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Designing a patient-specific search of transplant program performance and outcomes: Feedback from heart transplant candidates and recipients

Warren T. McKinney¹, Cory R. Schaffhausen¹, David Schladt², Marilyn J. Bruin³, Sauman Chu³, Jon J. Snyder⁴, Cindy Martin⁵, Tamas Alexy⁵, Bertram Kasiske⁶, Ajay K. Israni^{1,4,6}

¹Hennepin Healthcare Research Institute, Minneapolis, MN, USA

²Chronic Disease Research Group, Minneapolis, MN, USA

³College of Design, University of Minnesota, Minneapolis, MN, USA

⁴Scientific Registry of Transplant Recipients (SRTR), Minneapolis, MN, USA

⁵Cardiovascular Division, Department of Medicine, University of Minnesota, Minneapolis, MN, USA

⁶Nephrology Division, Hennepin Healthcare, Minneapolis, MN, USA

Abstract

Background: The Scientific Registry of Transplant Recipients provides transplant program-specific information, but it is unclear what patients and stakeholders need to know. Acceptance criteria for the candidate waitlist and donor organs vary by program and region, but there is no means to search for programs by the clinical profiles of recipients and donors.

Methods: We examined variability in program-specific characteristics that could influence access to transplantation. We also conducted three interviews and three focus groups with heart transplant candidates and recipients. Participants evaluated prototypes of a patient-specific search tool and its capacity to identify programs tailored to specific patient needs. Patient experiences and feedback influenced the development of tools.

Results: The distribution of recipient and donor characteristics influenced access to transplantation, as age and body mass index varied across programs (all with $p < .01$). Several

Correspondence: Warren T. McKinney, Nephrology Division, Hennepin Healthcare, 701 Park Ave., Minneapolis, MN 55415, USA. wmckinney@hhrinstitute.org.

AUTHOR CONTRIBUTIONS

A.I and CS contributed to research and study design; CS, M.B, and CM involved in data acquisition; WM, CS, M.B, DS, CM, and T.A analyzed/interpreted the data; AI, JS, BK, and S.C supervised and contributed to 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.

DISCLOSURES

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

themes emerged related to decision-making and the perceived usability of the patient-specific search. Perceptions of the prototypes varied, but were positive overall and support making the patient-specific search publicly available. Participants revealed barriers to evaluating transplant programs and suggest that patient-specific search results may optimize the process.

Conclusions: The patient-specific tool (<http://transplantcentersearch.org/>) is valued by heart transplant patients and is important to maximizing access to transplant.

Keywords

decision-making; heart transplantation; qualitative; registries

1 | INTRODUCTION

Transplantation is the ideal therapy to improve outcomes and reduce the burden of prolonged mechanical circulatory support (MCS) for patients with end-stage heart disease.^{1,2} Transplant programs offer varying levels of risk tolerance, yet there are limited resources available for identifying and comparing programs for patients. Clinicians may be aware of such center-specific differences.³ As the patient-centered phase of health care expands to include additional areas of clinical care, there is increased need for patient-centered resources that enable informed and shared decision-making among stakeholders.^{4,5} Currently, the Scientific Registry for Transplant Recipients (SRTR) offers a transplant program search that allows patients, family members, and providers to evaluate and compare programs in their area or nationally. The program search reports risk-adjusted measures for program performance and outcomes (eg, survival on the waitlist, getting a transplant faster, and 1 year post-transplant survival) and includes links to detailed program-specific reports (PSRs) for each transplant program.^{6,7} Each PSR includes information on waitlist acceptance practices, candidate and recipient demographics, and donor characteristics. However, the PSRs can be difficult to interpret and the PSR search does not offer customization beyond geography.^{8,9} Further, the use of such resources is complicated by gaps in knowledge about patient-specific factors such as older age¹⁰ and comorbidities such as diabetes¹¹ that may influence access to the waitlist, survival on the waitlist, and post-transplant outcomes.¹²⁻¹⁷ Our goal was to understand the context of decision-making and determine how heart transplant patients respond to prototypes of a patient-specific search of the SRTR PSRs. We hypothesized that there are significant differences between candidate and donor acceptance practices across heart transplant programs and that a patient-specific strategy is necessary for communicating to patients where chances of undergoing heart transplantation are optimal.

2 | CONCURRENT METHODS

2.1 | Qualitative methods

2.1.1 | Site and sample—The Institution Review Boards at the University of Minnesota—Fairview (UMNF) and Hennepin Healthcare (HHS) approved the study. Heart transplant candidates were recruited locally from the UMNF Transplant Program to participate in interviews and a focus group. Recipients of heart transplants were recruited nationally and

flown to Chicago to participate in focus groups. The study reimbursed recipients for costs of lodging and travel. Pilot Interviews and the focus group with UMNf patients took place in a clinic or conference room at the UMNf Transplant Center; focus groups with recipients took place in a hotel conference room in Chicago, IL. Each participant provided written consent and received a \$40 gift card as a stipend in exchange for their participation. All recruiting, interviews, and focus groups were completed between Fall 2017 and Summer 2018. See Methods Supplement for additional details about the study design and methods.

2.1.2 | Development of interview and focus group guides—Interviews with candidates were designed to evoke reflections on patient experiences and healthcare decision-making, pilot discussion points for the focus group guide, and inform the displays, language, and content included in prototypes of the patient-specific search. Focus group moderators (CS and M.B) presented the investigation as an initiative to collect patient experiences and feedback on iterative drafts of the prototype of the patient-specific search tool. All focus groups were conducted in the presence of a transplant physician (AI) who was not any of the participants treating physician. Discussions focused on four areas (1) resources used to learn about prospective transplant programs; (2) considerations that impacted decision-making about program selection; (3) new information and content for public reports; and (4) expectations about the efficacy and feasibility of the patient-specific search. For an example of additional questions from focus group guide and the COREQ 32-item checklist, see Tables S1 and S3 (in Supplement).

2.1.3 | Qualitative analysis—The analysis presented in this report is a sub-analysis of a larger set of interviews and focus groups with transplant candidates and recipients across solid-organ transplant groups (eg, kidney, liver, heart, and lung). In total, we conducted 35 interviews and 27 focus groups with transplant patients across organs. Organ-specific reports on the interviews and focus groups with kidney^{18,19} and liver²⁰ patients have been published elsewhere. Interviews with local candidates did not exceed 60 min; focus groups lasted between 60 and 120 min. Discussions were audio recorded and transcribed verbatim. Moderators captured information on each participant's demographics and comorbidities via a questionnaire at the start of each interview or focus group. Analysts (WM, CS, and MB) utilized Dedoose version 8.2.32 coding software (Los Angeles, CA: SocioCultural Research Consultants, LLC) to code and organize data to facilitate categorization of 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.^{21–23} Focus group transcripts were analyzed at the group level and did not segment responses by participant.²⁴

Each researcher (WM and CS) contributed to the development of a shared code book. Themes were identified by WM following a review of the 440 excerpts and were later verified by MB and AI. Representative quotations illustrating themes were identified and included in this manuscript. Three broad categories of codes emerged over the course of the analysis with codes relating to (1) decision-making on program selection, (2) past experiences, and (3) feedback on the patient-specific search. Unique codes emerged inductively to classify discrete factors that influenced past decision-making (eg, proximity

and the survival rate / transplant rate). Similarly, codes were developed and applied to excerpts that captured reflections on past experiences relevant to transplant care. For instance, unique codes accounted for discussions about support group experiences, communication with providers, the transplant evaluation, and the resources used to support decision-making. Codes paired to specific design elements on the patient-specific search organized feedback on prototypes. Additional codes emerged over the course of the analysis to qualify existing codes, highlight potential outliers, and guide the iterative development of prototypes. An “outlier” code was defined to capture comments that indicated an unexpected or unique case that differed from others, for instance, a patient who received a diagnosis of HF as a minor.

2.1.4 | Prototype development—Researchers on the study team first reviewed SRTR data and plotted the distributions of candidate and recipient factors to identify potential variables that limit access to the waitlist and transplantation. Clinician feedback (AI, CM, AT) informed the list of characteristics used in the earliest iteration of the patient-specific search. Early mock-ups included checklists or alternatively, entry fields for customizing the search to the user profile. Profile characteristics included distance a patient can travel, age, blood type, insurance type and comorbidities such as diabetes and hepatitis C (HCV) infection. Participants were shown iterative developments of still-images of the patient-specific search and the live SRTR program search during the pilot interviews and focus groups. Feedback from participants informed the content and presentation of information on the patient-specific search as well as the addition of interactive features. For examples of the user profile entry page and search results shown to participants, see Figures 1 and 2.

2.2 | Quantitative methods

This study used data from SRTR for the patient-specific search. The SRTR data system includes data on all donors, wait-listed 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 and donor characteristics that may affect access to transplant in the United States between July 1, 2017, and June 30, 2019. Analysis parameters are available in Table S4. The list of candidate characteristics shown on prototype images was expanded to include additional candidate and donor characteristics. Characteristics were first identified following consultation with cardiologists and transplant cardiologists (CM and TA) and a transplant physician (A.I).

2.2.1 | Quantitative analysis—Results were considered significant for $p < .05$. Chi-square tests were conducted to compare characteristics across transplant programs. The analysis was carried out using SAS version 9.4 (SAS Institute, Cary, NC USA).

3 | RESULTS

3.1 | Descriptive characteristics of study participants

Eight heart transplant candidates were recruited from the UMN; 12 recipients were recruited nationally to obtain a representative sample from each Organ Procurement and Transplantation Network (OPTN) region through patient organizations (eg, OPTN and Transplant Families). Overall, participant characteristics were Caucasian (80%), a majority attained a college or graduate degree (55%), and half (50%) had a household income over \$75 000. Candidates and recipients differed in terms of educational achievement with fewer candidates completing college and no candidates attaining graduate degrees. Candidates also reported lower household incomes with over half earning less than \$30 000 annually compared with no recipients earning less than \$45 000. Additional characteristics are reported in Table 1.

3.2 | Thematic synthesis

Heart transplant candidates' and recipients' responses to the prototype of the patient-specific search varied, but were positive overall. Opinions diverged on preferences for the language used to explain search results and the iconography for communicating variations. For instance, variations were depicted using solid-colored bars, or "tiers," tiers with a color gradient, and icons approximating a speedometer dial. Participants indicated that learning which transplant centers have a recent history of transplanting patients like them and information on how certain patient characteristics may restrict access to transplantation would be useful for decision-making. For instance:

I like the custom [patient-specific] search first because that's the first thing you're looking for yourself, where you fall into all of this. That's why you're there.

(Candidate—Female)

They also suggested that possessing such information enables informed engagements with their providers. Three additional themes emerged from reflections on past decision-making and expectations for waitlist and post-transplant outcomes. See Table S2 for additional excerpts representative of the themes presented below.

3.2.1 | Theme 1: Patient-specific search supports decision-making—

Participant responses to the patient-specific search revealed a limited understanding of patient characteristics that can impact access to transplantation. Their responses also revealed limited awareness of trustworthy sources of information on how programs differ. Participants appreciated that the patient-specific search interface highlighted how a user's clinical profile may restrict access to transplantation prior to displaying search results (eg, older age and high body mass index (BMI)). Similarly, receiving counts of the volume of recipients with matching profiles provided insight into program transplant criteria. Participants occasionally distinguished between impressions of concrete "cut offs" and programs where they simply have a reduced likelihood of receiving a transplant. Nonetheless, participants felt that the patient-specific search would better enable them to identify and evaluate transplant programs.

Ex

What I am hearing. What my mind tells me. This is designed to inform your decision and not point you to a decision.

(Recipient)

I think [transplant program choice is] for the individual to decide, and I think this is what helps them decide.

(Candidate – Female)

3.2.2 | Theme 2: Patients rely on a diffused decision-making strategy when selecting a transplant program—When questioned about past decision-making, participants indicated that family members, providers, and networks of patients were consulted during their search for a transplant program. For some, family members participated in the evaluation of options, while others sought out recipients from prospective programs to gain insight. Multiple participants indicated that information and insights from recipients weighed heavily on their decision to be evaluated for the waitlist at one or more programs. Candidates and recipients raised the significance of their trust in providers. When prompted to comment on a hypothetical center selection, they indicated a desire to discuss the results from the patient-specific search with their provider. Responses differed on preferences for discussing program options with providers before or after using the patient-specific search.

Ex

They also said I get the 30-day bonus being at the top of the list. *We decided, my wife and I and the kids*, decided [program name 1] would be a better fit for me. It turned out it was an excellent choice [emphasis added]

(Recipient)

There is a reason why you have to rely on your support network or your loved ones to help. Sometimes the more complex stuff is just more than... I mean, it's not that you can't understand it. But it takes a lot of mental energy that you maybe just don't have.

(Recipient)

3.2.3 | Theme 3: Patients' awareness of their discretion over program selection varies—Finally, when asked to discuss decision-making, participants revealed a wide range of experiences. Some participants travelled great distances for an evaluation at prospective programs while others were limited by clinical urgency and concerns for the feasibility of relocating. Some participants described their awareness of other programs, but noted barriers posed by distance and having to pursue treatment at a program within their insurance network. The resources used to evaluate and research programs were equally varied. Most participants relied on recommendations from their providers, but some participants described using the existing SRTR search tool, visiting the programs in person, and consulting with experts identified by their providers.

Ex

Would you believe this is the first I've heard there was a choice other than [my program].

(Candidate—Male)

There really wasn't any [choice]. It was pretty much, you want to go to the [program name] or you want to go to the [program name 2]? And there was no statistics on who is better

(Candidate)

3.3 | Variations in recipient and donor characteristics between transplant programs for highlighting in the patient-specific search

Characteristics of heart transplant candidates and recipients between July 1, 2017, and June 30, 2019, are reported in Table 2. Of the 12,322 candidates on the waitlist for heart transplantation, approximately 28% had diabetes, 10.5% had a BMI greater than 35, and 16.0% were age 65 and above. Recipients of heart transplants during that same period had similar distributions of characteristics. Just over 28.0% had diabetes and 8.23% had a BMI over 35 and 21.3% were age 65 and above at time of transplant. While our data are unable to definitively estimate the risks posed by specific clinical characteristics, it does suggest key differences in access to transplantation after listing across transplant programs. Over the same two-year period, we determined the number of recipients and donors matching certain clinical characteristics at heart transplant programs across the United States. Programs were divided into three categories based on the number of transplants performed over the 2-year period with small programs performing between 1 and 39 transplants, medium programs performing 40–59, and large programs performing more than 60 transplants. There were 43, 30, and 34 centers in each of the three groups, respectively.

This presentation of the distributions of transplants performed over the 2-year cohorts highlights trends that may improve patient decision-making should it be communicated in a patient-friendly format. For instance, candidates with advanced age (age ≥ 70) may have increased access to transplant whether they identify a program that conducts such transplants (see Figure 3). In this case, just under half of small programs performed 0 transplants on candidates older than 70, yet more than half of the medium-sized programs perform between 1 and 5 with a smaller proportion performing as many as 10. A majority of large program performed transplant on patients over 70, with some performing as many as 20 over the 2-year period. Similarly, for candidates considering public health service (PHS) increased risk donors (IRD), there are indications that such donors are utilized at a larger rate by some transplant programs (see Figure 4). For small programs, the range includes centers with 0 PHS IRD transplants over 2 years and others with as many as 20. The majority of large centers reported using 21 or more PHS IRD hearts. Approximately 75% of small programs did not transplant hepatitis C (HCV)-positive donor organs into HCV-negative recipients. In comparison, smaller proportions of medium (40–59 transplant per year) and large (60+ transplants per year) performed no such transplants. More than 75% of large programs performed such transplants and more than a quarter of programs performed more than 6.

These findings suggest the general availability of this donor option across programs. See Figure S1 for additional variations in recipient criteria.

4 | DISCUSSION

We found that certain heart transplant candidate and donor factors are unequally distributed among recipients at transplant programs across the United States (eg, age, re-transplant, previous non-transplant heart surgery, high BMI, and use of PHS increased risk donors). While not definitive of the existence of explicit cutoffs instituted around acceptance criteria, these variations offer insights into program-specific practices that shape the waitlist and influence whom has access to transplantation. We found that heart transplant candidates and recipients responded positively to a patient-specific search of SRTR data that communicate information on program and patient outcomes across programs. Participants indicated that receiving patient-specific information on waitlist and transplant outcomes at prospective transplant programs supports decision-making (Theme 1) and engaging stakeholders in healthcare decision-making (eg, family members and providers) (Theme 2). Participants also felt that the patient-specific search clarified that patients have discretion over where they seek an evaluation for the waitlist as well as identify treatment options that are not accessible at every program (eg, PHS increased risk donor and HCV-positive donors for HCV-negative recipients) (Theme 3).

The primary goal of the study was to evaluate the utility of developing a patient-specific search of the SRTR PSRs for reducing the burdens facing patients as they make decisions on transplant care. As studies have shown, patients often experience great difficulty interpreting the comparative information included in public reports of healthcare quality and outcomes.^{8,9,25} The feedback from heart transplant candidates and recipients who viewed prototypes of a 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/>.

The new patient-specific decision tool can help patients and their family members understand the variation in practices across transplant centers in the United States. The variation in waitlist mortality across transplant centers has been well described, ranging from 2.1 deaths per 100 waitlist-years in some donor service areas (DSA) to 23.9 deaths per 100 waitlist-years in others.²⁶ It is also known that 48% of donor hearts are declined in the United States.³ The new decision aid places some of this information about variation in practice in the hands of the patients in a format that they are likely to understand.

This study had certain limitations that should be considered when interpreting the results. First, the sample of heart transplant candidates and recipients was skewed toward higher earning individuals with a majority of participants earning over \$60,000 annually. The candidate sample was similarly skewed toward male gender (87.5%) and Caucasian racial identity (87.5%) and exceed national rates from 2018, 75.8% and 61.1%, respectively.²⁷ Likewise, our sample of recipients did not include patients with Medicaid as their primary insurance. Given the imbalance in recruiting, we lacked insight into the experiences of minority candidates and lower income earners, and the impact these factors have on the

number of program options and feasibility of listing at multiple programs. However, the prototypes and final web-based tool were designed using best practices for public reporting as published by the Agency for Healthcare Research and Quality (AHRQ). These best practices were determined through study in diverse populations.^{28,29} Additionally, the transcripts of focus group data did not include unique identifiers for each of the participants. Without unique identifiers, analysts were unable to distinguish between individual speakers for 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 numeracy, 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. Finally, we were unable to assess sources of variation on the types of transplants performed by programs due to the large number of centers and variation in transplant volume. We attempted to use logistic regression, mixed effects modeling, and correlation coefficients, but none produced robust models (analysis not shown).

In conclusion, the thematic analysis of responses from heart transplant candidates and recipients on patient-specific prototypes revealed that participants viewed the prototypes of the decision aid as a novel approach for communicating risk-adjusted information on access to transplantation and treatment. Patients responded positively to being provided information that allows them to evaluate transplant programs by the program's experience transplanting patients like them with indicators of clinical services that they may find beneficial. Despite the studies limitations, we feel that expanding access to information on program-level variations in waitlist outcomes and donor acceptance practices has value for all patients in need of cardiac transplantation. This information may be of increased utility for patients lacking the ability to consider multiple programs as the tool conveys decision support on donor options that can expand donor pools and reduce wait times. In the context of expanding patient-centered care, the findings of this study reinforce the need for developing patient-specific resources that assist patients as they weigh factors relevant for the treatment of end-stage heart disease. This research supports further investigation into the development of a patient-centered and patient-specific tools for identifying transplant programs, determining treatment options, and communicating information about candidate factors and donor acceptance practices that may reduce access to transplantation. Additional research evaluating implementation should determine when and how often the results of patient-specific searches should be reviewed as well as strategies for using the tool with providers in a clinic setting.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Transplant Center Search


Enter your medical profile to help find centers that transplant patients like you.

Distance You Can Travel


Within of

OR

Does This Limit My Options?

 Waiting time varies by region. A larger area gives you more choices.

Age of Candidate

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

Stroke / Cerebrovascular accident (CVA)

Height ft in

Weight lbs

Cause of the Heart Disease

Insurance Provider

Ventilator / Life Support

Hepatitis B or C Positive

Advanced Kidney Disease / Dialysis

Multi-organ Transplant

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

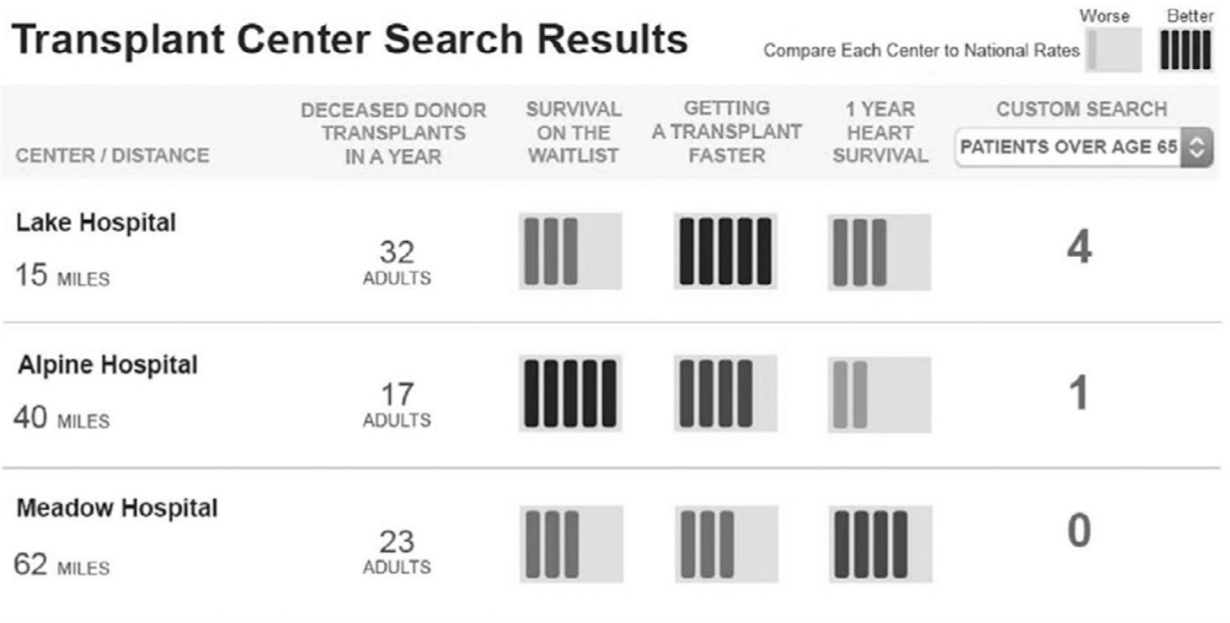


FIGURE 2.
Example of patient-specific results. Shown is an example of an early iteration of the results from the patient-specific search

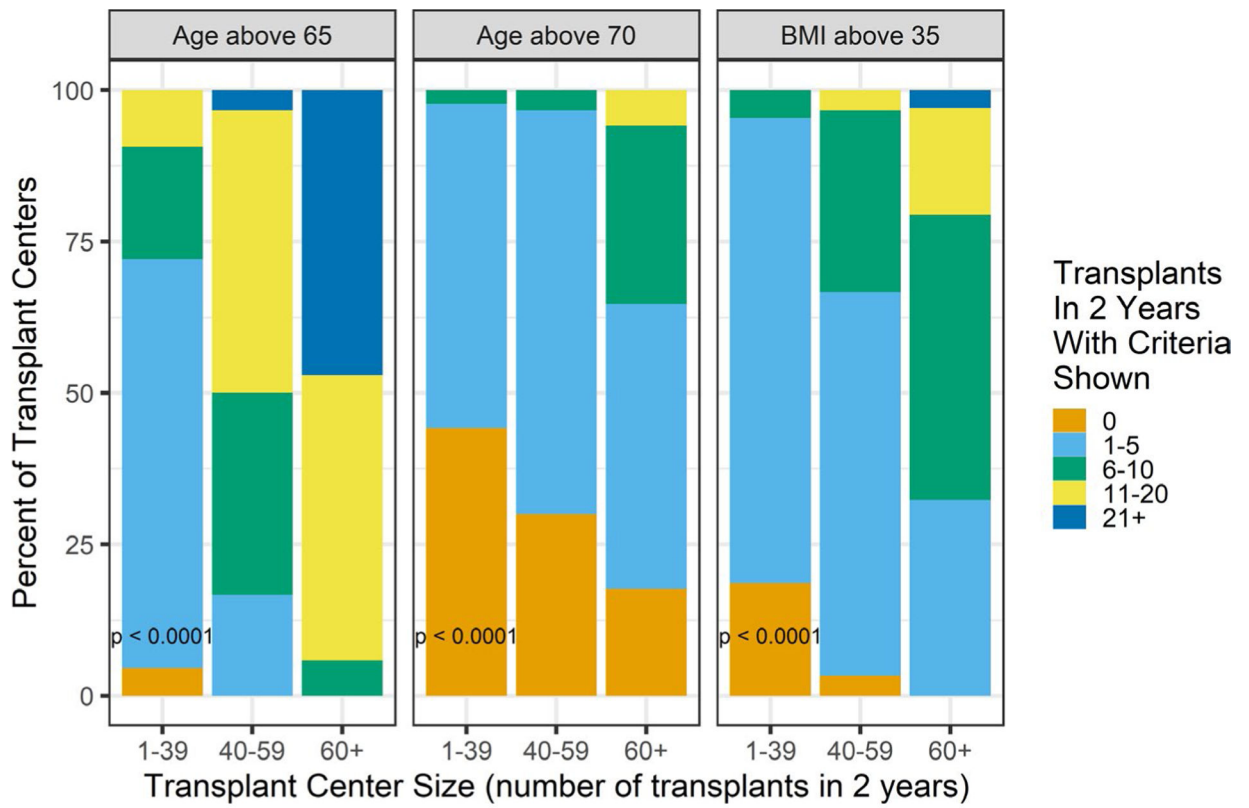


FIGURE 3. Distribution of heart transplant programs by select recipient characteristics between July 1, 2017, and June 30, 2019. Shown are the percentages of transplant programs with counts of recipients with age over 65, age over 70, and BMI over 35 at time of transplant. For example: in the BMI above 35 category, 20% of the small centers did not perform such transplants. All p -values $<.0001$

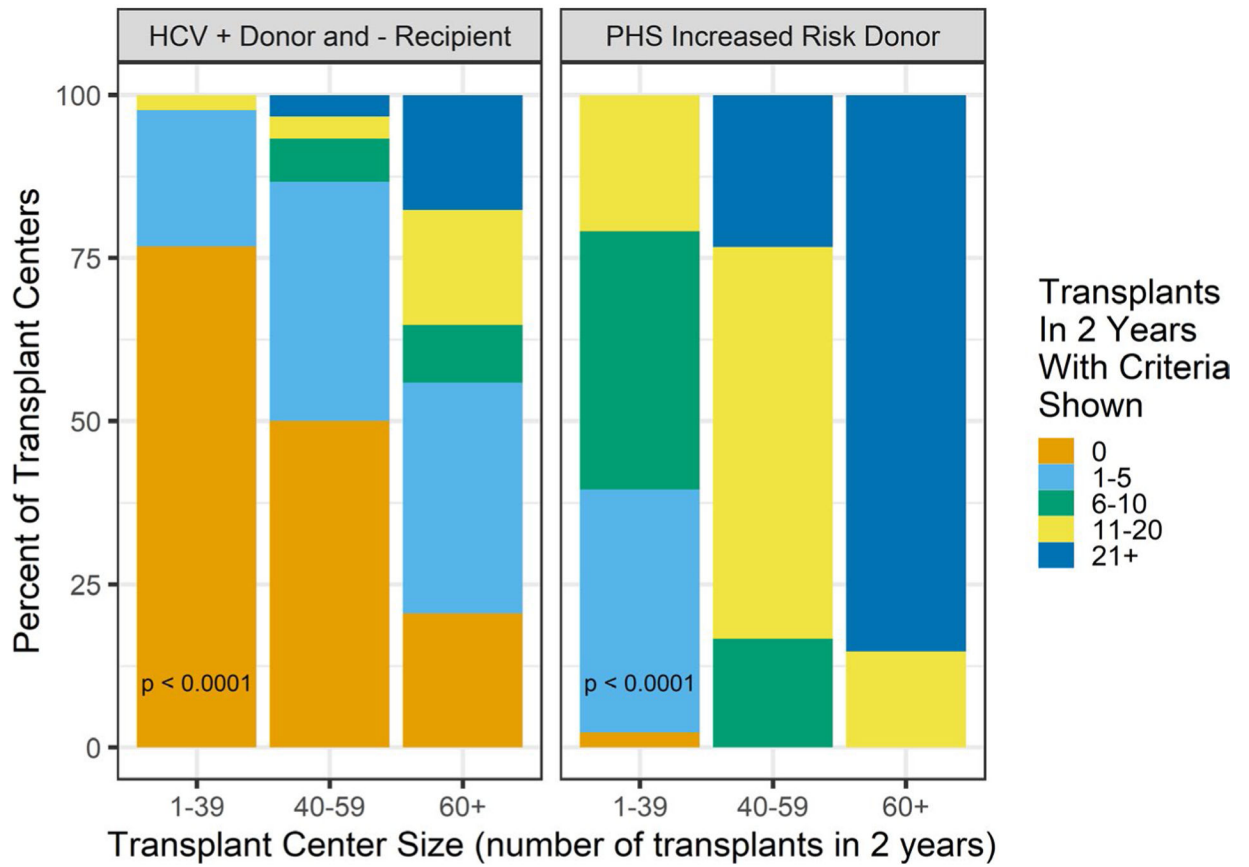


FIGURE 4. Distribution of heart transplant program by paired donor-recipient and donor characteristics between July 1, 2017, and June 30, 2019. Shown are the percentages of transplant programs with counts of paired donors-recipient and donor characteristics. Donor characteristics include the following: PHS increased risk donor; paired donor-recipient factors include HCV + donors and HCV- recipients. p -values $<.0001$

TABLE 1

Summary of demographic and clinical characteristics of study participants

Interview participants; n	Local candidates		National recipients		All participants	
	3	0	0	3	3	3
Focus group participants; n (number of groups)	5 (1 group)	12 (2 groups)	17 (3 groups)	17 (3 groups)	17 (3 groups)	17 (3 groups)
Age, mean (SD)	57.4 (11.0)	58.2 (12.4)	57.9 (11.9)	57.9 (11.9)	57.9 (11.9)	57.9 (11.9)
Sex; n (%)						
Female	1 (12.5)	2 (16.6)	3 (15.0)	3 (15.0)	3 (15.0)	3 (15.0)
Race; n (%)						
Black or African American	0 (0.0)	3 (25.0)	3 (15.0)	3 (15.0)	3 (15.0)	3 (15.0)
Hispanic	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Caucasian	7 (87.5)	9 (75)	16 (80.0)	16 (80.0)	16 (80.0)	16 (80.0)
Other	1 (12.5)	0 (0.0)	1 (5.0)	1 (5.0)	1 (5.0)	1 (5.0)
Education; n (%)						
Less than high school	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
High school	3 (37.5)	0 (0.0)	3 (15.0)	3 (15.0)	3 (15.0)	3 (15.0)
Some college	4 (50.0)	2 (16.7)	6 (30.0)	6 (30.0)	6 (30.0)	6 (30.0)
College	1 (12.5)	3 (25.0)	4 (20.0)	4 (20.0)	4 (20.0)	4 (20.0)
Graduate	0 (0.0)	7 (58.3)	7 (35.0)	7 (35.0)	7 (35.0)	7 (35.0)
Household income; n (%)						
Less than \$15 000	1 (12.5)	0 (0.0)	1 (5.0)	1 (5.0)	1 (5.0)	1 (5.0)
\$15 000–\$30 000	4 (50.0)	0 (0.0)	4 (20.0)	4 (20.0)	4 (20.0)	4 (20.0)
\$30 000–\$45 000	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
\$45 000–\$60 000	2 (25.0)	1 (8.3)	3 (15.0)	3 (15.0)	3 (15.0)	3 (15.0)
\$60 000–\$75 000	0 (0.0)	2 (16.7)	2 (10.0)	2 (10.0)	2 (10.0)	2 (10.0)
More than \$75 000	1 (12.5)	9 (75.0)	10 (50.0)	10 (50.0)	10 (50.0)	10 (50.0)
Number of cohabitants, mean (SD)	1.5 (0.5)	2.7 (0.96)	8.3	8.3	2.2 (1.0)	5.0
Insurance; n (%)						
Medicaid	1 (12.5)	0 (0.0)	1 (5.0)	1 (5.0)	1 (5.0)	1 (5.0)
Non-Medicaid (private, Medicare, other)	8 (100.0)	12 (100.00)	20 (100.0)	20 (100.0)	20 (100.0)	20 (100.0)

	Local candidates	National recipients	All participants
	3	0	3
Interview participants; n			
Transit to doctors' appointment; n (%)			
I or a family member, own a car	7 (87.5)	10 (83.3)	17 (85.0)
I have access to a car and ride with someone	1 (12.5)	1 (8.3)	2 (10.0)
I use public transportation/bus/metro	0 (0.0)	0 (0.0)	0 (0.0)
I take a taxi	0 (0.0)	0 (0.0)	0 (0.0)
I walk	0 (0.0)	1 (8.3)	1 (5.0)
Other	0 (0.0)	1 (8.3)	1 (5.0)
Comorbidity; n (%)			
Bypass heart surgery (CABG)	0 (0.0)	1 (8.3)	1 (5.0)
Coronary angioplasty	2 (25.0)	1 (8.3)	3 (15.0)
Cardiac arrest	1 (12.5)	1 (8.3)	2 (10.0)
Prior valve surgery	0 (0.0)	4 (33.3)	5 (20.0)
Cause of heart failure; n (%)			
Heart valve disease	0 (0.0)	1 (8.3)	1 (5.0)
Congenital disease	2 (25.0)	2 (16.7)	4 (20.0)
Cardiomyopathy	5 (62.5)	5 (41.7)	10 (50.0)
Coronary artery disease	1 (12.5)	0 (0.0)	1 (5.0)
Other	1 (12.5)	6 (50.0)	7 (35.0)
Don't know	1 (12.5)	0 (0.0)	1 (5.0)
Overweight; n (%)	6 (75.0)	5 (41.7)	11 (55.0)
Mechanical circulatory support (LVAD); n (%)	3 (37.5)	1 (8.3)	4 (20.0)
Time since transplant; median (SD)	—	5 (7.1)	8.3

TABLE 2

Distribution of variables in heart transplant candidates and recipients, July 1, 2017–June 30, 2019

Characteristics, % (n)	Candidates	Recipients
Total	12 322	5891
Cause of heart disease:		
Coronary artery disease	28.8 (3551)	30.2 (1778)
Cardiomyopathy	58.2 (7165)	62.3 (3667)
Congenital heart disease	6.6 (818)	3.7 (217)
Valvular heart disease	1.0 (117)	1.1 (64)
Other	5.5 (671)	2.8 (165)
High age at listing:		
Age <65	84.0 (10 349)	N/A
Age ≥ 65	16.0 (1973)	N/A
High age at listing:		
Age <70	97.5 (12 014)	N/A
Age ≥ 70	2.5 (308)	N/A
High age at transplant:		
Age <65	N/A	78.7 (4637)
Age ≥ 65	N/A	21.3 (1254)
High age at transplant:		
Age <70	N/A	95.9 (5652)
Age ≥ 70	N/A	4.1 (239)
High BMI at listing:		
Missing	0.5 (60)	N/A
BMI <35	89.5 (10 975)	N/A
BMI ≥ 35	10.5 (1287)	N/A
High BMI at transplant:		
Missing		(8)
BMI <35	N/A	91.8 (5399)
BMI ≥ 35	N/A	8.2 (484)
PHS increased risk donor:		
Missing		(1)
No	N/A	66.0 (3885)
Yes	N/A	34.0 (2005)
Willing to accept HVC+ donor:		
Missing	(8)	
No	60.4 (7443)	N/A
Yes	39.6 (4871)	N/A
HCV+ donor and + recipient:		
Missing		(6)
No	N/A	99.8 (5872)
Yes	N/A	0.2 (13)

Characteristics, % (<i>n</i>)	Candidates	Recipients
HCV+ donor and – recipient:		
Missing		(6)
No	N/A	91.8 (5401)
Yes	N/A	8.2 (484)
HIV + donor:		
Missing		(1)
No	N/A	100.0 (5890)
HIV + recipient:		
Missing		(5)
No	N/A	99.5 (5855)
Yes	N/A	0.5 (31)
Medicaid:		
Missing	(4)	(5)
No	84.4 (10 391)	87.8 (5165)
Yes	15.6 (1927)	12.3 (721)
Diabetes:		
No	72.1 (8881)	71.4 (4203)
Yes	27.9 (3441)	28.7 (1688)
Previous non-Tx cardiac surgery:		
Missing	(932)	(9)
No	60.6 (6899)	78.4 (4614)
Yes	39.4 (4491)	21.6 (1268)
Previous non-Tx lung surgery:		
Missing	(11 692)	(10)
No	98.9 (623)	99.7 (5865)
Yes	1.1 (7)	0.3 (16)
Previous heart transplant:		
No	N/A	96.8 (5705)
Yes	N/A	3.2 (186)