

Delays Despite Priority: Qualitative Interviews of Living Kidney Donors with End Stage Renal Disease

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Problem

- Since 1996, United Network for Organ Sharing (UNOS) gives priority to former living kidney donors (LKDs) who develop End Stage Renal Disease (ESRD) for a deceased donor kidney
- 2016 → Wainright et al. found that a substantial number of LKDs who developed ESRD had long wait times despite their priority

Former Living Donor Project at the University of Chicago

- National database with a growing sample of 220 participants who all donated a kidney and later went into kidney failure
- While the Living Donor Project is focused on finding genetic causes of why these donors develop ESRD, we noticed that **approximately 10% of our sample waited over 3 years to get a kidney after their kidney failed**

Goal

The aim of this project was to understand the delays in receiving a transplant experienced by former LKDs who developed ESRD.

Design

Study Design

Semi-structured interviews were conducted of LKDs with ESRD who waited at least three years before receiving a deceased kidney donation after self-classified “chronic kidney failure”. Participants were recruited from the University of Chicago Living Donor Project. The IRB at the University of Chicago approved this study (IRB#22-0827).

Recruitment

Potential participants were mailed a brief information sheet and asked to respond if interested. Follow-up calls were made in the following weeks.

Data Collection and Analysis

- Phone calls → participants provided oral consent to be interviewed and recorded
- A semi-structured interview guide was used to conduct 60-90 minute interviews
- Transcripts were reviewed by researchers and inconsistencies addressed through re-contacting participants
- Transcripts transcribed verbatim by Trint, then reviewed and corrected by MA
- Code book developed → 11 Codes:
 - Donation story, donation risks, health to sickness, listing, delay reasons, living donor considered by LKD, post-transplant reflections, priority points, renal replacement therapy (subcodes: donor on dialysis, dialysis experience, donor receives transplant), support, and multiple institutions
- Coded in Atlas.ti by two reviewers (MA, LFR)

Results

Age Range	55-80
Gender	Male (N = 5)
Race/Ethnicity	<ul style="list-style-type: none"> Black (N=2) Black and Native American (1) Hispanic (1) White (3)
Years between self-classified kidney failure and transplant	<ul style="list-style-type: none"> 3 years (N = 2) 5 years (1) 8 years (1) 9 years (1) 10 years (2)

Other Themes and Illustrative Excerpts

Lack of post-donation follow up care

“They only told me that the [donation] operation went fine. **The doctors came in and they said, you know, I can live a normal life.** At that time, I didn't have a primary doctor or anything to follow up. You know, they said, yes, it's going to be even. The only thing I'm just going to have a scar because how they had removed the kidney.” (F-119)

LKD's understanding of priority points

“I was seeing people die right beside me, and I'm watching people just come right in [to dialysis], and a couple of weeks later, they get transplanted. I'm watching people who had a transplant, get another transplant... And what am I to think, I should be at the top of the list. You know, and **they told me that you should be at the top of the list, you donated, what's going on?**” (B-305-309).

Not valued as a recipient like they were as a donor

“You know, when they want your kidney, everything gets done real fast. **When you need a kidney, nobody cares**” (E-509).

Obstacles

Note: Most participants experienced a combination of multiple obstacles

Obstacle 1: High Sensitization (N=4)

Obstacle 2: Psychosocial Factors (N=3)

Obstacle 3: Delays in Transition from Non-Transplant Center (NTC) to Transplant Center (TC) (N=3)

Miscellaneous Obstacles (N=3)

Interview Excerpts (Participant Letter – Paragraph #)

“I was listed at the hospitals in Chicago. I went to Wisconsin to do to study because **my antibody level was too high and there wasn't. They couldn't find a match...**But, yeah, I was on dialysis, you know, they couldn't do anything until after I had my baby, anyway. So took like majority of the year. The first year... And then I started the treatment, you know. That's another half of the year. And then was placed on the waiting list” (C-129-173).

“Some people were like, what's going on? Like the social worker. **I'm wondering if it was my drug use that they held back.**” (B-309)

“And when I got [to the transplant center] the guy said, I don't think we can help you because you need somebody to come here with you for two weeks. And I said, well, **I don't have anybody that can come here with me for two weeks**” (E-145).

“**And then the coordinator said I was talking mean to her. But then in the file they wrote that I wasn't taking my medication, which wasn't true. I don't know where they were getting it from.** That was three years later. So they denied me and said I had to do it again in six months” (C-281).

“I mean, why didn't [NTC] start looking for my past or whatever? When they knew I was a donor. Yeah, they had to know [about my priority], I probably they seemed like they had asked me, you know. Where had I [donated]? **I mean, they really were so gung ho about it... Until [University TC] got a whiff of it...** I mean, after [TC] found out that I was the donor, I was more interesting then before 2005, when I was um 1995” (B-489-501).

All three of these participants ended up waiting over 9 years for a transplant despite being eligible earlier

- COVID-19 vaccine refusal leading to waitlist removal
- Experimental heart valve operation
- Finding a healthcare team that would do non-steroid post-transplant treatment

Conclusions

While there's a wealth of literature on systemic issues within the U.S. transplant realm, what this study has done is highlight a unique group of patients' stories. **It reminds us that each individual in need of a kidney transplant experiences system failures in their own way.** That said, many barriers to getting listed and getting a transplant hold regardless of donor status, such as the psychosocial barriers discussed. But what makes donors unique is that the transplant community may have increased, or at least accelerated, the donor's risk of developing kidney failure, which explains at least in part WHY they're given priority for deceased donor transplantation in the first place.

We saw how priority may not overcome sensitization, so though we give priority implying individuals will not have a long wait, they still may have a long wait. While the study was limited by a small sample size, living donors with ESRD are more likely to be male and more likely to be Black, which was reflected in our sample. Another limitation was that we only had the donors' perspectives, not their providers' perspectives.

Next Steps

Moving forward, since the transplant community now knows that unilateral nephrectomy has short-term and long-term risks, **living donors need to be viewed as patients for life and receive adequate long-term follow-up care.** Many donors are currently NOT receiving long-term follow-up care, and this can be addressed, in part, by holding institutions accountable. Finally, out of respect to our donors, one could argue that **donors who go into kidney failure should be provided advocates to guide them through the listing and transplant process, just as they had an advocate team when they were becoming donors.**

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