Introducing kidney transplantation as 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 transplantation (LDKT) offers an alternative option to gain access to an organ and may result in a faster transplantation than the typical deceased donor transplant pathway. Additionally, a kidney from a living donor typically lasts 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

Patients were interviewed by phone between May and August 2021.

Interviews ranged in length 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.

Analysis involved the following stages:

- Review of the data to identify key patterns (themes) relevant to research
- Generation of initial categories whereby similar areas of text are grouped together across the data set
- Review of themes
- Coding of interviews with repeat report generation

Results

Study Participant Characteristics

<table>
<thead>
<tr>
<th>Type of Participant</th>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Kidney Disease (CKD) patients</td>
<td>9</td>
</tr>
<tr>
<td>In-Center Hemodialysis (ICHD) patients</td>
<td>12</td>
</tr>
<tr>
<td>Peritoneal Dialysis (PD) patients</td>
<td>7</td>
</tr>
<tr>
<td>Home Hemodialysis (HHI) patients</td>
<td>2</td>
</tr>
<tr>
<td>Care Partners (CP)</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
</tr>
</tbody>
</table>

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 diagnosis is or whether they might get better as they 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 don't feel comfortable doing that at all." (PD patient)

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 just don't want to risk hurting my kids. I don't know that it would be a danger to them." (CKD patient)

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

"I was concerned about the donor, that donor was 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)

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." (CHD patient)

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

"I don't think that they would be interested in doing that because they know I have kidney disease." (CP patient)

Conclusions

- Significant barriers to living donor kidney transplantation 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 transplant rates by helping patients craft a viable strategy to leverage all available networks and developing a script for conversations with these networks around living donation.

References


Acknowledgments

We extend our sincere appreciation to the teammates in more than 2,000 DaVita clinics who work every day to take care of patients and to the DaVita team members who work every day to provide better care for patients. We are thankful for the contributions of the DaVita Clinical Research (DCR®), and specifically acknowledge Kathryn Husarek of DCR for editorial contributions in preparing this manuscript.

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