

Barriers in Access to Transplantation in Central Texas (BATCT)

IC² Institute

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Project background

The burden of kidney disease

37 million people (11%) in the United States have chronic kidney disease (CKD). Nearly 570,000 suffer from end stage kidney disease (ESKD), the most severe form, and require chronic dialysis to avoid death from kidney failure.¹ The cost of ESKD to the healthcare system is considerable, accounting for over \$50 billion in Medicare expenditures in 2021. The best therapy for ESKD is kidney transplantation, which is both cost-effective and improves both quality and length of life. On average, transplanted kidneys last 15 years, but due to a shortage of viable living and deceased organ donors, only 24,000 kidney transplants are performed annually among the waitlist of nearly 100,000 patients; the remaining 470,000 patients with ESKD are not on the waitlist at all.²

From kidney failure to transplantation

Successfully undergoing kidney transplantation is a complex process that (1) begins with the development of ESKD, (2) necessitates the decision by a nephrologist or social worker to refer to one of approximately 250 kidney transplant centers in the US, (3) continues with evaluation by one of these transplant centers, (4) proceeds with the decision to place a patient on the transplant waitlist, and (5) culminates with a kidney transplant from either a living or deceased donor. The systemic barriers in the pre-evaluation steps (1 and 2) are poorly understood and represent a significant challenge to accessing transplantation.³

Structural inequalities in ESKD

Structural, institutional, systemic, and interpersonal barriers contribute to inequitable experiences of the social drivers of health, shaping health outcomes and access to care for patients with ESKD.³ One example: despite disproportionately higher rates of kidney failure, Black and Hispanic individuals are less likely (1) to be waitlisted for kidney transplantation and (2) to receive a kidney transplant than non-Hispanic Whites.^{4,5}

Project goals and motivation

Why engage with ESKD in central Texas?

Our adult kidney transplant program opened at the University of Texas at Austin and Dell Seton Medical Center in November 2021 with the goal of delivering equitable, world-class, and evidence-based care to all people of central Texas. As we grow and learn how to best serve our community, our abdominal transplant program at the University of Texas at Austin is uniquely positioned to study, address, and counteract local disparities via patient-centered research.

Core questions

To identify innovative, patient-centered solutions that advance equity⁶, we used our IC² funding to launch a parallel mixed-methods study to ask the following core questions about ESKD in central Texas:

- What are the social determinants of health that most strongly impact access to primary, nephrology, and transplant care?
- What are the barriers and facilitators of being referred and evaluated for kidney transplantation?
- How and to what extent can we better identify and serve patients of an underserved or marginalized community that would benefit from transplantation services?
- What does equity in access to transplantation mean to patients with ESKD and their caregivers?

Methods

Participants

Eligible participants were adult kidney transplant candidates who presented for evaluation at the Abdominal Transplant Center at Dell Seton Medical Center at The University of Texas from May 2022 through April 2023. Patients were approached for enrollment during their initial clinic evaluation visit. We excluded patients with cognitive impairment, impaired vision, and those who were unable to read in either English or Spanish.

Study design

To better understand local referral patterns against the known prevalent dialysis population, we first conducted a geospatial analysis of all patients who were referred to our clinic for evaluation. From the subset of patients that were evaluated in clinic, we conducted a parallel mixed-methods study with (1) a quantitative set of surveys and instruments and (2) a qualitative interview of patients and caregivers.

Eligible participants were approached for study consent during their kidney transplant. Patients who enrolled completed surveys collecting demographic information, mood (PHQ-9⁷ and GAD-7⁸), social needs (American Academic of Family Physicians Social Needs Screening Tool), quality of life (Kidney Disease and Quality of Life)^{9,10}, and they completed an in-person health literacy assessment (Newest Vital Sign) with the research team.¹¹ Surveys were administered in both English and Spanish which were completed either electronically through an iPad or paper depending on participant preference.

After completion of the survey instruments, patients and their caregivers were offered the opportunity to jointly participate in a semi-structured qualitative interview at a later date. The interview was designed around prompts to explore the underlying meanings associated with the structural barriers experienced by patients and caregivers dealing with CKD. All participants were individually compensated for a 45-minute interview with a member of the research team.

After our initial approach with patients who were referred, we partnered with community health workers from the Department of Population Health at Dell Medical School to identify and interview patients who had not yet been referred for kidney transplant evaluation. The inclusion of a community sample was designed to understand the impact of structural access on non-referred participants in the study of CKD. This sample reflected the perspectives, insights, and lived experiences of community members as they navigate the complexities of healthcare, highlighting ways to address care disparities. Additionally, the community sample served as a conduit for creating and disseminating tailored messages and information about kidney disease that resonate with the community's belief systems.

Geocoding and referral bases

We geocoded the addresses of 643 patients who were referred to our transplant center during the first year from the central Texas region. 73% of the referrals came from within 30 miles of our transplant center. There was significant spatial clustering for both referral pattern (local Moran's I 0.40, $P < 0.001$, Figure 1A) and ESKD prevalence (local Moran's I 0.32, $P = 0.002$, Figure 1B). We identified zip codes (figure 1C, bivariate local Moran's I , $P < 0.001$) with a high burden of disease and high proportion of referrals (purple) and a high burden of disease but low proportion of referrals (red). Notably, the zip codes with a high burden of disease and low proportion of referrals are in areas of greater socioeconomic disadvantage, defined by a lower median household income ($P < 0.01$). 36.6% of the patients came from high burden/high referral zip codes, and 6.1% were from low burden/high referral zip codes.

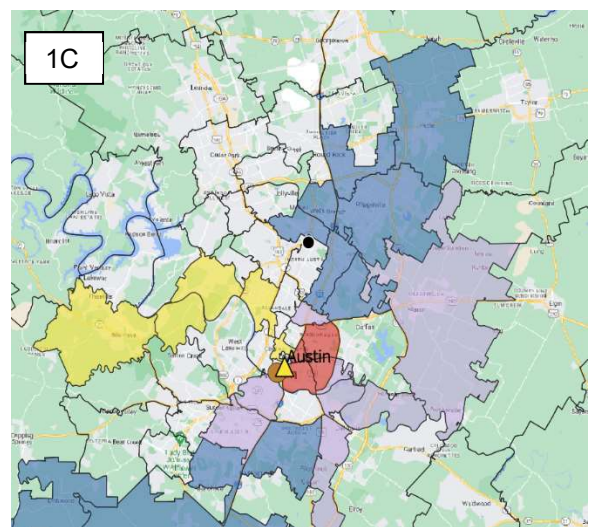
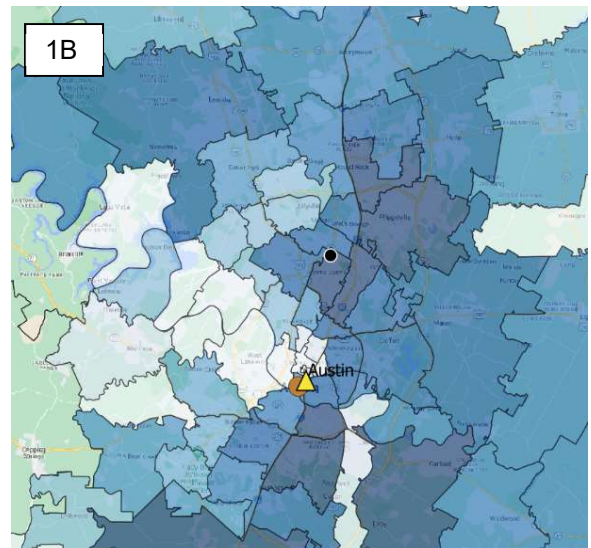
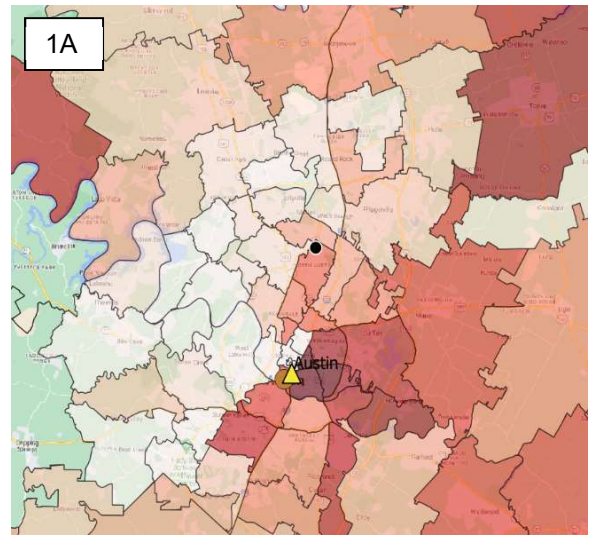
Quantitative results

217 patients participated in the quantitative instrument during their kidney transplant evaluation. Compared to the prevalent population, the participants were slightly younger (median age 53 vs 57 years), were less likely to be White (60.4% vs 70.5%) and were more likely to identify as Hispanic (52.1%). Referred patients were more likely to be on peritoneal dialysis (18.4% vs 8.7%) and were on dialysis for longer (4.5 vs 3.2 years). There were twice as many patients who had a prior kidney transplant (10.6% vs 5.0%). Medicare was slightly more common as primary insurance (44.2% vs 38.2%).

Other notable findings included nearly 40% of patients who spoke Spanish at home. 45.6% had been evaluated for kidney transplant before. By self-report, median household income was less than \$50,000. In terms of the social drivers of health (Table 2), 22.6% of participants identified food as a key social need. 16.1% of patients had at least mild anxiety, and 32.7% had at least mild depression. Limited health literacy was identified in 48.9% of participants. On the KDQOL (Table 3), the patients had a lower median burden of kidney disease (43.8 vs 52.8), higher (or similar) effects of kidney disease score (75.0 vs 74.1), higher symptoms/problems of kidney disease (84.4 vs 79.0), and a similar summary score (66.3 vs 73.0) compared to United States population norms.

Qualitative results

There were 16 patients with 6 caregivers interviewed. The participants referenced various topics related to the main emerging theme: access to care. These findings are reflected in three subthemes that support the emerging pattern: (1) access to care and patient-provider experience, (2) the meaning of illness to the patient's life, and



power over their own care decisions, and (3) the influence that social support and health information plays in their care. These themes capture the role and influence of health belief systems on the participants' experiences with healthcare providers concerning CKD. For example, a participant described being diagnosed in front of her parents at 18. When the time came to discuss treatment options, she was excluded from the conversation by the doctor, who instead turned to her parents, influenced by the fact that they possessed the health insurance. This event left a lasting negative impression on her view of doctors, as it made her feel disempowered and subsequently reluctant to work with medical professionals, feeling her autonomy and opinions were overlooked. This became an obstacle to her active involvement in decision-making. The identified themes offer a range of viewpoints and understandings about the everyday challenges navigating healthcare for CKD, specific obstacles faced throughout their healthcare experiences, and the diverse interpretations of CKD among the participants.

We also interviewed 8 non-referred patients who were identified with the assistance of community health workers. The community sample, primarily Spanish-speaking individuals experienced with CKD and dialysis, provided valuable insights into their diagnosis, healthcare interactions, and the barriers they face regarding access to health education. Emphasizing the critical role of public education and campaigns, participants highlighted the need to increase awareness of CKD, support for caregivers and patients, and integrate common knowledge with evidence-based methods to address systemic challenges.

Synthesis and future directions

This study, for the first time, takes into consideration the perspective of patients and caregivers on barriers to accessing transplantation in the setting of a new transplant center. We found that the majority of referred patients did not reside in local areas with the highest disease burden. We also identified a number of social drivers of health, many of which are consistent with themes surfaced in qualitative interviews with patients and their caregivers who identified access to transplant care. These challenges are reflected in healthcare and provider engagement as well as the impact of social support and health literacy in care access, which collectively provide a unique description of the barriers in access to kidney transplant that exist among patients with ESKD living in central Texas.

The current study broadens the understanding of transplant access barriers as it adds qualitative depth and caregiver perspectives to the knowledge gap. Participants noted that transplant referral is impacted by communication and engagement with physician providers, and that the role and influence of personal social networks that offset the lack of systemic support. Perspectives from patients complemented those shared by caregivers in our study, which further deepens our understanding of transplant access barriers by adding an important voice from key care partners and known facilitators to transplant access. The current study expands the understanding of transplant access barriers among patients and caregivers in the setting of a new transplant center, which also provides an example for future studies of this nature.

We hope that his work will lead to the development of Kidney Health Awareness for Texas (KHAFT), which is a health communication campaign that fosters collaboration and employs evidence-based, community-centered strategies to develop messages, information, and resources. These tools are designed to help Texans access comprehensive care tailored to community needs related to transplantation, dialysis, and kidney health management. The concept of KHAFT is inspired by the Pen-3 Model¹², which emphasizes cultural empowerment, cultural literacy, and a culturally informed perspective in addressing health adversities. This model has been featured in public health and health communication interventions prioritizing underserved or marginalized minority communities. It aims to minimize adverse health outcomes by incorporating cultural belief systems, representation, and knowledge to address health problems.^{13,14} KHAFT is recommended as an intervention to increase access to care and provide resources for cultural-health literacy concerning kidney health and CKD.

While not the primary focus of the study, we have collected much of the same data at followup with our kidney transplant recipients (11 total patients who enrolled pretransplant are followed posttransplant in the study). To date, we have 10 patients with 30 day, 7 patients with 3 month, and 4 patients with 6 month followup. Analysis is forthcoming, as we are waiting for the first 10 patients to complete at least 6 months followup.

Based on these initial findings, we obtained additional research funding to conduct a similar study with dialysis social workers. We learned that they were the primary assessors of transplant eligibility in the community, and they also performed the bulk of the transplant referrals. An ongoing mixed-methods study will complete data collection by the end of 2023, with initial analysis already ongoing. We plan to conduct a similar study with nephrologists about their referral patterns and assessments, and hope to combine all findings into a larger multi-site grant proposal in the future.

Additional funding applications

- St. David's Center for Health Promotion & Disease Prevention Research in Underserved Populations (St. David's CHPR): Understanding barriers in access to kidney transplantation in Central Texas. Not funded.
- Society for Transplant Social Workers (STSW): Barriers in access to kidney transplantation in Central Texas (BATCT): Characterizing the role of dialysis social workers. Funded, \$10k.
- Dell Medical School Health Transformation Research Institute (HTRI): Barriers in access to kidney transplantation in Central Texas (BATCT): Perspectives of nephrologists. In process.

Presentations and manuscripts

1. Chen G, Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Turgeon NA, and Adler JT. Barriers in access to transplantation in central Texas in the setting of a new transplant program. National Kidney Foundation Spring Clinical Meetings. Austin, TX. April 2023.
2. Chen G, Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Lubetzky ML, Blackwell LM, Young YL, Upshaw SJ, Turgeon NA, and Adler JT. Barriers in Access to Transplantation in Central Texas in the Setting of a New Transplant Program. Department of Surgery and Perioperative Care Research Day. Austin, TX. May 2023.
3. Adler JT, Lubetzky ML, Kuk AE, Molina A, Chen G, and Turgeon NA. Spatial patterns in ESKD prevalence and referral in the first year of a new transplant center: opportunities to improve access. American Transplant Congress. San Diego, CA. June 2023.
4. Chen G, Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Turgeon NA, and Adler JT. Barriers in access to transplantation in central Texas in the setting of new transplant program. American Transplant Congress. San Diego, CA. June 2023.
5. Chen G, Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Lubetzky ML, Blackwell LM, Young YL, Upshaw SJ, Turgeon NA, and Adler JT. Barriers in Access to Transplantation in Central Texas in the Setting of a New Transplant Program. Society of Transplant Social Workers Annual Meeting. San Diego, CA. June 2023.
6. Chen G, Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Turgeon NA, Adler JT. Barriers in access to transplantation in central Texas in the setting of new transplant program. Barriers in Access to Transplantation in Central Texas in the Setting of a New Transplant Program. Texas Transplantation Society Annual Meeting. Georgetown, TX. August 2023.
7. Anantharam B, Hu CF, Jimenez S, Slack AC, Kuk AE, Lee BK, Turgeon NA, Chen G, Blackwell L, Adler JT. Barriers in Access to Transplantation in Central Texas in the Setting of a New Transplant Program. Texas Society for Public Health Education Biennial Meeting. Austin, TX. October 2023.
8. Upshaw SJ, Adler JT, Young Y, Chen G, and Turgeon NA. Investigating sociocultural influences on barriers to access to kidney care services among patient and caregivers of color in Central Texas: A qualitative study. National Communication Association Convention. Washington, DC. November 2023.

Manuscripts (in preparation)

- Barriers in access to transplantation in central Texas: a mixed-methods study
- Utilizing the health belief model in culture-centered health communication: enhancing access to care for chronic kidney disease patients and caregivers in Central Texas.

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