OPEN

Development of a Patient-specific Search of Transplant Program Outcomes and Characteristics: Feedback From Kidney Transplant Patients

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Background. Patients face obstacles in finding a transplant program that meets their healthcare needs. Acceptance criteria and waiting times vary by region and program. The Scientific Registry of Transplant Recipients provides program-specific information, but it is unclear what patients and referring physicians need to know. **Methods.** We examined variability in program-specific characteristics that could influence access to transplantation. We also conducted 20 interviews and 16 focus groups with transplant candidates, recipients, and their family members. Participants were shown prototypes of a patient-specific search tool and evaluated its capacity to identify programs tailored to the needs of individual patients. **Results.** The distribution of recipient and donor characteristics that may impact access to transplantation, such as recipients on Medicaid, varied across programs (all with $P < 0.01$). Several themes emerged related to impressions of access to transplantation and the usability of patient-specific search functions. Perceptions of the prototypes and results varied, but were positive overall and support providing an individualized search of program level data. Participants revealed significant barriers to identifying and evaluating transplant programs and suggest that patient-specific search results reduce the anxiety associated with selecting a program. **Conclusions.** Providing patient-specific tools is valued by patients and important to maximizing access to transplant.

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INTRODUCTION

Patients needing kidney transplantation face many challenges when making healthcare decisions. Potential candidates, defined by acceptance onto a deceased-donor waitlist, must first decide between treatment options (eg, dialysis versus transplantation, living donor versus deceased-donor transplantation) and where they wish to be evaluated for transplantation. Patient discretion over program selection is limited by insurance, but it is not uncommon for potential candidates to be evaluated for the waitlist at >1 program.[1] Criteria for being accepted for a transplant program's deceased-donor waiting list, waiting time, and posttransplant allograft survival rates or outcomes vary widely by region and transplant program.[2] Patient-specific and program factors can limit access to the waitlist and

posttransplant outcomes as well.[3,4] The Scientific Registry of Transplant Recipients (SRTR) Program-Specific Reports (PSRs) offer patients and their families information on every transplant program in the United States and allow users to evaluate and compare programs nearby or at a distance. However, the complete PSRs and early versions of web-based tools for accessing the data can be difficult for patients and families to use to select transplant programs.[5-7] In addition, studies show that patients experience great difficulty in selecting programs and possess a limited understanding of how the process works and how it affects outcome.[1,8-13] We aimed to develop a web-based tool that allows patients, families, and stakeholders to conduct patient-specific searches of the SRTR PSRs to communicate information on program outcomes and characteristics relevant to their individual medical profiles and clinical needs. We hypothesized that there are substantial differences between transplant program candidate acceptance criteria and that a customized search of program outcomes is needed to better communicate to patients where their chances of undergoing kidney transplantation are optimal.

CONCURRENT METHODS

To assess program variation and inform the development of the patient-specific search of SRTR PSRs, we adopted an approach that combines quantitative and qualitative methods. In doing so, we are able to describe variations between recipient and donor factors at programs across the United States and incorporate patient experiences and feedback into the design and implementation process.

Assessing Program-specific Variation in Who Receives a Kidney Transplant in the United States

This study used data from the SRTR. The SRTR data system includes data on all donor candidates, waitlisted candidates, and transplant recipients in the United States, submitted by the members of the Organ Procurement and Transplantation Network (OPTN). The Health Resources and Services Administration (HRSA), US Department of Health and Human Services provides oversight to the activities of the OPTN and SRTR contractors. We first assessed variability in patient, donor, and transplant program factors that may affect access to transplant in the United States between January 2017 and December 2017 (eg, body mass index [BMI], Medicaid, and advanced age). Factors were first identified through consultation with providers. We stratified programs according to the prevalence of their recipient, donor, and transplant characteristics and by program size. For convenience and visibility, we defined small, medium, and large programs according to the number of kidney transplants performed over that timeframe; 1–36, 37–99, and 100 or more, respectively. We used chi-squared tests to determine whether the differences between kidney transplant programs and the proportion of recipients matching different characteristics were statistically significant. We then determined the number of candidates during the same timeframe on the kidney waitlist for deceased donors that had these characteristics. We also examined the proportion of recipients matching each characteristic over a 3-year period beginning in January 2015 and ending in December 2017 to assess the stability of our findings over time. The results of these analyses informed the

selection of content included in prototypes of the patient-specific search, supplemented with insights from the literature on disparities in transplantation.[3,14,15] Prototypes were designed to help patients identify centers with programs that transplant patients like them (eg, comorbidities, donor preferences, insurance type).

Interview and Focus Group Topics

Our goal was to evaluate how transplant candidates, recipients, and their families respond to prototypes of a decision aid with patient-specific search tool approximating the SRTR PSRs (Figures 1 and 2).[16] In addition, we examined how patients make decisions when selecting a program for evaluation for the waitlist[1] and what new content and presentation formats would be helpful in decision-making. Discussions explored 4 areas: (1) what resources patients used to learn about prospective transplant programs and the information acquired; (2) which considerations influenced patients' decision to be evaluated for the deceased-donor waitlist at 1 or more programs; (3) what new information should be added to public reports to enable better-informed decision-making; and (4) how participants anticipate incorporating prototypes of a customized and patient-centered decision aid into hypothetical decision-making scenarios. In instances when participants were unaware of their discretion over program selection and thought that they had no choice between treatment options, participants were prompted to speculate how the prototypes would influence hypothetical decisions.[17]

Discussions were initiated after first capturing reflections on past experiences, acknowledging that the experience of selecting a program, being evaluated for the waitlist, and receiving a transplant may affect the perceived importance of measures included in public reports. Discussion of factors related to hypothetical and *real* decisions was coded separately from one another. Examples of interview and focus group prompts within the scope of this analysis are included in Table S1 (SDC, http://links.lww.com/TXD/A266). Additional information on the study design is reported in the Methods Supplement and a COREQ reporting checklist is provided in Table S2 (SDC, http://links.lww.com/TXD/A266).[17]

Participants and Procedures

Each participant provided in-person written informed consent after receiving an invitation letter, speaking with a study coordinator and before completing any study activities. The study was approved by the Institutional Review Boards at Hennepin Healthcare System (HHS) and the University of Minnesota-Fairview (UMN-F) transplant programs. Potential participants were screened according to ability to speak and understand English, and recipients were later stratified according to self-reported involvement in transplant patient education and advocacy groups (see Methods supplement for additional information on inclusion and exclusion criteria). Participants received a $40 stipend as compensation.

We conducted 20 in-person interviews, 9 focus groups with adult (age 18 y and over) kidney transplant candidates, 3 focus groups with kidney transplant recipients, and 4 additional focus groups with the adult family members of local candidates. Participant characteristics are detailed in Table 1. Transplant candidates and family members were recruited locally from the HHS and UMN-F transplant programs; transplant recipients were recruited electronically via email,

Transplant Center Search
Enter your medical profile to help find the right center.

Distance You Can Travel
Within [50 miles ⌄] of [____]
OR [Minnesota ⌄]

Does This Limit My Options?
⚠ Waiting time varies by region. A larger area gives you more choices.

Age of Candidate
[70]

⚠ Centers have different age criteria for candidates that may impact your options.

Height [5] ft [10] in   **Weight** [190] lbs

Blood Type
[B ⌄]

⚠ Waiting times for Blood Type B are often longer than other types. Centers with "Blood Type B Programs" may have a wider range of donors available.

Cause of the Kidney Disease
[Not sure ⌄]

Insurance Provider
[Private ⌄]

Organ Type
[Deceased Donor ⌄]

HIV Positive
[No ⌄]

Hepatitis C Positive
[No ⌄]

[**Find Transplant Centers**]

FIGURE 1. Example of a patient-specific search tool. Shown is an example of an early iteration of the patient profile entry page of the patient-specific search tool.

social media, and national advocacy groups (eg, National Kidney Foundation). Interviews and focus groups with transplant candidates were conducted at HHS and UMN-F clinics; national transplant recipients were flown to Chicago, IL, to participate in the study focus group. Moderators presented the investigation as an initiative to collect patient experiences so that service providers and agencies responsible for creating public reports would have a better understanding of healthcare decision-making. Additionally, researchers presented the study as an opportunity to capture feedback on new measures and displays developed using SRTR data.

Interviews with candidates captured reflections on patient experiences, inform the development of focus group discussion guides and the displays, language, content included in prototypes of the patient-specific search. Prototype information displays and focus group guides evolved over the course of the data collection phase with subsequent iterations reflecting feedback from earlier participants. Examples of prototypes included search results with counts of transplant recipients in the past year matching patient characteristics (eg, BMI >35) as well as comparable indicators for program services matching patients' clinical needs (eg, A2/A2B to B; paired exchange

program). Interviews were conducted by C.S., trained in qualitative methodologies for human-centered design. All focus groups were moderated by the same individual (C.S.), while a senior social science researcher (M.B.), or a design specialist (S.C.), and a transplant physician (A.I.) were in attendance. Interviews and focus groups with candidates took place in an exam room or small conference room at HHS and UMN-F. Focus groups with national recipients took place in a hotel conference room in Chicago, IL. The scope of the current analysis includes *only* participant feedback on the prototypes of a customized and patient-centered version of the SRTR Program-Specific Report and reflections on choosing a program. Additional analyses of feedback from kidney transplant candidates and recipients focused on decision-making have been published elsewhere.[1,7]

Interviews with local candidates did not exceed 45 minutes; focus groups lasted between 60 and 120 minutes in length. Discussions were audio recorded and transcribed verbatim. Moderators captured information on each participant's demographics and comorbidities via a questionnaire administered before the start of each interview and focus group. Analysts (W.M., C.S., and M.B.) utilized Dedoose version

Transplant Center Search Results

Centers may vary in rates of complications and wait times. **Learn more.**

NAME / DISTANCE	TRANSPLANTS IN A YEAR	Before Transplant MOVING QUICKLY UP THE WAITING LIST	After Transplant HIGHER 1 YEAR SURVIVAL	Custom Search Information PATIENTS OVER AGE 70
Meadow Hospital 92 miles	73 adults	3 GOOD (AS EXPECTED)	4 SOMEWHAT BETTER THAN EXPECTED	7
Forest Hospital 120 miles	117 adults	2 SOMEWHAT WORSE THAN EXPECTED	4 SOMEWHAT BETTER THAN EXPECTED	2
Lake Hospital 15 miles	60 miles	5 BETTER THAN EXPECTED	3 GOOD (AS EXPECTED)	4

These centers are in your search area, but there is no recent information these centers have transplanted patients with your age or medical profile. **Learn more.**

| River Hospital 4 miles | 24 adults | 3 GOOD (AS EXPECTED) | 3 GOOD (AS EXPECTED) | 0 |
| Alpine Hospital 40 miles | 13 adults | 4 SOMEWHAT BETTER THAN EXPECTED | 2 SOMEWHAT WORSE THAN EXPECTED | 0 |

FIGURE 2. Example of a patient-specific search result. Shown is an example of an early iteration of the results from the patient-specific search tool.

8.2.32 coding software (SocioCultural Research Consultants, LLC, Los Angeles, CA) to code and organize data to facilitate the analysis of participant feedback and categorize narrative excerpts. Transcripts were open-coded and axially coded through an inductive and exploratory strategy that prioritized participants' feedback and reflections on past experiences and decision-making.[18-20] Codes were applied to excerpts that reflected a process orientation to decision making and conveyed participant attributes relevant to their decisions. These excerpts identified information resources, decision makers and stakeholders, and constraints on agency. Codes were also applied to excerpts that assigned value judgments to the mock-ups of the patient-specific search.[20] Focus group transcripts were analyzed at the group level and did not segment responses by participant.[21]

Two researchers (W.M. and C.S.) contributed to the development of a shared code book consisting of 202 mutually exclusive code definitions. W.M. and C.S. each read transcripts and utilized a blind-coding strategy that facilitated the review of each other's coding schemes and definitions. In instances when W.M. and C.S. could not reach an agreement, the code and excerpted text was presented to the research team and a decision was made to refine the code definition, reject the excerpted text, or reject the code entirely. If a code definition was altered, W.M. reexamined all of the transcripts to ensure consistency in the application of the code. Themes were identified by W.M. following a review of the 1679 excerpts and were later verified by M.B. and A.I. Representative quotations illustrating themes were identified and included in this article. For additional information on the study design, see Methods Supplement.

Statistical Analysis

Results were considered significant for $P < 0.05$. Chi-square tests were conducted to compare characteristics across transplant programs, and this analysis was carried out using SAS version 9.4 (SAS Institute, Care, NC).

RESULTS

Quantitative Analysis

Of the 144 912 candidates on the waitlist between January 1, 2017, and December 31, 2017, many had clinical characteristics that may influence their acceptance to the waitlist and transplantation, for example, the 10 832 (7.47%) waiting list candidates with diabetes and BMI over 35 or the 12 954 (8.93%) candidates willing to accept an organ from a hepatitis C virus positive donor (Table 2). Multiple patient characteristics were unevenly distributed across different programs. For instance, very few programs perform A2/A2B to B transplants and even fewer accept organs from HIV+ donors (Figure 3). We stratified these characteristics across transplant programs of different sizes as determined by volume of kidney transplants conducted over that timeframe (Figure 4; Figures S1 and 2, SDC, http://links.lww.com/TXD/A266). There was variation in volume of recipients transplanted with BMI over 35 (17.5%) between programs. Similarly, dual kidney-pancreas transplants were uncommon among smaller programs. For many patient and recipient characteristics, this variation was persistent over the 3-year period between January 1, 2015, and December 31, 2017. (Figure 5; Figures S3–7, SDC, http://links.lww.com/TXD/A266). For instance, centers of different sizes had limited ranges for the proportion of living donor

TABLE 1.

Summary of demographics and clinical characteristics of participants in interviews and focus groups

	Local candidates	Local family members	National recipients
Interview participants, n	20	N/A	N/A
Focus group participants, n (number of groups)	45 (9 groups)	7 (4 groups)	17 (3 groups)
Age, n (SD)			
≥65	12 (18.4)	1 (14.2)	3 (17.6)
Sex, n (%)			
Female	28 (43.0)	4 (57.1)	10 (58.8)
Race, n (%)			
Black or African American	20 (30.7)	0 (0)	3 (17.6)
Hispanic	1 (1.5)	0 (0)	1 (5.8)
White	42 (64.6)	7 (100)	13 (76.4)
Other	2 (3.0)	0 (0)	0 (0)
Education, n (%)			
Less than high school	5 (7.6)	0 (0)	0 (0)
High school	13 (20.0)	2 (28.5)	1 (5.8)
Some college	17 (26.1)	3 (42.8)	4 (23.5)
College	19 (29.2)	2 (28.5)	3 (17.6)
Graduate	11 (16.9)	0 (0)	9 (52.9)
Income, n (%)			
Prefer not to answer	2 (3.0)	0 (0)	4 (23.5)
<$15 000	10 (15.3)	1 (14.2)	1 (5.8)
$15 000–$30 000	20 (30.7)	2 (28.5)	3 (17.6)
$30 000–$45 000	5 (7.6)	0 (0)	3 (17.6)
$45 000–$60 000	5 (7.6)	0 (0)	1 (5.8)
$60 000–$75 000	4 (6.1)	0 (0)	2 (11.7)
>$75 000	19 (29.2)	4 (57.1)	2 (11.7)
Insurance, n (%)			
Medicaid	8 (12.3)	0 (0)	2 (11.7)
NonMedicaid (private, Medicare, other)	57 (87.6)	7 (100)	15 (88.2)
Transit to doctors appointment, n (%)			
I or a family member, own a car	41 (63.0)	2 (28.5)	12 (70.5)
I have access to a car and ride with someone	3 (4.6)	0 (0)	1 (5.8)
I use public transportation/bus/metro	7 (10.7)	1 (14.2)	3 (17.6)
I take a taxi	3 (4.6)	0 (0)	0 (0)
I walk	0 (0)	0 (0)	1 (5.8)
Other	2 (3.0)	1 (14.2)	2 (11.7)
Cause of end-stage renal disease, n(%)			
Diabetes	19 (29.2)	N/A	1 (5.8)
Glomerular disease	3 (4.6)	N/A	6 (35.2)
Hypertension	20 (30.7)	N/A	1 (5.8)
Polycystic kidney disease	5 (7.6)	N/A	4 (23.5)
Other	21 (32.3)	N/A	5 (29.4)
Don't know	8 (12.3)	N/A	0 (0)
Overweight; n(%)	31 (47.6)	N/A	4 (23.5)

Missing responses to items on the participant survey occurred at the following rates for local candidates: overweight (1.5%).
Missing responses occurred at the following rate for family members: age (14.2%).

transplants or recipients on Medicaid over the 3-year period, while there was greater variability for programs performing transplants on recipients over age 70 years or those performed on hepatitis C virus positive donors and recipients.

Qualitative Analysis

A total of 89 kidney transplant candidates, recipients, and their family members were participated; 20 candidates completed interviews and the remaining 69 participants joined focus groups. A greater proportion of local candidates were male (57.0%), white (64.6%), and not on Medicaid (87.6%). A majority of candidates completed high school (92.3%) and

29.2% attained a college degree. Recipients who participated in focus groups were disproportionately white (76.4%) and a greater proportion (59.2%) completed postgraduate education than other participant groups. Participants' reflection on past experiences captured during interviews and focus groups were similar. Likewise, interview and focus group responses to prototypes of the patient-centered decision aid with a customized search results did not reveal significant variations. Three themes emerged from the analysis of interview and focus group data that support the development and dissemination of patient-specific resources to patients and their families (Table 3). The first theme, patients feel that a patient-specific

Distribution of clinical variable in national kidney transplant candidates on the deceased-donor waitlist for kidney transplant, January 1, 2017, to December 31, 2020

Distribution of clinical variables in patients	n (%)
Total	144 912
Cause of end-stage renal disease	
Diabetes	50 810 (35.0)
Hypertension	31 600 (21.8)
Glomerulonephritis	20 887 (14.4)
Cystic kidney disease	13 716 (9.4)
Other	27 889 (19.2)
Age	
Age <70 y	137 999 (95.2)
Age ≥70 y	6912 (4.7)
Age (y), mean (SD)	50.7 (13.8)
High BMI	
BMI < 35	119 687 (82.8)
BMI ≥ 35	24 779 (17.1)
Blood type	
Other	121 523 (83.8)
B	23 389 (16.1)
Willing to accept hepatitis B + donor	
No	59 069 (40.7)
Yes	85 836 (59.2)
Willing to accept hepatitis C + donor	
No	131 955 (91.0)
Yes	12 954 (8.9)
Medicaid insurance	
No	130 782 (90.2)
Yes	14 060 (9.7)
Diabetes	
No	80 227 (55.3)
Yes	64 685 (44.6)
BMI greater than or equal to and diabetes as cause of kidney disease	
No	133 634 (92.5)
Yes	10 832 (7.5)
BMI ≥ 40 and diabetes as cause of kidney disease	
No	142 580 (98.6)
Yes	1886 (1.3)

Data from the Scientific Registry of Transplant Recipients.
BMI, body mass index.

search offers added decision support over resources that are program-specific and do not offer customization, emerged from reflections on the resources patients relied on when making decisions about their treatment preferences and program. The second theme, customized search results about program outcomes alters how patients perceive their access to the deceased-donor waitlist and transplantation, reflects gaps in patient knowledge. The final theme, patient-specific search results provide insight into factors (eg, BMI) that a patient may change to improve access to the waitlist and transplantation, captures feedback on prototypes of the patient-specific search and discussions of its use in hypothetical scenarios.

Theme 1: Patients Feel That a Patient-specific Search Offers Added Decision Support Over Resources That Are Program-specific and Do Not Offer Customization

Responses to viewing prototypes of the decision aid with the patient-specific tool indicate that participants found that the prototypes provided them with information useful for identifying programs that transplant *patients like them*. Comments suggested that the patient-specific results reduce the difficulty of selecting a program by directing users to programs with recent experience transplanting patients with similar clinical profiles. Along these same lines, participants reported that they felt that patient-specific results would allow them to evaluate transplant programs according to variations in waitlist acceptance practices that are perceived to be prohibitive of transplantation. Respondents suggested that the prototype offered the only source of such information and that past healthcare decisions would have been easier to make—even if they chose the same program.

Example(s):

The patient specific one, I mean. Yeah. If your diagnosis is the reason why you need a kidney transplant. It is different than somebody else's. You want to be able to drill down and start eliminating the places that don't specialize; or aren't capable of doing that stuff with transplants. [Focus group-Candidates]

I don't know how long this had been a site, but prior to his first transplant I went to each [program website] – I went to [Center name], I went to [Center name 2], I went to – he could have also gone to Pittsburgh or Nashville through the [hospital system name]. So I looked at everybody's information and tried to determine what was gonna work best for us as a family unit. This would have been so much easier. [Focus group-Family Members]

Theme 2: Customized Search Results Alters How Candidates Perceive Their Access to the Waitlist and Transplantation

Participant responses to viewing prototypes of the decision aid with patient-specific search tool indicate that receiving search results customized to the user's clinical profile impacts expectations for accessing the waitlist and transplantation. Participants reported appreciating receiving information that manages expectations for treatment and offers a convenient and clear means to evaluate potential transplant programs (Table 3). Even further, responses suggest that patients value learning that certain programs have no recent experience transplanting patients like them. Participants did express the desire to review customized search results with their nephrologist and transplant surgeon to confirm their interpretation.

Example(s):

No, it's good to know that stuff, because I guess I didn't even think about that when I was looking, because no one really said that was a really hard blood type five years ago when I was looking, but that's a really good thing to know now if I would want to switch. [Focus group—Candidates]

Interviewer: So, now, that you're looking at [patient specific results] in particular, how do you interpret what's shown here? What do you think that means?

Participant: They don't have any other patients on their list with your blood type or your age. So, if I entered an age of 75, that means these guys wouldn't take me, but these guys would. [Focus group—Candidates]

Theme 3: Custom Search Offers Insights Into Acceptance Criteria and Patient Factors a Candidate May Change to Increase Access to the Waitlist and Transplantation

Participants indicate that the prototype provides insights into waitlist acceptance practices and patient characteristics
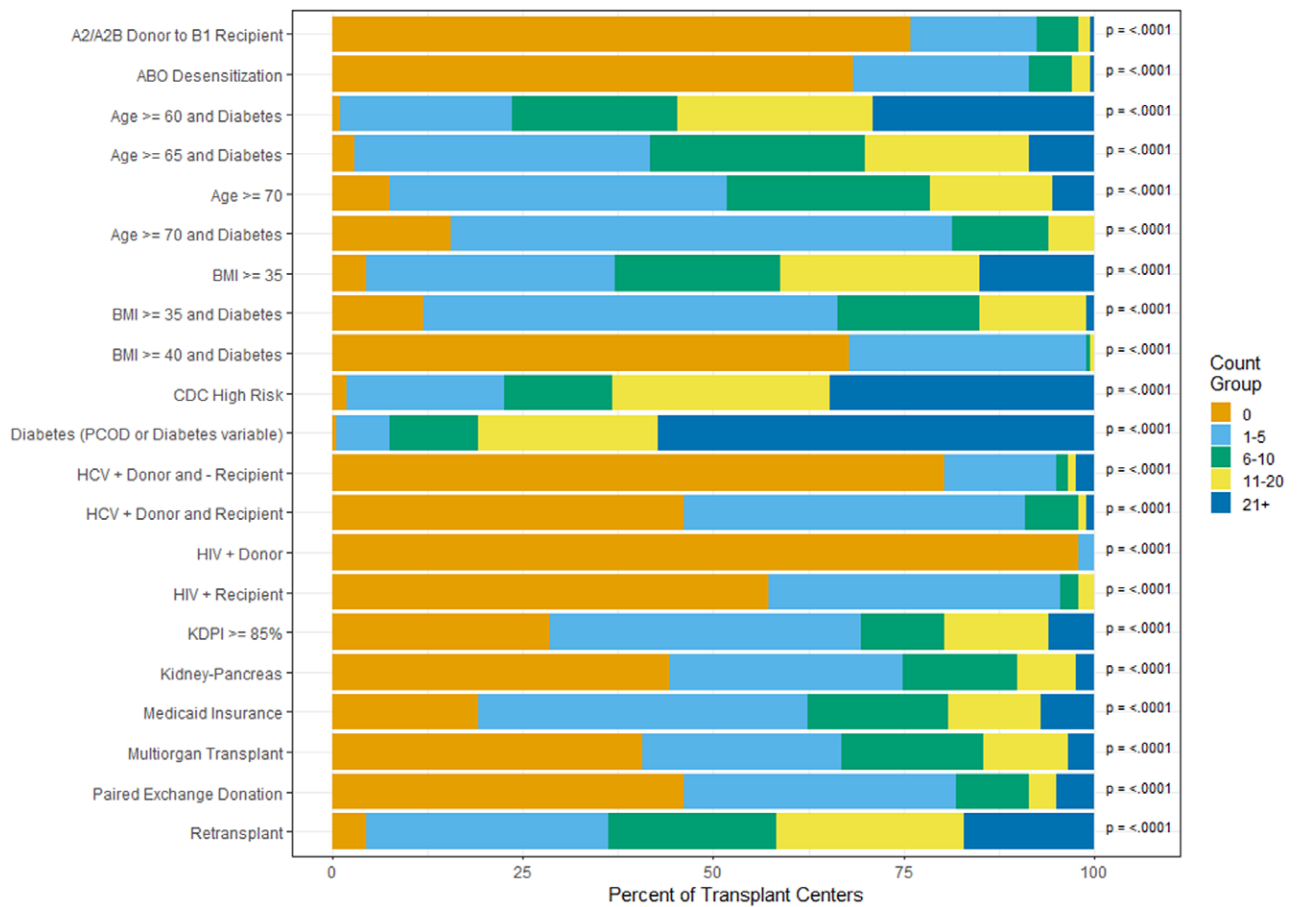
FIGURE 3. Distribution of transplant programs by recipient characteristics in 2017. Shown are percentages of transplants with recipient characteristics unless otherwise indicated. Each are $P<0.01$ by chi-square. Data are from the Scientific Registry of Transplant Recipients. BMI, body mass index; CDC, centers for disease control; HBV, hepatitis B virus; HCV, hepatitis C virus; KDPI, kidney donor profile index; PCOD, primary cause of disease.
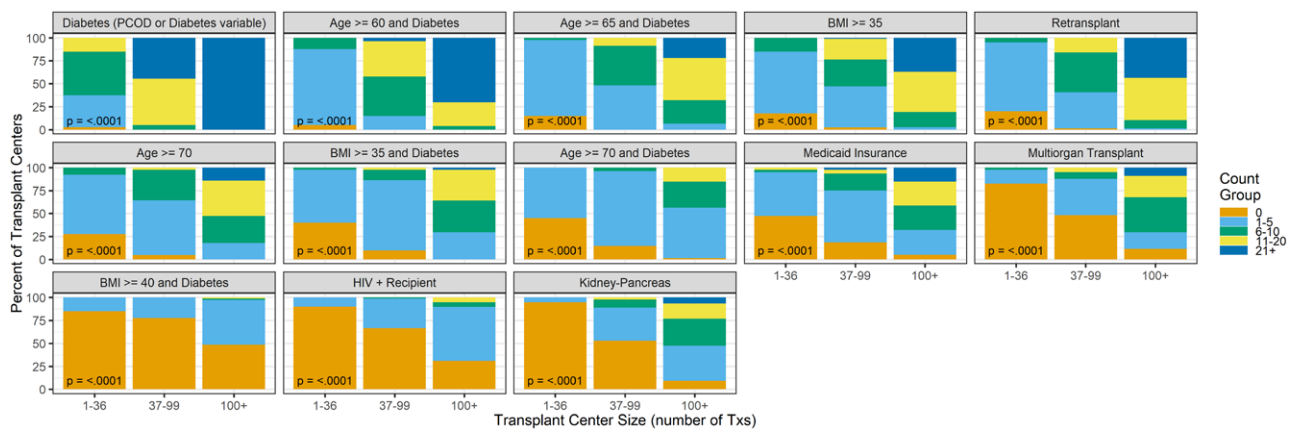

FIGURE 4. Numbers of transplant recipients with different characteristics stratified by program size in 2017. Distribution of transplant recipients and donor volumes for small (1–36), medium (37–99), and large (+100) programs for recipients and donors matching each characteristic that may impact access to transplant ($P<0.01$ for all characteristics). For example, over 50% of large programs had >21 recipients with age ≥60 y and diabetes. Data are from the Scientific Registry of Transplant Recipients. BMI, body mass index in kg/m²; CDC, centers for disease control; HBV, hepatitis B virus; HCV, hepatitis C virus; KDPI, kidney donor profile index; PCOD, primary cause of disease.

that they may change to increase access to the deceased-donor waitlist and transplantation. Factors include weight, preferences for program distance, donor type, and insurance coverage. Equally significant, however, is the revelation that many participants—even those who previously received a transplant—were unfamiliar with patient characteristics that they may change to improve access before making real decisions on their treatment.

Example:

Honestly, that [indication that a program does not have recent information on patients with matching characteristics] was the thing that caught my attention. I want to click that one more time.
Group Members: [Laughter]
Participant: It's because I want to know what's going on with those other two centers and why I don't meet that criteria. Is there something I can do to adjust? [Focus group—Recipients]
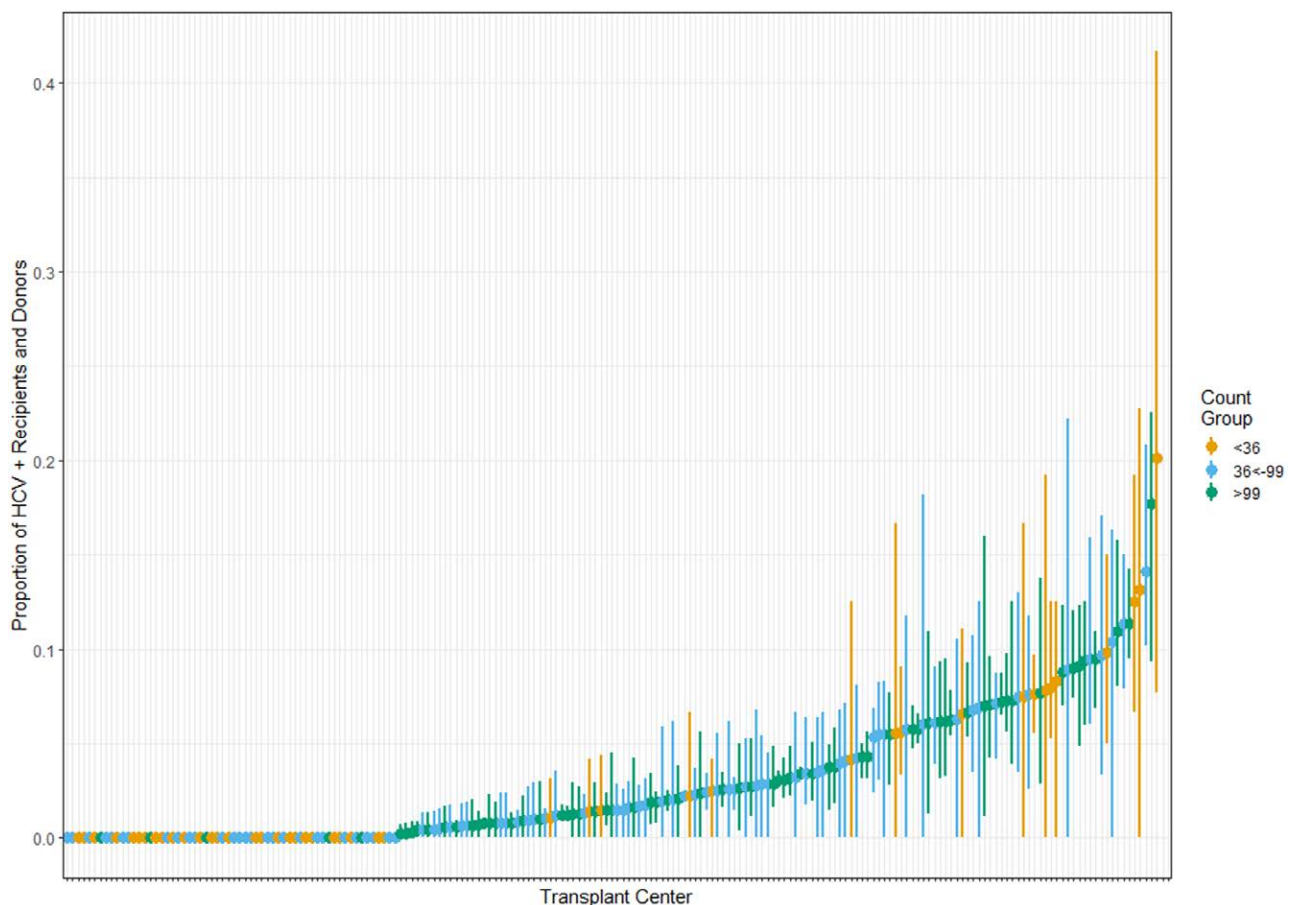
FIGURE 5. The proportion of hepatitis C positive donor and recipient transplants for each US program for 3 consecutive 1 y periods, January 2015–December 2017. Points represent median proportions for each center. Shading represents overall transplant volumes for donor and recipient characteristic. Data are from the Scientific Registry of Transplant Recipients. HCV, hepatitis C virus.

Taken together, these themes emphasize the significance of developing information resources that help patients understand their individual clinical profile and identify transplant programs that address their specific healthcare needs.

DISCUSSION

The findings of this mixed methods study of kidney transplant candidates and recipients suggest that the utility of public reports detailing transplant program outcomes and performance can be improved by creating resources with patient-specific tools. Further, quantitative assessments of the clinical profiles of kidney transplant recipients and donors supports providing patients in need of kidney transplantation with information tailored to their clinical profile, as select patient characteristics appear to limit access to transplant, even among the largest programs (eg, requiring simultaneous organ transplants and having BMI >40 with Diabetes). Innovative interactive formats conveying information based on SRTR data on transplant programs that are both patient-centered and customizable present patients and their families with a *unique* perspective on treatment options tailored to their individual clinical profile (theme 1). Customized prototypes have been shown to help patients and their families manage expectations for treatment and reduce patients' anxieties over accessing the waitlist and transplantation (theme 2). Similarly, participants suggest that patient-specific resources

provide insights into waitlist acceptance criteria and patient factors that they may change to improve their access to the deceased-donor waitlist and transplantation (theme 3). Each of the findings suggests that patients can make better-informed decisions about their health care when provided with information on transplant programs that is tailored to their particular clinical needs.

The primary goal of the study was to evaluate the utility of developing a patient-specific decision aid with SRTR program-specific reports for reducing the cognitive burdens facing patients as they make decisions on healthcare alternatives. As studies have shown, patients often experience great difficulty interpreting the comparative information included in public reports of healthcare quality and outcomes.[1,5-7] Seeking to remedy this challenge from the perspective of reporting agencies, capturing feedback from kidney transplant candidates and recipients after viewing prototypes of a patient-centered and patient-specific search allowed us to reflect on patient experiences and incorporate considerations for how such a resource would influence hypothetical decisions. This new patient-specific decision aid is available at http://transplantcentersearch.org/. Participant responses indicate that the presentation of patient-specific information alongside standardized search results creates a patient-centered and easy to understand means to evaluate transplant programs and identify those programs that transplant patients like them. Likewise, the results of this study suggest steps clinicians may

TABLE 3.

Additional supporting quotations illustrating themes

Theme 1: Patients feel that a customized and patient-centered search is more effective than relying on center-specific resources and standardized public reporting

Unidentified female: I love it then, because it really helps you narrow down all of the stuff because say you're relocating, or you, yeah, that would be awesome. Unidentified female: I think it's good. Unidentified female: That's a lot more help than I believe I got five years ago trying to figure it out. (Focus group—candidates)

I think that is very smart, too. Anything you can do to further educate patients and help them, because by this you are personalizing it more by having these little pop-ups come up. And I think, as with statistics it is mean, median, and mead that gets kind of boring after a while. This focuses more on the individual, and I think in the spirit of making <it only> for you, this may happen because you are overweight or because your 70 or because you are this or that. I would like to know that instead of them assuming that I know that already. (Focus group—candidates)

I would say overall that just the questions provide information is educational, just the question. And then if you have a popup, it's even better. So, yeah. (Focus group—recipients)

One thing that is a frustration for me is that my blood type makes it difficult for me to have a match. So, I would want to know how centers are dealing with certain blood types and the transplants from my specific blood type. (Focus group—candidates)

Theme 2: Receiving customized search results alters how candidates perceive their access to the waitlist and transplantation

I guess part of it, too, is that it seems pretty similar as far as the ratings for those ones. Certainly not much, much better. If they were all 5's down there, then maybe I would want to look into them more, but they seem pretty similar. I'd probably rather spend more time looking up places that I knew had a good chance of finding matches. (Focus group—family)

Female participant: Right, because it's not worth looking at fours. Well, in the previous slide fours look very good if I remember correctly. So now, when you put the … Moderator: We're just adding it the same way. Female participant: Right, but when you customize the data to you and you're an older patient, then you're like; whoops, we better be look at Meadow (Focus group—recipients)

I kind of like it. I mean I think it's good to know certain things are going to potentially give you fewer options. To some extent, that might encourage people to put on a larger radius for their search. So, if they know they're type B or overweight or whatever, that it's going to be harder to find a center that's going to be able to match them to a donor, then they may be willing to search for centers that are further away. (Focus group—family)

I started to digress about the blood type B, but it's like, oh, it's right in my face again. No, it's good to know that stuff, because I guess I didn't even think about that when I was looking, because no one really said that was a really hard blood type five years ago when I was looking, but that's a really good thing to know now if I would want to switch. Where is a better blood type or hospital? (Focus group—candidates)

If you are doing a search for a transplant center those are things HIV positive and Hepatitis C those are things that could weigh pretty heavily on your chance of receiving a kidney. If you are looking for a transplant center that can serve you the best that would be helpful information to know where you would fit into their program. (Focus group—candidates)

Theme 3: Custom search offers insights into acceptance criteria and clinical factors a patient may change to increase access to the waitlist and transplantation

Those little bullets that come up I would consider those useful information. Interviewer: Okay. Participant: Because it would, there are things that I can do to come within the guidelines if I know what the guidelines are ahead of time. Interviewer: Sure. Participant: The information is great, I do not think it would have changed our decision, but it would have helped us feel more informed. (Focus group—candidates)

Yeah. Just the things you can changes, like my weight. If I know I can drop ten pounds and my options are better then that's fine. But I can't change my blood type nether. So you know what I mean, just the things that you can changes. (Focus group—candidates)

take to improve patient experiences including confidence in selecting a transplant program. Several participants indicated that they would prefer to view patient-specific results and comparative performance measures with their providers.

This study has several limitations. In particular, we were unable to assess the statistical significance of variations in donor and recipient factors, in part because the considerable number of programs and variations in transplant volume posed problems for analysis. We attempted to use logistic regression, mixed effects models, and correlation coefficients, but none produced robust models (data not shown). Additionally, SRTR data only includes information on patients who were added to the waitlist for deceased-donor organs. Patients who were deemed ineligible for entry onto a waitlist and those who have end-stage renal disease, but have not yet sought evaluation are not included in the data or this analysis. This omission potentially limits the applicability of our findings. However, it is also possible that candidates with high BMI are accepted on to a waitlist but most are not eligible for transplant until they lose weight. Therefore, our study focused on types of transplant recipients at a program instead of access to the waiting list. Our qualitative findings were limited by the small sample size (n=20) of the interviews with transplant candidates and their geographic concentration around 2 transplant programs. However, our national focus groups invited transplant recipients from all OPTN regions. Future studies will benefit from wider recruitment of transplant

candidates in other OPTN regions. Further, the transcriptions of focus group data did not include unique identifiers for each participant. Without unique identifiers, analysts were unable to distinguish between the sources of feedback on the patient-specific prototypes of the decision aid and were forced to interpret the focus group data at the group level. Likewise, analysts were unable to link participants' demographic information to responses and in turn, had a limited ability to comment on factors that may affect participants' impressions of prototypes, capacity to correctly interpret the information provided to them, or even access to the resource (eg, race/ethnicity, healthcare literacy, and socioeconomic status). This limitation also impacts the visibility of focus group effects (eg, group size, interactions between participants, and researcher effects) on participant responses. In addition, the study relied on patients who have already made a decision about where to be evaluated for transplantation. While reflections on past decision making and hypothetical decisions were important, we were unable to capture information from patients who have yet to make a decision and might incorporate a patient-specific search into their program selection process.

In conclusion, the thematic analysis of responses from kidney transplant candidates and recipients on patient-specific prototypes revealed that participants viewed the prototypes of the decision aid as an improvement over the SRTR program-specific reports that do not offer customization. Patients responded positively to being provided information that

allows them to evaluate transplant programs by their experience transplanting patients like them with indicators of clinical services that they may find beneficial. In the context of widespread disparities in access to the deceased-donor waitlist and transplantation, the findings of this study reinforce the need for developing patient-specific resources for reporting program characteristics and outcomes that can assist patients as they weigh factors relevant for their treatment of end-stage renal disease. This research supports further investigation into the development of a patient-centered and patient-specific search tool for identifying transplant programs.

Data Sharing Policy

Data available on request from the authors.

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