Barriers to "The Big Ask" and Opportunities to Increase Living Donor Kidney Transplant among Dialysis Patients and Care Givers

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Introduction

- Kidney transplant is the best treatment option for patients with kidney failure; however, there are more patients who need a transplant than there are available organs from deceased donors.
- Living donor kidney transplant (LDKT) offers an alternative option to gain access to an organ and may result in a faster transplantation than the typical deceased donor transplant path. Additionally, a kidney from a living donor typically lasts about twice as long as a kidney from a deceased donor.
- Previous studies indicate that while many dialysis patients and care partners are aware of LDKT, they are unable to leverage their personal networks to obtain a living donation.

Objective

- In this study, we sought to understand the current barriers to kidney transplant and living donation for dialysis patients and their care partners.

Methods

- Participants were interviewed by phone between May and August 2021.
- Interviews ranged in time from 10-45 minutes and included a spectrum of participants including dialysis patients and their care partners.
- Interviews were recorded and transcribed verbatim; responses were analyzed separately using the inductive thematic analysis procedure.[1]
- Analysis involved the following stages:
  - Review of the data to identify key patterns (themes) relevelant to research topic
  - Generation of inital categories whereby similar areas of text are grouped together across the data set
  - Review of themes
  - Coding of interviews with report generation

Results

Study Participant Characteristics

Type of Participant	Number of Respondents
Chronic Kidney Disease (CKD) patients	9
In-Center Hemodialysis (ICHD) patients	3
Peritoneal Dialysis (PD) patients	7
Home Hemodialysis (HHD) patients	2
Care Partners (CP)	5
Total	26

Patients are reluctant to make "The Big Ask" of individuals in their network

- Almost all respondents say that their closest family members/ friends have prior knowledge of their kidney issues, so there is not a "dramatic reveal" of kidney failure or need for a donor.
- Most LDKT conversations between patients and potential living donors are informational; establishing the need for dialysis and sharing prognosis information.
- Some respondents indicate a difficulty getting past this "information-only" stage with certain people. A few patients expect that simply talking about their health issues will lead to an offer of a kidney.

"I did as [go] far as maybe mentioning, you know, that I have kidney failure and that I need a kidney. Um, usually people kind of turn away from that you know. [I say] you know I'm being tested because I have kidney failure and I need a kidney [and] I'm doing everything that I can to try to save myself. I guess[...]I don't go past that stage" (PD patient)

- Male respondents tended to report more "organic" living donor conversations, while more women report proactively bringing up the topic of living donation.

Patients who have successfully identified a living donor are likely to have had someone volunteer

- Of the 26 patients and care partners interviewed, 5 have identified a living donor and are at various stages of testing/evaluation.
  - ***4/5 were proactively offered a kidney***

Reluctance to "ask" for a kidney is complicated, but a key driver of LDKT hesitancy

- Reasons why patients hesitate to request a kidney from family/friends are varied; however, the most common reason given was that patients feel they have already lived a "good" life and do not wish to put anyone through a life-changing event.

"I felt guilty asking someone to do something like that. If I was much younger maybe I would have a different way of feeling about it but I am 75 and to ask somebody who is younger to give up a kidney when you don't know what their situation may be when they get older. I just thought at my age, I have lived a decent life and I didn't feel I could impact somebody like that by asking them to give up an organ. I didn't feel comfortable doing that at all." (PD patient)

Patients are especially averse to accepting a kidney from their own children, even if the child has expressed initial interest

"I just don't want to risk hurting my kids. I don't know that it would be a danger to them as much as it would be to me. But I wouldn't want to take a chance. [Either of my 2 daughters...] would jump at the chance to help me if they could. But I would be the leery one to ask them to give up anything." (ICHD patient)

"It's not for me. I don't want to put my own children through the operation that's why." (PD patient)

"A living donor, they're putting their life at risk also for infection and um big surgery and there's pain and suffering, recovering. And I would never do that to someone because one day down the road they may have a problem and then their remaining kidney fails and then what? So I would never jeopardize someone else's health. That's my feelings. Especially my family, I would never want to do that." (CKD patient)

Results

Almost all patients and care partners acknowledge some concerns for prospective donors

"That maybe they eventually down the line develop a disease that would affect their only kidney that they have? Whether it's diabetes or heart disease." (CKD patient)

"I would be concerned about that donor, if that donor were let's say one of our children or whatever I would be worried about the fact that if he's developed this advanced kidney disease so are they going to be prone to that as well?" (Care Partner)

"[T]he medical billing and their work place absenteeism. They would be penalized for that." (ICHD patient)

Conclusions

- Significant barriers to living donor kidney translant consideration were largely social and psychological, including:
  - unwillingness to make the "big ask" of their social network
  - inability to identify a suitable donor within their own network
  - feeling that younger patients/patients raising families are more "worthy" of a LDKT
  - financial burden for donor
- An area of opportunity to increase living donor transplants lies in helping patients craft a viable strategy to leverage all available networks and developing a script for conversations with these networks around living donation.

References

1. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

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