Opportunities to Leverage Personal Networks to Increase Living Donor Kidney Transplant

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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 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 dialysis patients’ and care partners’ knowledge, beliefs, and attitudes toward transplant and living donation.

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.
• Analysis involved the following stages: – Review of the data to identify key patterns (themes) relevant to the research topic.
• Generation of initial categories whereby similar areas of text are grouped together across the data set
• Review of themes
• Coding of interviews with report generation

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 (ICH) patients:</td>
<td>4</td>
</tr>
<tr>
<td>Peritoneal Dialysis (PD) patients:</td>
<td>7</td>
</tr>
<tr>
<td>Home Hemodialysis (HHD) patients:</td>
<td>2</td>
</tr>
<tr>
<td>Care partners (CP):</td>
<td>26</td>
</tr>
<tr>
<td>Total:</td>
<td>70</td>
</tr>
</tbody>
</table>

Transplant almost always discussed and LDKT perceived to be superior to deceased donation and dialysis

• Almost all patients and care partners indicate that LDKT was discussed with them by the dialysis team or nephrologist.
• Patient and care partner perceptions of LDKT are almost always positive. Many citing that organs from living donors:
  – lead to better clinical outcomes
  – are in "better condition"
  – improve quality of life for longer

Personal experience with negative outcomes colors perceptions

• Of the few patients who do not hold positive perceptions of LDKT, all cite knowing someone with a poor experience.

For some patients, dialysis is the worst option, thereby increasing the importance of transplant

• "I had a friend that went through this journey and she got her transplant and the day my husband ended up in the ICU she died from complications from it, from the transplant." (Care Partner)
• "And you know just having a major surgery you can have blood clots, infections. As in my father’s case 3 ½ months [after the LDKT] he died so it’s not all rosy." (CKD patient)

LDKT knowledge varies among patients and care partners

• While all patients are familiar with LDKT, the amount of knowledge is not consistent among patients.
• Common misconceptions include: – having to be on dialysis for a minimum of years
  – inaccurate information about chain/paired donations
  – "and then it was like well how do I know when I give the kidney that it’s going to go to you." (PD patient’s prospective donor)
• requirements for the donor
  – ["Donor] has to be at (at least) 23" (CKD patient)
• health requirements for recipients

Transplant conversations

• Of the 42% of patients who have had a LDKT conversation with a prospective living donor, most broach the topic with a close relative:
  – 4 with their child/in-law
  – 3 with siblings
  – 4 with other friends/family

Few patients see their dialysis care team (DCT) as a key information source for transplant education

• When asked where they get LDKT information, patients cite transplant centers and online resources, but rarely mention their DCT. Reasons for this include the patient’s perception that:
  – DCT lacks expertise/abundant alternatives for information/prefers for PCP/nephrologist information
  – DCT is not invested in helping patients get transplants, increased transplants represent a threat to dialysis business
• Patients stated that the optimal support DCT can provide is by connecting prospective LDKT patients with past ESKD patients who have had a successful transplant.

Results

 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
  • A cousin of mine when I was first diagnosed with kidney disease offered to give me a kidney, so I wasn’t like I had to go ask" (DCT patient)
  • "My daughter in law actually volunteered...everybody [in the family] knew that I had [ESKD] and I was trying to get a transplant...so she just out of the blue kinda surprised me [and] volunteered. I am sure you want to do this and she said yes...[It was] more herself. She initiated it herself after me asking her" (CKD patient)

Conclusions

• Families are not always skilled in leveraging all resources to identify potential donors and patients/care givers could use assistance crafting their donor pitch as well as a viable strategy to leverage personal and extended networks.

References


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