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

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Abstract

OBJECTIVE—To define how ethnicity affects donation rates in New Mexico as compared to the United States. We hypothesized that deceased donation rates in NM would reflect the ethnic rates of the population.

DESIGN—We performed a retrospective review of the Organ Procurement Database for NM from 2009 to June 2012.

MEASUREMENTS—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 US and NM rates differed. Rates were scaled to 100,000 patient-years for reporting.

RESULTS—Non-Hispanic White age-adjusted donor rates per 100,000 patient years were 2.58 in NM vs. 2.60 in US, Hispanic donor rates were 1.98 in NM vs 2.03 nationwide, and American Indian donor rates in NM were 0.26 vs. 1.23 nationwide (Rate Ratio = 0.21, 95% CI 0.05,0.86) American Indians have significantly lower donor rates in NM compared to Non-Hispanic Whites (Rate ratio = 0.11) and Hispanics (RR = 0.13) and nationally (Non-Hispanic Whites: RR = 0.32 and Hispanics: 0.43). Hispanics and Non-Hispanic Whites had similar donor rates regardless of geographic strata (Hispanics vs Non-Hispanic Whites NM: 0.83; US: 0.75). In NM 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 US 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.

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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.

Keywords

organ donation; ethnicity; transplant

INTRODUCTION

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 (UNOS) data from 1999–2008 demonstrated that the number of African American donors increased from 653 to 1278 between 1999 and 2008, and the number of Hispanic/ Latino donors increased from 612 to 1112 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 health care 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 (Figure 1) (10). Only 40 percent of the New Mexico population self-identifies as Caucasian or Non-Hispanic White. Forty-six percent identify as Hispanic, and 10 percent identify as Native American. In comparison, only 1 percent of the United States general population is Native American, and 17 percent 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.

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 <40y and ≥40y) for American Indians, Hispanics and non-Hispanic Whites and scaled to 100,000 person-years for reporting (11). Wait list Confidence intervals for donor rates and transplant wait lists were calculated using Uhl's method (12). Comparisons of NM and US rates within race/ethnicity were based on a Poisson model. Rate ratios (US referent) and approximate Wald 95% confidence intervals 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 (OR) and Wald 95% confidence intervals were used to summarize the strength of the association. SAS v9.3 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 White, 3,614 (13%) were Hispanic, and 111 (0.4%) were American Indian. 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 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 US rate (1.23 per 100,000 person-years, Rate Ratio (RR) = 0.21, 95% CI 0.05,0.86 Table 2). There was no difference between New Mexico and US

rates for Hispanics (2.03 per 100,000 person-year) 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 White, 18,149 were Hispanic, and 1,072 were American Indian. In comparison, there were 465 candidates in New Mexico on the kidney transplant wait list in December 2012, with 122 Non-Hispanic White, 212 Hispanic, and 96 American Indian based on Organ Procurement and Transplant Network data as of January 1, 2013. Number of wait list candidates per 100,000 in Table 3 are based on typical 2010 candidate wait list numbers for each race/ethnicity in New Mexico. American Indians in NM 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 NM.

We conducted univariate and multivariable analyses for NM 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 5% 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 $\times$ race/ethnicity interaction, $P = 0.015$). Among non-Hispanic Whites age <40 years 13% declined compared to 16% among age 40 years (adjusted OR = 1.46 95% CI 1.38,6.10), but among younger Hispanics 24% declined compared to 35% of Hispanics 40 years (adjusted OR = 3.13 95% CI 1.05,9.94).

DISCUSSION

This study addresses a critical disparity in health care: 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 US 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 US overall, but wait list rates for Hispanics and non-Hispanic Whites in NM were lower than the US overall.

New Mexico Donor Services (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. Over 500 tribes from around the United States and Canada

travel to New Mexico to participate in this gathering that features Native American traditions.

While 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.: 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 (15). 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 National Minority Organ Tissue Transplant Education Program (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 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 story-telling, 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 rate ratios 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 rate ratios. Finally, New Mexico is a predominantly rural state, and access to health care 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.

This data spawns many directions for further research. Further research is necessary to determine potential causes for the low rate of deceased organ donation amongst 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 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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Figure 1.

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

Table 1

New Mexico Deceased Organ Donor Characteristics

	ALL	Non-Hispanic Whites	Hispanics	American Indians
Age – mean (median), yrs	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

National and New Mexico Donor Rate by Race/Ethnicity (per 100,000 person-yr) 2009–2012

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

NM rates are age-adjusted to US 2010 population.

* age-adjusted donors per 100,000 person-yr

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 popn)	95% CI	Rate Ratio	95% CI
American Indian	NM	100	55.2	(44.9,67.1)	1.37	(1.12, 1.69)
	US	1,034	40.2	(37.8,42.7)	1.00	
Hispanic	NM	200	20.9	(18.1,24.0)	0.60	(0.52,0.69)
	US	17,664	34.8	(34.3,35.3)	1.00	
Non-Hispanic White	NM	120	14.1	(11.7,16.8)	0.80	(0.67,0.96)
	US	35,280	17.6	(17.4,17.8)	1.00	

Table 4

Factors associated with donor status in New Mexico (2009 – 2012)

	Donors N (%)	Family Declined N (%)	Consent Not Recovered N (%)	OR (95% CI) for Declined vs Donor or Consent Not Recovered
All	170 (60.7)	77 (27.5)	33 (11.8)	-- ^a
Age , <40y	90 (64.3)	38 (27.1)	12 (8.6)	1.04 (0.59,1.81)
40+y (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

^aNot tested.