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Decision support needs of kidney transplant candidates regarding the deceased donor waiting list: A qualitative study and conceptual framework

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Abstract

Background—Kidney transplant candidates face complex decisions about transplant options such as living donation or acceptance of lower quality kidneys. We sought to characterize knowledge and decision support needs regarding kidney transplant outcomes and options.

Methods—We conducted 10 interviews and 4 focus groups of 28 adult kidney transplant candidates from 2 centers in Minnesota. Transcripts were analyzed thematically using a grounded theory approach.

Results—We identified four themes: First, candidates have a limited understanding of treatment options, and demonstrate confusion or a lack of awareness about waiting list outcomes and prognosis. Second, candidates desired frank discussions about likely outcomes and individualized prognosis. Third, emotional barriers impact how patients make informed decisions. Finally, participants relied on the support of family and friends to help process information, and many favored the medical community engaging their family and friends in their medical decisions. These findings were incorporated into a conceptual model to support kidney transplant candidates in medical decision making.

Conclusions—Transplant candidates had limited understanding about treatment options and outcomes on the kidney transplant waiting list. Individualized risk information and cognitive approaches that recognize how patients process information and balance competing risks may improve informed decision making.

Keywords

Kidney transplant; decisions; knowledge; waiting list; outcomes

INTRODUCTION

For patients with end stage kidney disease, kidney transplant confers significant survival and quality of life benefits over dialysis.^{1–3} Demand for deceased donor kidney transplants outstrips the supply; however, access to transplant also remains limited by modifiable factors, including underutilization of living donor kidney transplantation and lower quality or increased infectious risk deceased donor organs.⁴

Patient education requires significant resources, and many studies have examined the attitudes and beliefs of patients with chronic kidney disease in order to guide educational approaches. Studies describing barriers to living donor kidney transplant have identified both emotional and knowledge barriers about the risks and benefits specific to living donation.^{5–14} Among dialysis patients, Gordon et al found that a perception of doing well on dialysis, fear of surgery, and anecdotal stories of unsuccessful transplants were common reasons not to pursue kidney transplant.¹⁵ A systematic review and thematic synthesis of qualitative studies of patients with chronic kidney disease found that difficulty confronting mortality (including prognostic uncertainty), lack of information about choices, and the timing of information influenced a patients' ability to make informed treatment decisions.¹⁶ Another thematic synthesis of studies of kidney transplant candidates regarding the psychosocial impact of waitlisting cited common themes of “waiting in limbo” and “waiting times that exceeded expectations”.¹⁷

In addition to these barriers, studies of patients with end-stage kidney disease have found that patients underestimate their likely mortality, and perception of mortality risk and listing status influenced their stated preferences for medical treatment.^{18,19} Studies also show that nephrologists do not consistently discuss mortality risks with patients, both in the care of dialysis patients and during the kidney transplant evaluation education process.^{18,20} This barrier has prompted the development of patient-centered tools to help patients understand transplant options^{21–23} as well their likely outcomes if they were transplanted versus on dialysis^{20,24}. However, knowledge gaps remain about how well kidney transplant candidates who have undergone the evaluation and education process weigh the competing risks of remaining waitlisted versus accepting different transplant options, such as living donor transplant, increased infectious risk kidney and lower quality (“high KDPI” kidneys). In addition, how much kidney transplant candidates want to know about their specific mortality risks while waitlisted has not been fully explored.

We sought to first describe what kidney transplant candidates understand about outcomes on the waiting list and the relative risks and benefits of kidney transplant options, and what kind

of information about outcomes they prefer. Second, we sought to incorporate this information into a conceptual model of interventions to facilitate informed decision making, delivering complex information that facilitates understanding for the broadest range of patients possible.

PATIENTS AND METHODS

We report the methods using the Consolidated Criteria for Reporting Qualitative Health Research approach²⁵. The institutional review board at both participating institutions approved this study.

Participants

Adult (age ≥ 18), English-speaking kidney transplant candidates were recruited by a research coordinator from 2 transplant clinics in Minneapolis, either at their initial transplant evaluation or waiting list clinic follow up. Recruitment and participation is outlined in Figure 1. “Transplant candidate” was defined as having completed the transplant education process (clinical visits at the transplant center with a nephrologist, surgeon, pharmacist, dietician and social worker, and a review of Explore Transplant®²⁶). For participants recruited in the clinic who were not yet listed for transplant, eligibility was screened during the clinic visit, with the interview or focus group subsequently scheduled if the clinical transplant team deemed them suitable candidates pending additional testing. Transplant candidates with a previous kidney transplant were included, but multi-organ kidney transplant candidates were excluded, given the different allocation and outcomes. Non-English speaking candidates were excluded. Subjects were provided with a \$40 honorarium for participation and all provided informed consent. No targeted recruitment by characteristic occurred.

Data Collection

Ten transplant candidate semi-structured interviews were conducted between March 2016 and August 2016. Interview guides were piloted with 3 adult volunteers who were not kidney transplant candidates to ensure understandability by a lay audience (Supplemental Table S1). Discussions were guided but allowed for exploration of participant-driven topics.

Four focus groups were conducted between October 2016 and April 2017 in order to augment interview data with the benefit of group dynamics and interaction. Information obtained from the interviews informed the development of the focus group guide, which included an exploratory phase to more deeply explore candidates’ experiences and views learning about survival and probability of outcomes with their providers. Following the exploratory phase, participants shared feedback about a draft pamphlet outlining treatment options, pros, and cons. The feedback provided initial impressions about the content’s understandability.

Transplant candidate interviews and focus groups were continued until data saturation was obtained (no new information gleaned from subsequent interviews). All interviews and focus groups were audio-recorded and transcribed verbatim, and analyzed along with detailed field notes. Member checks (summarizing responses for participants to check for misperceptions,

accuracy, and elaboration) were conducted throughout the interviews and focus groups to verify accuracy. Additional detail about the researchers and their roles is provided in Supplemental Material S2.

Analysis

We used a grounded theory approach^{27,28} to code text, categorize concepts, and identify themes in the interview and focus group transcripts. Text was coded line by line, first inductively to identify themes, then deductively to identify data specific to the established research questions, and finally a specific search for outliers or deviant examples. We selected quotes from the transcriptions to illustrate themes. Two researchers (AH and MB) independently coded the text and then compared and merged codes through focused research team discussions. Investigator triangulation was to be completed through review by a third researcher (SC); however this approach was not necessary for this analysis given coder agreement. Transcripts were coded using HyperRESEARCH software (version 3.7.5; ResearchWare Inc.).

RESULTS

Participant Characteristics

Ten individual in-depth interviews and 4 focus group interviews of 3-7 adult (aged ≥ 18) kidney transplant candidates were conducted, for a total sample size of 28. The average length of an interview was 31 minutes, ranging from 19 to 60 minutes, while the average focus group was 73 minutes, ranging from 55 to 89 minutes. Candidates represented a wide range of ages, race, sex, socioeconomic status, educational background, self-reported health status, and experience with dialysis and transplant as detailed in Table 1. Themes and supporting quotes are separately reported for interview and focus group data. Overall study themes are shown in Figure 2 with additional supporting quotes in Table 2.

Interview Themes

Unrealistic expectations—Patients demonstrated limited understanding of likely outcomes on the waiting list and limited ability to weigh competing risks. Only one patient cited dying while on the waiting list as a concern; most fears cited were related to dying during the transplant surgery, getting an infection from a deceased donor, or rejecting the kidney after transplant. All but one participant interpreted the average recipient wait time (commonly quoted as 5 years on the waiting list) as an *expectation* of their wait time as a candidate, followed by a guaranteed transplant. When asked, “What do you expect to happen over the next 5 years after listing for kidney transplant?” patients reported the following:

“I will not have to have dialysis.”

“A healthy kidney. I expect a new life, more freedom.”

Need for individualized information—Patients described a range of waiting times and experiences, from those who had not yet started dialysis to those who had been on dialysis for more than 5 years, and recognized that differences in age, health status, and diagnoses requires information tailored to themselves.

“What happens to me won’t [necessarily] happen to you, won’t happen to Uncle [Leroy] or Aunt [Louise]. Everybody’s different, so please, don’t tell me what happened to your Uncle Leroy because I am not Uncle Leroy..”

“...there are people ... at my dialysis unit, they just get up and rush out the door and hop in the car and off they go...well if I get out to the car I am feeling lucky today. I know that a lot of people are not affected to the extent that I am, and some are affected more than I am.”

Knowledge as empowerment—Transplant candidates reported that obtaining information was “relieving” and “empowering,” with all candidates reporting they want more information about outcomes, even when the likely outcomes are poor.

“You always want to think the positive part but then you want to be realistic, and it’s better to know what you’re up against...That way you can deal with it...You can physically and mentally prepare for it.”

“You need the truth to help you make the right decision. See, so you shouldn’t be scared of the pros and cons or whatever. Let them tell you the truth. It will help you take the right decision.”

Patient education was overwhelming—Candidates reported extensive but “overwhelming” education efforts, and reported having difficulty retaining information they were given. They described “marathon” transplant evaluations, much of which was focused on the post-transplant period.

“...you [are] deluged with so much information up front that it takes over a year to sort through it...”

“...people just come and throw everything in front of you and expect you to make up your mind and decide. It doesn’t work well like that.”

Candidates described fear and discomfort that resulted from the “unknown,” subjectively greater than the distress associated with hearing bad news.

“[It] was always the unknown...that is what I was so afraid of.”

Isolation and disconnection—Patients described feelings of isolation and disconnection, as well as reluctance discussing their chronic illness with others:

“...there is no discussion about this. It is not obvious, you do not lose your hair [like cancer]. You could be next to someone at the park and be on dialysis, too, and you would not know it.”

Patients expressed a need for more time, better communication and coordination, and more emotional support from providers.

“When you’re sitting a dialysis chair and you’ve gone through all this panic and upheaval, they’ve got no time to spend with you... they’ve got five minutes to talk to you and they’re on to the next person.”

All participants described anxiety associated with care fragmentation, in particular the transfer of care between their pre-dialysis nephrologists to dialysis nephrologists to transplant nephrologists, making them uncertain about where they should seek information when questions arose. One patient noted,

“It’s quick, quick, quick in and the people at the dialysis clinic, there’s a disconnect... They do their job but they’re not the people who are involved with transplant.”

Focus Groups Themes

Knowledge gaps and misperceptions—The focus group discussions regarding specific living and deceased donor kidney transplant options, such as increased infectious risk kidneys and lower quality kidneys, revealed additional knowledge gaps beyond unrealistic expectations. Only 2 patients demonstrated an understanding of the risk of dying while on the list. When asked about the benefits of living donor kidney transplant compared to deceased donors, only about half cited graft survival as an advantage:

“[A living donor kidney] is just the same as if you receive from someone who passed away.”

Three patients knew about quality measures for deceased donor kidneys, and all but 3 substantially overestimated the risk of infectious diseases.

“AIDS doesn’t show up until five years later in your body. If they’re on the four and a half year and they get that transplant... it may show up in your body, and that’s just AIDS.”

Desire for frank, individualized prognostic information—All patient participants reported wanting a frank discussion about mortality with their physicians. However, while most reported wanting an individualized prediction of their likely mortality, 2 participants did *not* want individualized predictions of outcomes; these participants were both aged > 65 with multiple comorbidities, and described feeling that their fate was in a higher power’s hands. One of these participants did say that patients in a different situation from his would likely benefit from individualized information:

“Everybody is going to be terminated at a certain point in time... to tell me that I am going to have 25% mortality rate or 50% doesn’t matter, not to me. Now, to somebody [else], if he is a young man, married, with two young kids, he wants to know what his chances are, yes.”

Patients described being given national averages for many outcomes, but struggling to determine how this was relevant to their personal experience. All but 2 participants reported wanting more individualized predictions to better determine how subsequent information applied to them.

“I think it would be nice if I knew my own individual outcomes instead of averages. I mean, average helps, but I mean, it’s better to know... what’s wrong with you... [Individualized information] might change your mind of which kidney you would be willing to take.”

Cognitive and emotional decision support from friends and family—Many patients relied on a family member or friend to review information from the transplant evaluation. One patient, feeling overwhelmed, skimmed the information packet, whereas his mother “devoured it.” Another patient’s wife read the information and gave him relevant sections to read. Members of patients’ support networks were instrumental in helping patients move forward when they wanted to run away:

“I remember when I was going through this... I wanted to run so bad... the thing that really helped me the most was family... That was the key because they were like, “We can do this....it’s okay... we will work with you with it.”

While nearly all patients cited friends and family as an important source of support, a key theme of difficulty communicating with them arose in the interviews and focus groups. Patients reported feeling isolated:

“I wanted to talk about it to people, because it is important. It is like my life now, and I felt like people get really freaked... it is like when you lose someone, like you lose your parent ... and nobody knows what to say to you.”

Some reported difficulty conveying what little they understood about their diagnosis and options to friends and family, while the barrier for others was difficulty reaching out. One patient summarized a sentiment echoed by many:

“I just don’t like asking for help from anybody.”

All but one participant expressed a desire to have physicians communicate directly with friends and family, and to have more resources that facilitate their support networks’ understanding of their diagnosis, prognosis, and needs.

“I tried to talk to my daughter about it, she has no clue.... when I say these words to her, she is like well, what does that mean?”

Describing what she would do with individually tailored information about her likely outcomes and treatment options, one patient said:

“I think the family should see it...they need to know.”

Thematic Synthesis and Conceptual Framework

The interview and focus group themes were synthesized into larger study themes, and additional quotes supporting each theme are detailed in Table 2: 1) Knowledge gaps and misperceptions, 2) Desire for frank, individualized information, 3) Emotional barriers including fear and feeling overwhelmed, and 4) Decisional support needs including social network involvement and increased support from the medical community. These themes were incorporated into a conceptual framework to guide approaches to better support kidney transplant candidates (Figure 2), the Kidney Transplant Candidate Support Framework, which incorporates the concepts of Family Systems^{29,30} and Social Ecological³¹ Theories.

DISCUSSION

We found that kidney transplant candidates have significant knowledge gaps and misperceptions, desire frank and individualized information, struggled with emotional barriers to making medical decisions, and needed more involvement of their support systems and nephrologists to address these barriers. These findings suggest that patients face critical decisions with limited understanding of the options or likely outcomes or the resources to process the information, despite extensive efforts on the part of transplant centers and providers to provide education and the use of high-quality educational material developed by leaders in the field of patient-centered transplant education²⁶. The knowledge gap is apparent even in highly educated patients and patients who have undergone previous kidney transplant, suggesting that simply providing more data to patients may be insufficient to surmount the problem.

The knowledge gap is concerning for many reasons. A lack of knowledge made patients particularly vulnerable to myths and misinformation, with many participants repeating misconceptions that were learned from the internet or their peers. The fact that transplanted patients tend to live longer, a central fact nephrologists take for granted, was simply not understood by many patients who were more attuned to the quality of life concerns associated with transplantation. This central misunderstanding may contribute to low rates of completing evaluations,^{32,33} or willingness to overcome obstacles such as weight loss in order to become active on the transplant list. Some may dismiss options such as living donation, high kidney donor profile index (KDPI), or increased infectious risk organ offers due to an inability to weigh competing risks.

The need for individualized information was also illustrated by these data. The diversity within our sample exemplified the challenges in developing any standardized educational process for patients with end stage kidney disease. Providing national averages about outcomes provides little information for the 25 year-old with glomerulonephritis but no other comorbidities compared to a 65 year-old with diabetes and hypertension. Geographic differences in organ availability cause wide variation in the probability of transplant and, therefore, the need to consider options that increase the likelihood of transplant³⁴. The diversity in prognosis, education level, and culture necessitates the development of educational approaches that are individualized, helping patients access and revisit the information that they need when they need it. The patients in our study also expressed a desire to have frank discussions about outcomes and mortality with their nephrologists. Previous studies of nephrologists' comfort providing difficult prognostic information has demonstrated discomfort or even unwillingness to discuss prognosis, even when patients report wanting it,¹⁸ but research in patients with incurable cancer shows that giving poor prognostic information improved patients' ability to participate in medical decisions without decreasing hope³⁵.

Providing facts is necessary but not sufficient to help patients make medical decisions, and emotional barriers to this process were evident. Patients repeatedly used the word "overwhelming" to describe the experience of having a chronic illness, as well as the transplant evaluation and the education process, underscoring the need to incorporate the

cognitive science of decision making into educational interventions. When overwhelmed or stressed, patients tend to rely more heavily on implicit, or subconscious, decision making³⁶, often putting disproportionate weight on the risks of a “bad” (lower quality) kidney, contracting HIV, or a loved one developing end-stage kidney disease after donating a kidney. The highly complex topic of kidney transplant, necessitates a great deal of learning on the part of patients. Addressing how people process information about risk is as important as giving numerical risk estimates themselves^{37,38}.

The unsolicited theme of the importance of friends and family in acquiring and processing knowledge to make decisions reflects the need to incorporate these individuals into educational processes. Friends and family may mitigate the stress response and help to make complex information more digestible. Furthermore, patients expressed a desire for help communicating their options and prognosis with their friends and families, underscoring the importance of tools that help patients and physicians communicate with members of patients’ support networks.

Given our findings, we incorporated our data into a conceptual framework for the development of patient interventions (Figure 2). This framework illustrates how to better counsel patients to process and use the information presented by transplant centers, incorporating the need for informational, emotional, and structural support to address the needs of this diverse and complex patient population.

Our study has several limitations. Qualitative studies provide information about the range of barriers, but additional quantitative data are needed to assess the prevalence and magnitude of these barriers. A survey developed from this qualitative data on a random sample of candidates would provide these estimate. Second, while the patients represented a range of clinical and demographic characteristics, they were all recruited from two transplant centers in one geographic region. Patients from other regions may provide additional insights and opinions. However, our participants represented a broad range of racial, educational, and socioeconomic backgrounds, and underwent an extensive transplant education process including the Explore Transplant education materials and visits with transplant providers. Finally, our sample was heterogeneous, including patients who had previously been transplanted, patients already waitlisted and some still in workup. We included these patients because we were interested in information about a breadth of patient experiences, perceptions, and needs, especially given that a substantial proportion of patients listed now are listed for repeat transplant. However, and significant to our analysis, we found that even the 3 patients who had previous transplants demonstrated the same misperceptions, needs and struggles as patients who had not undergone transplant.

In summary, we found that patients had limited understanding about treatment options (dialysis versus transplant, living versus deceased donor kidneys, kidney quality acceptance, and increased infectious risk kidneys) and outcomes on the kidney transplant waiting list. Patients desired information that was simple, could be revisited, and easily shared with friends and family. Individualized risk information and cognitive approaches that recognize emotional responses and implicit decision bias may improve informed decision making in transplant patients. Future research and evaluation is needed to develop educational

approaches for transplant candidates that incorporate this framework, and assess their impact on patient decisions and clinical outcomes.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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*Data collection on the number of potential subjects screened for participation at one of the two study sites began 2 weeks after 1 subject had already been enrolled at that site, therefore the total number screened but not meeting inclusion criteria (n=86) is underreported.

Figure 1.
Consort diagram of recruitment and participation for interviews (panel a) and focus groups (panel b).

Figure 2.

The Kidney Transplant Candidate Support Framework Illustrates how the themes developed from these data can be applied to help patients cope with end stage kidney disease and the need for transplant.

Table 1.

Baseline characteristics of kidney transplant candidates

	Overall (n=28)	Interviews (n=10)	Focus Groups (n = 18)
Age; mean (sd)	53.8 (13.9)	53.4 (13.4)	54.0 (14.6)
Sex (Female); n (%)	13 (43.2%)	3 (30.0%)	10 (55.6%)
Race; n (%)			
Black	13 (43.2%)	4 (40.0%)	9 (50.0%)
White	14 (50.0%)	6 (60.0%)	8 (44.4%)
Native-American	0 (0.0%)	0 (0.0%)	0 (0.0%)
Hispanic	1 (3.6%)	0 (0.0%)	1 (5.6%)
Education; n (%)			
HS or Less than high school	8 (28.6%)	1 (10.0%)	7 (38.9%)
At least some college	19 (67.9%)	9 (90.0%)	10 (55.6%)
Graduate education	1 (3.6%)	0 (0.0%)	1 (5.6%)
Annual Household Income; n(%)			
< \$15,000	9 (32.1%)	3 (30.0%)	6 (33.3%)
\$15,000 - \$30,000	6 (21.4%)	1 (10.0%)	5 (27.8%)
\$30,001 - \$60,000	6 (21.4%)	4 (40.0%)	2 (11.1%)
\$60,001 - \$75,000	0 (0.0%)	0 (0.0%)	0 (0.0%)
> \$75,000	6 (21.4%)	2 (20.0%)	4 (22.2%)
Declined to answer	1 (3.6%)	0 (0.0%)	1 (5.6%)
Self-Reported Health Status; n (%)			
Excellent	0 (0.0%)	0 (0.0%)	0 (0.0%)
Very Good	7 (25.0%)	5 (50.0%)	2 (11.1%)
Good	9 (32.1%)	1 (10.0%)	8 (44.4%)
Fair	8 (28.6%)	3 (30.0%)	5 (27.8%)
Poor	4 (14.3%)	1 (10.0%)	3 (16.7%)
Cause of Kidney Disease; n (%)			
Diabetes	9 (32.1%)	4 (40.0%)	5 (27.8%)
Hypertension*	11 (39.3%)	4 (40.0%)	7 (38.9%)
Polycystic Kidney Disease	2 (7.1%)	1 (10.0%)	1 (5.6%)
Glomerular Disease	4 (14.3%)	0 (0.0%)	4 (22.2%)
Other/Don't Know	5 (17.9%)	2 (20.0%)	3 (16.7%)
Previous kidney transplant (Yes); n (%)	3 (10.7%)	0 (0.0%)	3 (16.7%)
On dialysis (Yes); n (%)	16 (57.1%)	7 (70.0%)	9 (50.0%)
Time on dialysis (yrs); mean (sd)			
mean (sd)	1.76 (2.83)	1.71 (2.07)	1.96 (3.27)
median (range)	0.35 (0 - 9.84)	0.53 (0 - 5.35)	.06 (0 - 9.84)
Already listed for transplant (Yes); n (%)**	8 (28.6%)	1 (10.0%)	7 (38.9%)
Time since listing (years)			
mean (sd)	.45 (.46)	0.16 (0)	.49 (.58)

	Overall (n=28)	Interviews (n=10)	Focus Groups (n = 18)
median (range)	0.17 (.01 - 2.4)	.16 (.16 - .16)	.18 (0.01 - 2.4)
Listed within 1 year of evaluation (Yes); n (%)	17 (60.7%)	4 (40.0%)	13 (72.2%)
Subsequently transplanted (Yes); n (%) ***	3 (10.7%)	0 (0.0%)	3 (16.7%)

* Some marked both diabetes and hypertension, therefore totals do not add up to 100%

** At the time of interview or focus group

*** As of September 28,2018, range of follow up 1.5 – 2.5 years

Table 2.

Additional quotes illustrating combined main themes of both the interviews and focus groups

Theme 1: Knowledge gaps and misperceptions	
Misperceptions	Interviewer: "What do you expect will happen over next 5 years after getting listed for transplant?" "... the life expectancy (on dialysis) is 15 years compared... how much longer a transplant is, over double." (Interview participant) "... a higher risk of dying while waiting [for a deceased compared to living donor]? That's not true." (Focus group participant)
Theme 2: Desire for frank, individualized information	
	"Just tell me the truth, and more based on my profile and ... people that are similar to me... I realize [there are] people with cancer, diabetes, all of these other issues... somebody should be saying, "To be honest with you, you've got maybe a 50/50 chance of lasting five years..." (Interview participant)
Theme 3: Emotional barriers	
Fear	"... it would have been helpful to have more knowledge of where you were going to end up because that is where the fear—that was the end of the road... I had to get so sick to—I maybe would not have been as afraid of it had I known more" (Interview participant) "Doctors speak with caution. I find it funny because ... you don't know what to think because you'll look at their face and your face looks like, oh God, they don't want to tell me that I'm about to die, right now... when you don't know what's happening, it looks like, "Why does she look so serious?" (Interview participant)
Overwhelm	"I didn't go through [the information packet] right away because I felt it was overwhelming." (Focus group participant) "They're throwing information left and right. I'm smart... but you throw all of this at me... And I'm literally trying to process it at the same time..." (Focus group participant) "I felt like I was being bombarded with information when I met with the first kidney doctor... it was information overload that I was getting, so there was this confusion." (Focus group participant) "And there are all these different websites doing all these different places to draw this information and that can get overwhelming and confusing too." (Focus group participant)
Theme 4: Decisional support needs	
Social support networks help digest information	"... when I got my packet, my mom devoured it. She read the thing cover to cover... I have probably read about half of it." (Focus group participant) "[My wife and I] went through the packet ... and she said, "Okay, you have to read this." She gave me the important parts of the whole packet... I probably didn't see but maybe less than half of it... I wasn't bombarded with all this information at one time." (Focus group participant)
Isolation and difficulty asking for help	"... it is hard for anyone to admit that they are chronically ill... you do not want to talk about it, you do not want to own it. You want to be in denial and be healthy and to admit to being chronically ill is a burden in itself..." (Interview Participant) "... with my daughter, I think I pretty much tried to hide it for a while. I did not want her to know that... to scare her." (Focus group participant) "... I don't like to talk about it, personally, myself. So, I'd rather have tools for [my family] to learn on their own." (Focus group participant)
Wanting more support from medical community	"It does not feel connected between [the transplant center and my nephrologist]... So I'm kind of putting the pieces together and making them fit a little bit better there so there's more continuity..." (Focus group participant)