, 0.95)	0.21	(0.05, 0.86)
	United States	111	1.23	(1.01, 1.48)	1.00	
Hispanic	New Mexico	76	1.98	(1.56, 2.48)	0.97	(0.78, 1.22)
	United States	3,614	2.03	(1.97, 2.10)	1.00	
Non-Hispanic White	New Mexico	88	2.58	(2.07, 3.18)	0.99	(0.80, 1.22)
	United States	18,241	2.60	(2.57, 2.64)	1.00	

[a]Age-adjusted donors per 100,000 person-years.
New Mexico rates are age-adjusted to United States 2010 population.

TABLE 3. National and New Mexico Transplant Candidate Wait List by Race/Ethnicity (per 100,000 Population) 2009–2012

Race/Ethnicity	Geography	Transplant Wait List (*n*)	Transplant Wait List (per 100,000 Population)	95% CI	Rate Ratio	95% CI
American Indian	New Mexico	100	55.2	(44.9, 67.1)	1.37	(1.12, 1.69)
	United States	1,034	40.2	(37.8, 42.7)	1.00	
Hispanic	New Mexico	200	20.9	(18.1, 24.0)	0.60	(0.52, 0.69)
	United States	17,664	34.8	(34.3, 35.3)	1.00	
Non-Hispanic White	New Mexico	120	14.1	(11.7, 16.8)	0.80	(0.67, 0.96)
	United States	35,280	17.6	(17.4, 17.8)	1.00	

around the United States and Canada travel to New Mexico to participate in this gathering that features Native American traditions.

Although many studies have focused on ethnic and racial disparities in deceased organ donation, these generally focus on African American and Hispanic minority populations (1, 2, 13–15). Five obstacles to deceased donation were defined in African Americans by Hall et al (15): lack of awareness of transplantation, religious beliefs and misperceptions, distrust of the medical community, fear of premature declaration of death after signing a donor card, and fear of racism. The importance of a dialogue between culturally sensitive and ethnically similar healthcare providers, transplant recipients, transplant candidates, donors, and donor family members was identified as a simple strategy to address these obstacles (2, 13). It is likely that many of these same factors are important barriers to deceased organ donation in Native Americans. From these preliminary interviews, the MOTTEP was created (2, 13).

The mission of MOTTEP is to decrease the number of ethnic minority Americans needing organ transplantation. The program strategies involve the following approaches: community

TABLE 4. Factors Associated With Donor Status in New Mexico (2009–2012)

Demographics	Donors *n* (%)	Family Declined *n* (%)	Consent Not Recovered *n* (%)	OR (95% CI) for Declined Versus Donor or Consent Not Recovered
All	170 (60.7)	77 (27.5)	33 (11.8)	–
Age				
< 40 yr	90 (64.3)	38 (27.1)	12 (8.6)	1.04 (0.59, 1.81)
40+ yr (referent)	80 (57.1)	39 (27.9)	21 (15.0)	1.00
Sex				
Female	70 (62.5)	28 (25.0)	14 (12.5)	0.81 (0.45, 1.44)
Male (referent)	100 (59.50	49 (29.2)	19 (11.3)	1.00
Race/ethnicity				
American Indian	2 (7.4)	23 (85.2)	2 (7.4)	32.0 (9.5, 142)
Hispanic	76 (61.8)	35 (28.5)	12 (9.8)	2.29 (1.17, 4.62)
Other	4 (50.0)	1 (12.5)	3 (37.5)	0.83 (0.02, 7.10)
Non-Hispanic White (referent)	88 (72.1)	18 (14.8)	16 (13.1)	1.00
Registered				
Yes	117 (83.0)	4 (2.8)	20 (14.2)	0.03 (0.01, 0.08)
Undetermined	5 (29.4)	10 (58.8)	2 (11.8)	1.34 (0.43, 4.42)
No (referent)	48 (39.3)	63 (51.6)	11 (9.0)	1.00

OR = odds ratio.
Dash indicates not tested.

participation and direction to target specific community differences; face-to-face presentations especially to smaller audiences to foster discussion; collaboration and partnerships with religious, social and civic organizations; media promotion of MOTTEP's message; dissemination of culturally sensitive and informative brochures, videos, public service announcements, and other information to the community; and comprehensive evaluation to gauge effectiveness of the program. The methodology has been applied nationally with the goals to increase the number of ethnic minorities who are knowledgeable about organ donation and transplantation, who have family discussions about donation, who are willing to donate, and who are willing to adopt a healthier lifestyle (13).

The small studies that have further investigated barriers to Native American deceased organ donation have largely centered in the Midwest. In a qualitative study involving Lakota Sioux participants living on the Pine Ridge Indian Reservation in South Dakota, the following strategies were identified to address barriers to donation: 1) develop outreach programs respecting traditional beliefs while presenting organ and tissue donation within a cultural context, 2) communicate personal experiences of community members affected by both diabetes and donation, and 3) adequately prepare healthcare personnel with respect for traditional beliefs before approaching potential donor families (8). This study was subsequently followed with an intervention developed to address the barriers identified (16). The intervention was designed with community members and included the oral tradition of storytelling, materials that reflected generosity rather than traditional Western values of accumulated wealth and power, as well as traditional music, prayer, and personal interviews. Prior to the culturally focused deceased donor education program, approximately 55% of participants were not thinking about serving as a deceased donor, and after the intervention, a significant number of participants (approximately 30%) had registered as potential donors (16).

There are several limitations to this study. The development of end-stage renal disease in different ethnic groups varies by age, and the rate of end-stage renal disease in young American Indians is on the rise (17). This study does not adjust donation rates or transplant candidate rates by age, which would provide a more accurate description of the true disparities in access to organs. In fact, given that American Indians tend to develop end-stage renal disease at a younger age, the true need for deceased organ donation may be underrepresented in this study. In addition, donation RRs are normalized for living ethnic populations of the same race. The living population is used as a surrogate for the number of deceased hospitalized patients, and thus may not be a true representative of the number of potential deceased organ donors when calculating RRs. Finally, New Mexico is a predominantly rural state, and access to healthcare is limited in many rural counties, particularly access to ICU-level care. Many American Indian Reservations are located in largely rural counties, and thus a large portion of the American Indian population in New Mexico lives in a rural area. This may impact donation rates for residents in rural counties. Further research is needed to determine if rural residence impacts donation rates, particularly on American Indian Reservations.

These data spawn many directions for further research. Further research is necessary to determine potential causes for the low rate of deceased organ donation among Native Americans in New Mexico. Previous small studies have identified several possible factors. These include generalized mistrust in the healthcare system, cultural beliefs such as the need to be buried with an intact body, uncertain knowledge of the organ procurement and transplant process, and cultural taboos about discussing death and factors in reluctance for consent to organ donation. Local organ donor coordinators have identified that certain traditional Native American tribes believe that the body must remain whole to transition to the next world. Therefore, when presented the option of deceased donation for a family member, they decline. In addition, within the family, younger Native Americans often defer any decisions to elders out of respect. In this way, the traditional beliefs are passed from generation to generation.

Along the same belief system, these Native American cultures are accepting of kidney transplantation because the diseased kidney is not removed, therefore, the body will remain whole. However, these cultures will decline transplant of other organs because the diseased organ would be removed. Further investigation will determine if these beliefs hold true in the majority of Southwest Native Americans, a diverse population made up of several tribes, each with distinct cultural attitudes.

Additionally, once factors responsible for the low rate of Southwest Native American deceased organ donation are determined, outreach programs will need to be instituted to address the factors and provide culturally sensitive education on the donation process.

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