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How patients choose kidney transplant centers: A qualitative study of patient experiences

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Abstract

Little is known about how patients make the critical decision of choosing a transplant center. In the United States, acceptance criteria, waiting times, and mortality vary significantly by geography and center. We sought to understand patients' experiences and perspectives when selecting transplant centers. We included 82 kidney transplant patients in 20 semi-structured interviews, nine focus groups with local candidates, and three focus groups with national recipients. Sites included two local transplant centers in Minneapolis, Minnesota, and national recipients from across the United States. Transcripts were analyzed by two researchers using a thematic analysis. Several themes emerged related to priorities and barriers when choosing a center. Patients were often unfamiliar with options, even with multiple local centers. Patients described being referred to a specific center by a trusted provider. Patients prioritized perceived reputation, comfort, and convenience. Insurance coverage was both a source of information and a barrier to options. Patients underestimated differences across centers and the effects on being waitlisted and receiving a transplant. Barriers in decision making included an overwhelming scope of information and difficulty locating information relevant to patients with unique medical needs. Informed decisions could be improved by the dissemination of understandable information better tailored to individual patient needs.

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AUTHORS' CONTRIBUTIONS

AI and CS: Researched the idea and designed the study; CS, MB, and AM: Acquired the data; CS, WM, and MB: Analyzed/interpreted the data; AI, JS, and BK: Involved in supervision or mentorship. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

Keywords

center; choosing; kidney; qualitative; transplantation

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1 | INTRODUCTION

Patients seeking kidney transplant must weigh options for several pretransplant decisions, including the choice of a transplant program. The number of feasible choices may vary; patient surveys show a majority of respondents could consider multiple center options,¹ and many patients choose centers far from their homes^{2,3} or list at multiple centers.⁴ This choice may have significant consequences, for example, higher mortality rates.^{5,6} Center-specific variations exist in candidate acceptance criteria⁷⁻⁹ and offer acceptance practices.¹⁰ Specialized services are important for individual patients, such as living donor exchanges¹¹ and use of blood group A2/A2B deceased donor kidneys for B recipients.¹² Geographic variation exists in waiting time, pretransplant, and post-transplant outcomes^{13,14} and disparities persist under the kidney allocation system (KAS).¹⁵ Previous qualitative reviews summarize studies describing the attitudes, values, and behaviors of patients for some pretransplant decision points.¹⁶ These included pretransplant experiences, such as wait listing and evaluation processes, which are difficult to understand and can be associated with disillusionment and despair among patients.¹⁷⁻¹⁹

However, little is known about the related patient experience of selecting a transplant program, or what information gaps may exist related to choosing a program. To date, research on patient experiences during referral is limited to pediatric transplantation.²⁰ Our current qualitative study sought to better understand the experiences and perceptions of adult patients as they previously learned about kidney transplant center options, including the barriers to using available information about centers and how information was prioritized when making decisions. Recent debates highlight a need to inform patients about patient-centered program quality measures.²¹⁻²³ A better understanding of patient experiences can inform the development of new quality measures and information resources and can provide important patient perspectives to those counseling patients about transplantation and what center options could be considered.

2 | PATIENTS AND METHODS

We conducted semi-structured interviews and focus groups with local and national adult (age 18 or older) transplant candidates and recipients. Local participants were transplant candidates, in order to minimize the time that had passed since choosing a center. National participants were recipients who were more likely to be healthy enough to travel, compared to candidates. Interviews served to elicit patient experiences and inform the development of focus group discussion guides and prototype information displays, while focus groups allowed for group interactions and more efficient data collection from national participants.

The candidate interviews and focus groups were conducted at Hennepin Healthcare System (HHS) and the University of Minnesota-Fairview (UMN) clinics in the Upper Midwestern United States. Candidates were recruited by research coordinators during or after a regularly

scheduled transplant appointment or by mail. The convenience sample included candidates proceeding with an initial evaluation, a retransplant evaluation or a waitlist follow-up. The first ten candidates from each site were interviewed in person; remaining candidates were recruited for focus groups.

National transplant recipient focus groups were conducted in Chicago, IL. Recipient expenses were paid, including airfare and lodging. Recipients were recruited through email and social media via national patient groups (eg, National Kidney Foundation). Inclusion criteria for national groups were a previous kidney transplant (or retransplant). Potential participants were screened to determine years since transplant, living donor or deceased donor, and location of transplant program to determine Organ Procurement and Transplantation Network (OPTN) regions. When possible, focus groups included more recent recipients and a mix of living and deceased donor recipients. Recipients were stratified based on known advocacy experience in order to increase uniformity and rapport within groups, for example, participants with previous involvement in local or national patient groups were included in the same group. National participants were purposively recruited to insure there was at least one participant from each OPTN region for all groups combined.

Non-English-speaking candidates were excluded. Each participant gave written, informed consent, and the study was approved by each institution's Human Subjects Research Committee (HHS Study #16-4130/UMN Study #1606S89161). Participants received a \$40 stipend as compensation.

Interviews and focus groups were moderated by the same individual (CS), trained in qualitative research for human-centered design, and periodically attended by a second social sciences researcher (MB). Interviews and candidate focus groups took place in a clinic examination room or small conference room. National recipient focus groups took place at a hotel conference room. Moderators explained confidentiality and emphasized that no identifiable information would be shared. No clinic personnel were present during the local interviews, and a nephrologist (A.I) was present during focus groups to address potential clinical questions. The study was described as an opportunity to learn about patient experiences when choosing a transplant center and to discuss feedback about new graphic information displays. The scope of the current analysis includes only discussions about choosing a center. Table 1 includes examples of interview and focus group questions within the scope of choosing a center.

Each interview was between 30 and 45 minutes; focus groups were 60-120 minutes. All participants completed a demographics and comorbidity questionnaire. Postal codes provided were used to determine how many kidney transplant centers were located within 100 miles (excluding “Children’s” hospitals and any center with 0 adult transplants in the previous year).

A structured guide included questions and prompts based on a phenomenological approach to understand how patients choose a center.²⁴ Discussions progressed through three topics: What information patients learned about transplant center options, how the patient decided

on a specific center, and what new information would be valued. To gather feedback and discuss priorities among patients who were previously unaware of choices, participants considered how the information would influence a hypothetical decision, as a type of mental simulation.²⁵ Hypothetical discussions were generally introduced with a scenario applicable to the transplant population. For example, patients who lived near the centers were asked to imagine if they lived halfway between two urban transplant centers and needed to decide which one to visit. Discussions of hypothetical decisions occurred after describing actual experiences and acknowledged that participants' priorities and knowledge may have changed since choosing their own center. The facilitator used probes and encouraged discussion among focus group participants until saturation was reached or the generation of new concepts ceased. Discussions were audio-recorded and transcribed verbatim.

Transcripts were reviewed by two analysts (CS and MB). Transcripts were open-coded and axial-coded through an inductive, thematic analysis.^{24,26} Themes emerged as qualitative analysis was used to interpret the words of participants and perceptions of their decision-making process and outcomes.²⁴

Each researcher (CS and MB) read transcripts and coded independently, reviewed each other's coding schemes, and discussed themes together to reach agreement. HyperResearch coding software (Researchware, Inc., Randolph, MA) was used to organize data and identify supporting quotations. The analysis of transcripts resulted in codes for 34 actions or types of information; codes were refined over multiple reviews and were organized into two general categories and nine themes.

3 | RESULTS

Interviews were conducted over a period of 4 months; focus groups were conducted over a subsequent 4-month period. A total of 82 kidney candidates and recipients participated: 20 interviewees and 62 focus group participants. The 12 groups averaged five participants each and are detailed for each site in Table 2. Patient questionnaires provided the demographics and general health status of participants (Table 3). The participants in this study had a median number of centers within 100 miles of 5 and 3, for local and national participants, respectively.

The patient experiences reported in interviews were similar to those from focus groups; therefore, supporting quotes from each are shown with themes. Themes are organized into 2 categories: (a) Deciding on a center and (b) Barriers to Decisions. Each theme is summarized with supporting patient quotes, and themes are numbered as a convenience rather than a prioritization. A more thorough listing of supporting quotes is included in Table 4. Quotations originating from a hypothetical scenario are denoted by [H].

3.1 | Deciding on a center

3.1.1 | Theme 1: Patients accept decisions from trusted providers and friends—Participants described decisions about transplant centers as influenced by a trusted relationship with providers or friends, and these recommendations were generally followed. Some decisions were simple, as they felt presented with one stated option; others

perceived a recommendation for one particular center although they were made aware of several options. However, after learning about options they were not aware of, some expressed interest in receiving more thorough information.

Well, I, first, was to ask my nephrologist where he would go if he were going to have a transplant. He said he would go to [this center]. So, that is where I started as far as getting information.

[focus group]

I really believe she sent me here. We made an appointment and that was it. ...I mean, if you have these choices you'll know where to go versus the doctor picking that for you. That's what my doctor did and that's what I remember.

[interview]

Who said [this center] is a place you should visit? ...“My girlfriend”.

[interview]

I think one of the deciding factors was my daughter was familiar with it and the length of time they have been in the transplant business.

[interview]

3.1.2 | Theme 2: Confidence in perceived reputation of center—Several participants, who were candidates at an academic health system, described academic systems as having high-quality care. Participants often associated a greater number of years as a transplant center with reputation and quality of care. Similarly, decisions were influenced by an interest in the training and reputation of clinical staff. Confidence in a center was associated with comfort or trust with a center, and this level of comfort was discussed as a priority.

It is a learning hospital, so I just know this. It is a place where it is constantly moving forward with research and learning and everything.

[interview]

I chose a little further distance because I had confidence in the providers there and the research they were doing there.

[focus group]

What's important to me is the care and the quality and how they do the research to make sure you get what's best. You probably can get a kidney from anybody.

[H] [interview]

I am kind of that way I guess with doctors as far as if I am comfortable with them and I feel they know their stuff.

[H] [interview]

3.1.3 | Theme 3: Personal relationships and convenience were important—Several factors related to relationships and convenience emerged as influential themes.

Decisions were commonly based on familiarity with a particular hospital system or proximity or the convenience of a system with shared records. In addition, participants making hypothetical decisions expressed interests in learning more about local amenities such as convenient lodging and availability of patient support groups and services (see Table 4).

It was easy, go with the easiest route.

[interview]

I ruled [the other center] out for a non-logical reason. It's just too damn far away. I don't want to keep stomping down there for every meeting and every appointment.

[focus group]

All of my doctors can tell on my chart. They communicate back and forth instead of going to search for records and stuff like that. Any doctor I go to, they can go into my chart and pull up anything. That's what makes it convenient for me so I don't have to remember so much, because I have this plus my personal life. It gets a little hectic. So, it's just easier to be able to pull records right there.

[focus group]

When you come in and you see a friendly face, any little thing sometimes just makes my day. I know they're looking out for me.

[H] [interview]

3.1.4 | Theme 4: Insurance coverage was both a source of useful information about choices and a barrier that limited choices—A majority of participants reported private insurance and/or Medicare, and the impact of insurance on decisions varied across a spectrum. On one extreme, some patients benefited from insurance representatives who provided detailed information about multiple options. On the other end, some patients described an inability to choose a particular center due to coverage constraints or a perception of a constraint.

I am talking to [my insurance provider] and they go well here is our list and then they rate the transplant places right,... telling me, where are you going to have this done?

[interview]

“And I was saying, all right, my insurance will, generally speaking, travel with me, which is another factor ... that can be a self-limiting issue.

[interview]

I was referred to [this center] and felt like I didn't have a choice due to my insurance.

[focus group]

My insurance company basically said these are the ones that we work with in network. And I had one in the city where I lived at the time, but it wasn't in my

network, so if I wanted it paid for by my insurance I went to this other one, which turned out to be a really great center.

[focus group]

3.1.5 | Theme 5: Unique medical circumstances create a need for more information—Several participants had previously researched centers in great detail, in order to find a center that would treat a particular condition, and several had been previously declined at a center. Participants described reasons they had been declined or needed specialist care, including insufficient weight loss, calcified vessels at the transplant site, options for antibody desensitization, and a complex pediatric medical history. The process to identify specialists or “lenient” centers was often described as lacking support from providers, although some providers proactively shared information on potential weight restrictions.

All they did was shut the door and they said we're closing your case, and we're recommending that you will do better on dialysis. I said, ‘Do you have any suggestions for me?’ Well, you can always get a second opinion somewhere, not to hold out false hope they said. Well then, my sister did some research.

[interview]

They said it was because of my weight. He said that [this center] was more lenient towards the weight limit than other places were.

[focus group]

One has to be careful in treating it too much like a transplant patient has the world by the tail, and they're out shopping for a car... a lot of us are in a situation where there's some very limiting factor, whether it's transportation, whether it's insurance coverage, whether it's like me and you need a specialist that is only at one place.

[H] [interview]

3.2 | Barriers to decisions

3.2.1 | Theme 6: Incomplete information—Many participants were not informed about options for transplant centers, in some cases being unaware of multiple centers in a local metropolitan region. Some participants who were aware of multiple local options reported being presented with only basic information about each option, for example, the address and phone number of each center. A minority of participants discussed learning about or seeking multiple listing (see Table 4).

My doctors never said anything about what places to go to for transplant centers at all.

[focus group]

No. It was here's the information for [this center] because she's affiliated with them so I didn't even think to look anywhere else.

[interview]

Yeah, I got a pamphlet and everything of all the different places, and numbers, and that you can call.

[interview]

3.2.2 | Theme 7: Unaware of center differences and risks that are relevant to mortality—Participants rarely shared that they were aware of local and regional differences in transplant waiting times and outcomes. Some participants recalled learning about these disparities through third-party transplant “classes,” for example, “Kidney Smart” (www.kidneysmart.org). Other patients who were aware of regional differences but not the underlying causes expressed confusion (see Table 4). Participants who had not faced limitations to transplant due to individual characteristics often perceived centers to be homogenous in their criteria, for example, for candidates based on age, body mass index, or other factors.

Discussions about transplant center characteristics highlighted misunderstandings about actual risks. Waitlist mortality was confusing, in particular the risks of prolonged dialysis were not accurately described. Few participants described comparisons of risks and benefits between dialysis and transplantation. In another example, a participant viewed a shorter waiting time as a negative indicator rather than evidence of better organ availability.

Well who is, you know, you put on here 6 out of 100 people are dying waiting for transplants. Well, with kidneys there is a lot of explaining to do, right. Hearts maybe not so much, but kidneys I mean why would somebody die waiting for a transplant - because they are elderly, ill, you would not put them on dialysis? It was their choice. Why are they dying would be my question?

[H] [interview]

And why is one [wait list] shorter than the other. Because right away you are going to stay away from the short list because you are going to think no one is lining up over there. And everybody is lining up over here.

[H] [interview]

Between all these different hospitals that transplant, I would have thought their outcomes are pretty much the same, but to see that there is different outcomes in different areas is really surprising.

[H] [interview]

I would have thought if you were a candidate at one hospital, you would be a candidate at all of them, or that if you were not a candidate, you would not be a candidate anywhere.

[H] [interview]

3.2.3 | Theme 8: Overwhelmed with information—For candidates facing a first transplant, the decision to visit a specific transplant center was often made in the context of learning about kidney disease, dialysis, and the risks of different treatment alternatives. The

scope of new information was described as overwhelming and created difficulties considering and retaining information.

It was hard to understand the system. I didn't even understand the pyramid of how it went - local, regional, and then national - so, I think the patients themselves, when they're going through the process they're not focusing. They're focusing on just what they have to do to stay alive.

[focus group]

When I went to the meeting, I think that it is a little overwhelming with all the information that they have to explain to you. So I think sometimes they might skip some things or just forget to explain some things to you.

[interview]

3.2.4 | Theme 9: Limited access to or mistrust of Internet—Several participants had previously used the Internet for research on transplantation. However, only a small number had used online resources to identify and evaluate a particular center. Some participants had limited access or limited computer literacy. Some participants expressed reservations about the trustworthiness of online information and a preference for shared decision making after viewing online information.

I am more than willing to go on the internet, but I just think that there is so much information out there, that I would much rather ask someone who has got very specific experience with the area that I am asking about.

[H] [interview]

4 | DISCUSSION

When making decisions, candidates relied on trusted providers, family, and friends (Theme 1), perceived reputation of a center (Theme 2), valued relationships and convenience (Theme 3), and worked within potential constraints of insurance coverage (Theme 4). Participants who considered criteria beyond these factors often described unique medical circumstances and sought information relevant to specific medical conditions (Theme 5). However, candidates faced barriers to making informed decisions. Many transplant candidates had a limited understanding of what transplant center options were available (Theme 6). A lack of knowledge about how different options might impact risks or mortality (Theme 7) may limit incentives to learn about options. However, providing any additional information would need to account for individual differences and external constraints to accessing information (Themes 8 and 9).

The results are relevant for two stakeholder groups. First, researchers and clinicians have proposed new quality measures that could inform where a patient goes to seek transplantation.²¹⁻²³ One objective of the project was to involve patients to “ensure that transplantation quality metrics measure what is important to them”.²² Second, gaps currently exist in providing information to candidates, particularly those with higher risks of being turned down. Providers who counsel patients about transplantation and choosing a center

can potentially direct patients to resources that would increase awareness of available options.

While qualitative themes describe information that was important to patients, more research is warranted to determine whether these perspectives are based on sufficient understanding of how measures impact mortality. Participants were often uninformed about alternatives that might confer lower mortality risks. This information was rarely requested, likely due in part to underestimating how individual risks might vary by transplant center or region (Theme 7). Geographic disparities and inter-transplant program variations in waiting times and mortality are substantial in the United States.¹³⁻¹⁵ Center-specific variations exist in candidate acceptance criteria⁷⁻⁹ and offer acceptance practices.¹⁰ Few participants described the variation across programs with regard to use of higher-risk organs^{10,27,28} although these higher-risk organs have a survival benefit for many candidates.²⁹ The limited acknowledgement of waitlist mortality related to choosing a center is consistent with studies demonstrating that patients underestimate mortality risk on dialysis³⁰ or engage in denial as a means to cope.³¹

Similarly, unless participants had been turned down after an evaluation, they did not describe awareness of variation in acceptance criteria for a waitlist. Previous results confirm inter-center variation in acceptance criteria due to candidate age and body mass index.⁷ Some participants experienced these differences first hand and struggled to find information (Theme 5). In some programs, 50% of patients evaluated are declined.³² Several participants had previous living donor transplants and the acceptance criteria of living donors also varies by center.³³ The potential benefit of understanding how center criteria vary is particularly relevant for candidates needing specialized services or expertise and face greater barriers in access to transplant.

Insurance providers were mentioned as either a source of information about choices or a barrier to options (Theme 4). Some patients used insurance providers to understand options, including a potential to view rankings of centers or lists of in-network and out-of-network centers. Other patients were restricted from listing at a preferred center or perceived that options were limited. Given that many patients made decisions based on referral and had not explored multiple options (Theme 6), some patients may not have become aware of how insurance coverage could impact their choices. In summary, not all candidates have equal discretion over center selection due to insurance coverage, requirements for specialist treatments, or financial constraints of travel. However, the participants in this study had a median number of centers within 100 miles of at least three (see Table 3). Given the potential mortality effects of a center^{5,6} patients may benefit from knowledge of center options and the relevance of quality metrics to mortality risks.

Patients may accept a recommendation or make a choice based on convenience or perceived reputation (Themes 1-3) and not be aware that other centers may be more likely to list them or have lower waiting times or mortality rates. New forms of patient-friendly information and comparison data may facilitate informed decisions. However, expectations to reduce risk with additional information must be tempered by the reality of patient experiences and

existing cognitive demands. Candidates face a daunting task to weigh treatment options and prepare for dialysis and transplant.

The barriers to processing this information (Themes 8 and 9) can potentially be reduced with several approaches. First, established patient-friendly methods, such as Agency for Healthcare Research and Quality (AHRQ) guidelines for public quality reporting, can minimize cognitive demand. For example, confidence intervals can be omitted from reports for public audiences and the meaning of results can be interpreted in lay language.^{34,35} Dissemination of information can be implemented to best support patients, for example, by offering printable handouts to improve knowledge gain³⁶ and to build trust by communicating the noncommercial interests of the information sponsor.³⁷ Graphic displays can reduce cognitive burden and should be quantitatively evaluated in controlled studies to verify impacts on decision making.^{34,35}

Among the study participants, detailed program-specific information was not utilized unless the individual patient multi-listed or had been declined by a center because of specific risk factors, and the patient possessed sufficient initiative to find and interpret technical reports. Some waiting time and post-transplant outcome metrics are provided in program-specific reports (PSR) produced by the SRTR, although these reports have historically not been designed for a nontechnical audience.³⁸ SRTR has developed new patient-friendly online search tools to compare center options²³ and disseminating data to patients early in the transplant education process is one approach to minimize observed information gaps. In addition, some preferred information (eg, transplant center staff training) is not available to SRTR and may best be presented in other locations (eg, transplant center websites). Dissemination can also support shared decision making through outreach with partner organizations. For example, patients have reported learning about transplant through fellow patients, not nephrologists³⁹; therefore, patient advocacy groups and support groups may provide important support. Patients proceed along more pretransplant steps when a transplant navigator is used^{40,41} and the use of navigators could increase awareness of center options.

This study raises additional new questions, such as how to best provide patients with information that is valued and aids in decision making, and how the experience of being turned down by a center impacts a patient's perspectives on kidney disease and treatment options. These answers will require more focused qualitative research.

While this study gives new insights into previously undescribed patient experiences in choosing a transplant center, it has several important limitations. While the study participants included a national sample, this may not represent all patients. This qualitative study is descriptive and considers factors influencing decision making. It cannot provide national, quantitative data measuring how patients decide on a transplant center. The study participants were recruited during or after transplant evaluations; any decisions about visiting a specific transplant center had already been made. This limited real-time discussion of how a decision could have been impacted by additional information. However, recruiting patients at an earlier stage would limit discussions about what information was considered prior to making decisions. The study did not separate participants seeking living or deceased

donation or analyze differences in these experiences; however, the decision to seek an evaluation at a specific center often precedes a decision to seek living donors. Audio recordings for focus groups did not include speaker identities; therefore, the demographics of individual speakers is not reported.

In conclusion, kidney transplant candidates often have limited knowledge about transplant center options and how center differences in both pre- and post-transplant measures might impact their mortality. Patients described factors used to make decisions which reflect important values, but the potential gaps in knowledge about variations across centers create challenges to understanding patient priorities. The findings emphasize the need to design and disseminate patient-friendly resources with information about transplant center options that helps patients weigh relevant factors and facilitate informed decision making in this population.

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TABLE 1

Questions on discussion guides

Interview and focus group topic: what patients learned about transplant center options

1. What information do you remember learning about different transplant centers?
2. What options were you told about before getting a referral to a center?
3. Have you done any research about centers on your own [eg internet, support groups]?
4. [If yes] What did you learn?

Interview topic: deciding on a specific center

1. What centers did you consider?
2. [If several] Did you compare any of them? How did you compare them?
3. [If several] What was most important in comparing them?
4. What could be done to help make choosing a transplant center easier?

Interview topic: new information and hypothetical decisions

[Questions tailored to participants, eg local residents discussed criteria if choosing a non-local program]

Example #1: Imagine if you lived halfway between two cities with transplant centers and needed to decide which one to visit. What information would be important to you to make this decision? Example #2: Imagine if you were given a list of nearby centers but your doctor did not give a specific recommendation. What information would be important to you to make this decision?

TABLE 2

Summary of local and national participants (number of focus groups)

	Hennepin Healthcare candidates	University of Minnesota candidates	National recipients	Total participants
Interview participants	10	10	N/A	20
Focus group participants	22 (5 groups)	23 (4 groups)	17 (3 groups)	62 (12 groups)
Total participants	32	33	17	82

TABLE 3

Characteristics of kidney transplant candidates and recipients

	Local candidates (N = 65)	National recipients (N = 17)
Kidney transplant centers within 100 miles; median (min, max)	5 (0, 5)	3 (1, 24)
Age; mean (SD)	54.0 (11.6)	52.3 (13.3)
Sex; n (%)		
Female	28 (43%)	10 (59%)
Male	37 (57%)	7 (41%)
Race; n (%)		
Black	20 (31%)	3 (18%)
White	42 (65%)	13 (76%)
Hispanic	1 (2%)	1 (6%)
Other	2 (3%)	0 (0%)
Education; n (%)		
Less than high school	5 (8%)	0 (0%)
High school	13 (20%)	1 (6%)
At least some college	36 (55%)	7 (41%)
Graduate education	11 (17%)	9 (53%)
Annual household income; n (%)		
<\$15 000	10 (15%)	1 (6%)
\$15 000-\$30 000	20 (31%)	3 (18%)
\$30 001-\$45 000	5 (8%)	3 (18%)
\$45 001-\$60 000	5 (8%)	1 (6%)
\$60 001-\$75 000	4 (6%)	3 (18%)
>\$75 000	19 (29%)	2 (12%)
Declined to answer	2 (3%)	4 (24%)
Number of household members; mean (SD)	2.2 (1.2)	1.9 (1.0)
Form(s) of insurance; n (%) ^a		
Private	32 (49%)	12 (71%)
Medicare	33 (51%)	10 (59%)
Medicaid	8 (12%)	2 (12%)
Not insured	0 (0%)	0 (0%)
Other	7 (11%)	2 (12%)
Self-reported health status; n (%)		
Excellent	2 (3%)	3 (18%)
Very good	10 (15%)	8 (44%)
Good	26 (40%)	5 (29%)
Fair	22 (34%)	1 (6%)
Poor	5 (8%)	0 (0%)
Blood type; n (%)		
A	13 (20%)	4 (24%)

	Local candidates (N = 65)	National recipients (N = 17)
AB	3 (5%)	2 (12%)
B	6 (9%)	1 (6%)
O	26 (40%)	8 (44%)
Not sure	3 (5%)	0 (0%)
No answer	14 (22%)	1 (6%)
Has had previous transplant, n (%)	14 (22%)	17 (100%)
Currently on the waiting list, n (%)		
Yes	31 (48%)	0 (0%)
No	11 (17%)	16 (94%)
Not sure	9 (14%)	0 (0%)
No answer	14 (22%)	1 (6%)
Body mass index; mean (min/max)	29 (15/42)	25 (20/36)
Comorbidities; n (%) ^a		
Hypertension	59 (91%)	14 (82%)
Diabetes	26 (40%)	2 (12%)
Asthma or emphysema	8 (12%)	3 (18%)
Cancer	13 (20%)	4 (24%)
Stroke or cerebrovascular accident	5 (8%)	0 (0%)
High cholesterol	32 (49%)	6 (35%)
Coronary artery disease or heart attack	9 (14%)	2 (12%)
Heart failure	2 (3%)	0 (0%)
Irregular beating of the heart or cardiac arrest	11 (17%)	2 (12%)
Hepatitis or liver disease	5 (8%)	2 (12%)
Overweight	31 (48%)	4 (24%)
Angina or chest pain	2 (3%)	1 (6%)
Shortness of breath	14 (22%)	2 (12%)
Bypass heart surgery	4 (6%)	0 (0%)
Coronary angioplasty	4 (6%)	1 (6%)
Cause of kidney disease; n (%) ^a		
Diabetes	19 (29%)	1 (6%)
Hypertension	20 (31%)	1 (6%)
Polycystic kidney disease	5 (8%)	4 (24%)
Glomerular disease	3 (5%)	6 (35%)
Other/don't know	29 (45%)	5 (29%)

^aSome marked multiple options; therefore, totals do not add up to 100%.

TABLE 4

Additional quotations illustrating main themes of interviews and focus groups

Theme 1: Patients accept decisions from trusted providers and friends	"I didn't know any other places. I just knew [my doctor] was good in his field because I heard a lot about him at work. A lot of people have [him] as a doctor. He had a good reputation, so I knew he wouldn't steer me wrong." [interview] "Well, I guess I really didn't get a choice only because the nurse practitioner at the nephrologist office, she said to me one day, she said, where do you want to go for transplant. She goes, you got three choices. And she said, [center 1] or [center 2] or [center 3]. And evidently, I had a look on my face like I didn't really give a rat's butt, so she says, you're going to [center 2]." [focus group] "Well, let me see, how do I put it? I don't want to say it wrong, but I'm thinking they have said there were other clinics but [my doctor] was saying that this one would be better for me. This clinic would be better for me, that's what he told me." [interview]
Theme 2: Confidence in perceived reputation of center	"[The surgeons at this center] were the first people to ever do it. So that makes you feel comfortable about it. Because if they were the first people that were doing it and are still doing it... so obviously it has to be good" [interview] "I think learning about the doctors. I do not know that facilities are all that different, are they? Because, you know, it is the doctors in the end that is the important thing." [H] [interview] "I think for me, what's important, too, is just the follow-up care afterwards and making sure that they're following along with you closely." [H] [focus group]
Theme 3: Personal relationships and convenience were important	"I would have liked to see more information on travel since I live, I just moved, so I live four and a half hours away now." [interview] "They treat you with like a human being." [H] [focus group] "Now for me it is familiarity even though this is a different office than it was before. Why fix it if it is not broke?" [interview] "I decided to go with the one that was not a teaching hospital because I preferred to develop a more direct relationship with the doctors rather than having residents and medical students always in the room and asking questions and stuff like that." [focus group] "I guess if there is a way that the transplant center could help find housing close for like a week's stay, what they talk about as far as after your transplant." [H] [interview] "A lot of people are, but you know, having an outreach program or a person or people—who are willing to take a half hour to three hours to have family members, answer their questions, to me is extremely important because you have got all these emotional things going on." [H] [focus group]
Theme 4: Insurance coverage was both a source of useful information about choices and a barrier that limited choices.	"My insurance only covered [two centers] and [my doctor] said that [one of these] was at the time going through some organizational changes" [focus group] "My insurance wouldn't approve me to go on their transplant list." [focus group] "My insurance did recommend that I go to the scientific registry to find out about different hospitals." [focus group]
Theme 5: Unique medical circumstances create a need for more information	"I talked to them while I was in the hospital ... the coordinator came and talked to me and she was like well, you're awfully complicated so I'm going to show your medical history to the surgeon and see if he even wants to try, or even wants to evaluate you at all. He was like 'no' so I never got evaluated there." [interview] "I want a list of the most risk tolerant facilities in the nation, who still apply safe practices and have relatively good statistics. Because it's clear [the first center], who is relatively risk adverse, is not going to speak for me." [interview] "I read it online as an option because my antibodies are at 100 percent so I knew I needed to do something so I had just checked out what they had. They claim to offer more than the [other center] so I had to check out my options down there." [interview]
Theme 6: Incomplete information	"[This center] was it; I didn't know much of anything else at the time." [interview] "Then, the only reason why I knew about the four different places, the four different transplant centers in this area is because I got a slip of paper with four different names, with four phone numbers. That's it. That is all. It was pretty much up to me to do my own digging for it." [focus group] "I did not really honestly research any other places, but we were made aware of other lists that you can go on and that if you were on other lists, you would have to go to those facilities." [interview] "I wasn't told that I can even look at other places although I knew about both [nearby centers] from family and friends and coworkers who have had kidney transplants through those other facilities. But, I was never told that I had a choice to go look at any of the other places. So, I just kind of went with what was thrown at me." [focus group] "I wasn't told anything about any transplant centers at all. I still haven't been told." [focus group] "My dialysis center had a list of four hospitals in Minnesota that do transplant. They gave it to me and said, 'You are on your own.' Basically, Very daunting. Very frustrating. Like anybody that has had a new disease, you are trying to find out what it is you have got, much less where to go next. Lots of confusion." [focus group] "I was on dialysis and one of the nurses there said to my caregiver, where else is she listed? You know she's too young to be on dialysis. She's too alert. Where else is she listed? We didn't really know anything about multiple listing. I mean I might have been told, but I wasn't in the right frame of mind to be listening. But from that point on I got listed at four other places." [focus group]

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Theme 7: Unaware of center differences and risks that are relevant to mortality

“Yeah. It raised more questions than answered them. So it’s just confusing. Like I said before, you have to put your name on a certain list and you have to go to all these different places to – [another center] had the best, one of the best turn-arounds. It was only a couple years versus other places. And it was like, why the heck does it – [that center’s] only a few hundred miles away. Why the heck is it – you know what I’m saying? So it just didn’t make sense to me why.” [focus group]
“Right, [a center with different criteria for listing] has a lot to do with how risk adverse the center is.” [interview] “No, I just assumed everybody was going to be the same [for listing criteria].” [H] [interview].

Theme 8: Overwhelmed with information

“I think anybody here who has ever been through a diagnosis and trying to figure out what is next, you get shuffled into the treatment and you still do not know what it is you have got or where you are going with the transplant.... It takes time for people to understand.” [focus group]
“At my age, I feel a little bit more overwhelmed by all the minutia, paperwork, and the insurance, and just dealing.” [interview]
“You know, it’s unfortunate that patients have to do as much as they have to do.” [interview]

Theme 9: Limited access to or mistrust of Internet

“It kind of concerns me a little bit the development of a web site, because in this day and age of technology it is easy to say, “Well, just go check our web site.” And it is only as good as the information A) it is there and B) the capability of the people to absorb that. And not everybody is going to be tech-savvy.” [H] [focus group] “The internet is just so vast and then I find myself trying to apply things to myself that maybe do not apply and trying to make it fit. So I think it is better off just to wait and ask a doctor.” [interview]