

The Lived Experience of American Indian Organ Donors and Recipients: Stories of Cultural, Physical, and Spiritual Triumph

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To provide knowledge to the future generations

To honor the land of the future

To honor the memory of the past

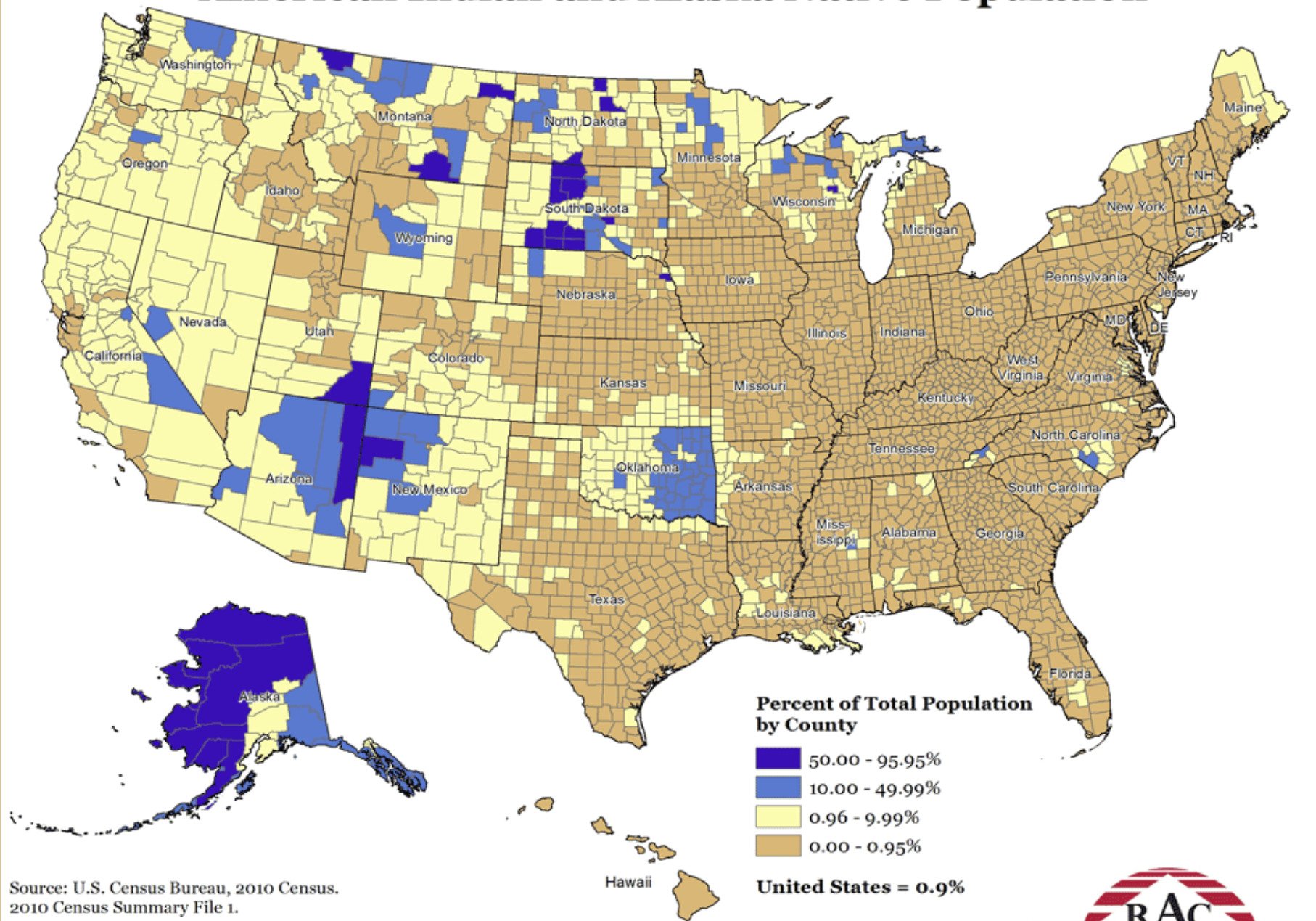
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American Indian and Alaska Native Population



Source: U.S. Census Bureau, 2010 Census.
2010 Census Summary File 1.

Note: Alaska and Hawaii not shown to scale

Statistics for American Indians

- 5.2 million American Indian and Alaska Natives
- 2% of the US population
- 566 federally recognized American Indian tribes
- 30% live in poverty (US national average is 15%)



Cultural Factors

- Family oriented
- Strong connection to reservation and other American Indians
- May struggle with traditional vs. religious beliefs
- Traditional belief of body needing to remain whole
- Indian Health Service contract health issues
- Deceased organ donation is rarely done



Background

- $\frac{1}{2}$ of American Indian (AI) adults are diagnosed with diabetes
- AI are 3.5 times more likely to have end-stage renal disease
- Minorities make up 58% of the transplant waiting list in the US
- There are over 1,000 AI waiting for organs



Literature Says....

- American Indians are not willing to be organ donors
- Diabetes has reached epidemic proportions in American Indians
- American Indians are more likely have ESRD requiring dialysis than other races
- American Indians wait longer on transplant waiting lists compared to other populations



Methodology

- Phenomenology
 - Both a philosophy and method
 - Utilized van Manen's Lifeworld Existentials of lived body, lived time, lived space, and lived relationality as a priori codes
 - Synthesized data so readers can see, feel, hear, *experience* what participants are describing



Data Collection Procedures

- Participants recruited through community fliers, newspapers, radio
- Informational letter sent to participants with questions to reflect on prior to interview
- Semi-structured interviews lasted 40-100 minutes
- Encouraged to tell their story in a temporal aspect



Participant Demographics

- Enrolled members of Ojibwe tribes, 6 females and 4 males
- Ages ranged from 29 to 72 at the time of interview
- 4 donors and 6 recipients
- All lived on home reservation except one
- All were of Christian faith or traditional practitioners



Findings for Donors

- Lived Body
 - *I Hope We're Compatible*
 - *Reflecting on Recovery since Organ Donation*
 - *No Regrets about Giving the Gift of Life*



Findings for Donors

- Lived Relationality
 - *You Don't Need to Ask Me to be the Donor– I'm the Caregiver, I'll Donate*
 - *Broken Body, Broken Spirit– Healed by One Donation*
 - *Sharing My Experience with Others*



Findings for Donors

- Lived Space
 - *Overwhelming Fear and Anxiety*
 - *We Live More than a Mile Away*



Findings for Donors

- Lived Time
 - *Waiting*



“I would tell [other potential donors] to look into it more about how they feel about it. Emotionally, spiritually—it’s a good gift and a person who is giving it I commend them on what they do because they actually give another individual a second chance to maybe correct some of the things in the rest of the life that the patient might have... I wouldn’t change any of the things that I ever did, even the surgery. The surgery did turn out good things. It might not have turned out the best things for [brother/recipient] but it actually turned out good for me. Between here and that time I would never have changed anything but it got me—it gave me my second chance.”

– Donated to brother



Findings for Recipients

- Lived Body
 - *Sick of Being Sick– Finding a New “Normal”*
 - *Relying on AI Tradition*
 - *Hopelessness to Hope-Filled*
 - *Another Chance at a New Life*
 - *Fearing Rejection*



Findings for Recipients

- Lived Relationality
 - *Family and Community Support*
 - *Relying on Health Care Team and God*



Findings for Recipients

- Lived Space
 - *Staying Spiritually Connected*
 - *Accepting Reality– Living Life to the Max*



Findings for Recipients

- Lived Time
 - *Waiting*



“The day before [surgery] was a hard night. I will always remember that night before... I didn't get much sleep, you know thinking about a thousand things...[but now] one thing that always sticks in my mind is that a kidney will last for about 15 years from transplant time. Eventually I will have kidney failure again. I think about that from time to time. I know when the time comes, when that day comes, it will be hard to prepare for that. I try not to think about it but again I have to think about it once in a while. Who knows how long I will be here?” —
Received kidney from brother



Limitations

- Lack of generalizability due to the use of phenomenology
- Study sample only included enrolled members of Ojibwe tribes



Implications for Practice

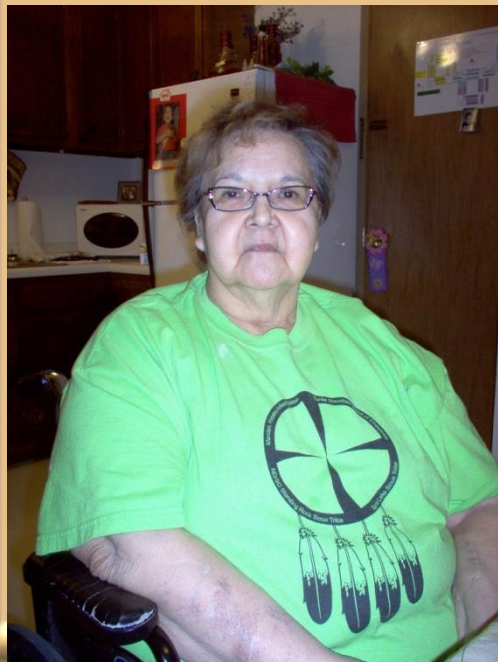
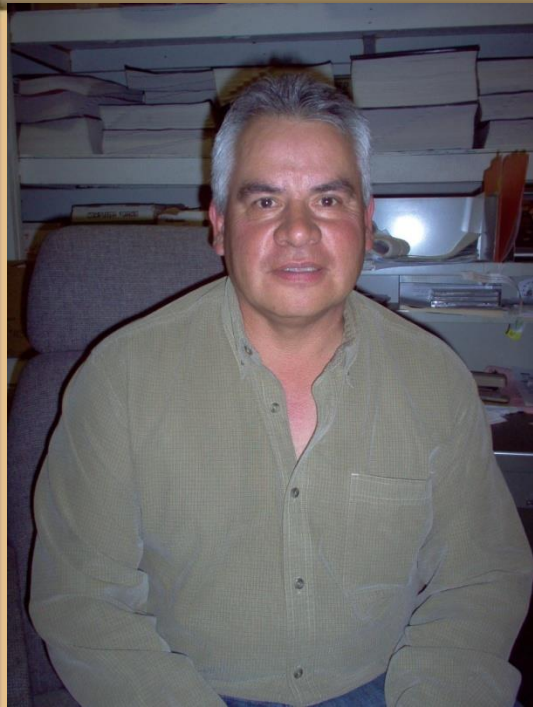
- Participants were grateful for care provided by nursing staff, including patient education
- Nurses can be confident when approaching AI about organ donation
- Awareness of culture and employment of AI nurses in transplant programs would help increase the number of AI willing to be donors



Future Research

- Follow up with current quality of life after organ donation and transplantation
- Study AI families that have participated in the decision to donate a deceased loved one's organs
- Replicate study with other tribes and indigenous peoples
- Study potential organ donors and recipients and their decision-making process
- Study issues related to deceased organ donation in AI communities





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