Design and Testing of New Education on Living Kidney Donation and Transplantation for Native Americans

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Research Program Partners

- **Tribal Communities**
  - Leaders, Advisors, Facilitators, Tribal Colleges and Universities, Tribal Health Directors and Staff, and Community Members

- **Health & Allied Health Organizations:**
  - SD Lions Eye Bank, Dialysis Centers, Health Centers, Sanford Research, Sanford Transplant, Hennepin County Medical Center, Minneapolis Medical Research Foundation, LifeSource

- **Project Teams**
  - Students, Co-investigators, Staff
  - Advertising firms, Photographers
Funding Sources

US DHHS, HRSA, Division of Transplantation:

- CFDA 93.134 Social and Behavioral Interventions to Increase Solid Organ Donation
  - #R39OT01211, 2003-2007 “Sharing the Gift of Life”
  - #R39OT07542, 2006-2010 “Tribes Sharing Life”
  - #R39OT24207, 2012-2016 “A Circle of Learning”

US DHHS, NIH, Nat’l Center for Minority Health Disparities

- #U54MD008164, 2012-2017, “LKDT Education for Dialysis Patients”
  - Amy Elliott, Sanford Research, Center PI - “Collaborative Research Center for American Indian Health,” Fahrenwald, Research Project PI
  - Funding Source for Presentation
Background

- Chronic Disease Prevalence and Population Differences
- End Stage Renal Disease
- Treatment options
- State of the Science in Education on Living Kidney Donation and Transplantation
- Purpose
Donation Need & Consent

- Demand for kidney donors
- Low deceased donor consent rates
- Willingness to donate a kidney is present
- HLA-match better within tribes
- Better outcomes with transplant
Working Together

Tribal priorities: relate to the community need
Trust: committed presence, integrity
Values & beliefs: respect, community benefit
Message: community based approach
Specific Aims

- **AIM 1**: Explore the contextual factors that impact LKDT attitudes and educational needs among American Indians.

- **AIM 2**: Create a new educational program designed to increase knowledge of the benefits and risks of living kidney donation and transplant (LKDT).

- **AIM 3**: Conduct a group randomized test of the intervention and examine its effect on the outcomes of knowledge of LKDT and related conversations with family members.
Theoretical Context

Contextual Factors

- Decisional Balance
  - Pros/Cons

- Self-Efficacy

- Knowledge

Intention

Conversation about LKDT

Stage of Motivational Readiness

Derived from the Transtheoretical Model of Behavior Change: Prochaska, DiClemente, & Norcross, 1992
Aim 1 Methods

- **Qualitative Description Study Design**
- One on one recorded interviews with people receiving dialysis
- 5 American Indian adults
- Audio Recorded
- Constant Comparative Method
- Themes:
  - cautious approach toward living kidney donation and transplant conversations
  - concern for others
  - expectations for culturally-sensitive education
Aim 2 Methods

- Formative Evaluation Method and Design
- Messaging for the Education Program
  - Derived from Aim 1 interview themes
  - Derived from the literature
  - Derived from the theoretical framework
  - Derived from stakeholder input
- Process of Educational Program Development
- Evaluation of the Program
HOPE and HEALING
Through Living Kidney Donation and Transplant

24 minutes

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http://youtu.be/YHV3QY9qIAk
Aim 3 Methods

- **Site Randomized Trial**
  - Sharing Hope and Healing intervention (24 minute DVD, companion brochure)
  - Two groups
    - Experimental & delayed intervention control
    - 2 week delay, pre/post measures
  - Protocol Summary

- **Setting and Sample**
  - Renal Dialysis Centers (n = 7)
  - American Indians, 139 enrolled (70/69 Exp/Control)
  - 129 completed

- **Measures**
  - LKDT Knowledge, Stage of Readiness to talk with family, and Hope
Results

LKDT Knowledge (16 items, T/F, score range 0-16)

- Difference scores calculated as post-score minus pre-score to evaluate intervention effects (n = 129)
- Linear mixed model with dialysis site as a random effect
  - no significant difference between the intervention and control groups in LKDT knowledge post-intervention (p = 0.8; adjusted for baseline knowledge score, baseline hope score, gender, education and age).
  - The adjusted mean post-intervention knowledge score (range: 0 to 16) for the intervention group was 11.0 (SE=0.3) and for the control group was 10.9 (SE=0.3)
Results

Change in Stage of Readiness to Talk with Family/Friends

- 48 individuals analyzed (2 intervention/4 control sites)
- Exclusions related to inconsistent responses or being at the highest level of readiness
- Binary regression using generalized estimating equations
- Intervention group was 5-times more likely than the control group to improve readiness to talk about kidney donation

Gender-adjusted OR = 5.0 (95% CI = 1.9, 13.6)
Results

Hope (HHI scale, 12 items, scores range 12 – 48)

- At baseline, female scores were slightly higher than males (Mean ± SE: 39.6 ± 0.5 (79) and 38.3 ± 0.6 (58), p = 0.07).
- Association of the intervention and change in hope evaluated using a mixed effect model including baseline hope, baseline LKDT knowledge, gender, education, and age — no significant association was found.
- In a mixed model for the change in knowledge score, baseline hope had a marginally significant association with the change in knowledge over the intervention (beta mean ± SE: 0.08 ± 0.04, p = 0.07).
Conclusions

- The site randomized trial was a pilot study
- Replication and further testing is needed
  - Different populations
  - Family members