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The importance of transplant program measures: Surveys of three national patient advocacy groups

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Abstract

The Scientific Registry of Transplant Recipients (SRTR) provides federally mandated program-specific transplant data to the public. Currently, there is little understanding of how different program measures are prioritized by patients in selecting a program for transplantation. This study recruited 479 transplant advocacy group members from mailing lists and social media of the National Kidney Foundation (NKF), transplant families (TF), and Transplant Recipient International Organization (TRIO). Survey participants identified how many different programs would be reasonable to consider and viewed four measures that have recently been displayed on SRTR public search result websites and six measures not recently displayed and indicated importance on a 5-point scale. Four hundred two completed the survey (TF = 26; TRIO = 34; NKF = 342). Seventy-eight percent indicated that considering more than one program would be reasonable. Linear mixed models adjusted for organization, education, and gender. Likert scores for pretransplant (transplant rate) and transplant volume measures were similar and were very or extremely important to over 80% of participants. Posttransplant (survival after transplant) was rated as 0.52 points higher, confidence interval (0.41, 0.64). Results indicate that many patient advocacy group members find a choice between two or more programs reasonable and value multiple measures when assessing programs where they may want to undergo transplantation.

Keywords

national; patient; quality metrics; survey

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

1 | INTRODUCTION

The Scientific Registry of Transplant Recipients (SRTR) provides federally mandated program-specific transplant data to the public, including data about program characteristics and outcomes.¹ Public search results have included measures such as distance, transplant volume, transplant rate,² and posttransplant outcomes.³ Currently, there is little understanding of how different program measures are prioritized by patients when selecting a program for transplantation. Kidney-specific surveys have identified the importance of broad categories of metrics, but do not identify individual metrics to inform public reports.⁴ Patients and family members who contact SRTR and United Network for Organ Sharing (UNOS) help desk phone numbers and email addresses ask for information that is relevant to their needs, including program statistics and general listing information.⁵ However, these requests originate from a self-selected group who have already initiated online research. Understanding priorities of a broader patient population can guide the development of patient-friendly information about transplant programs and improve informed decision making for transplant candidates.

Three national patient advisory groups were engaged to reach transplant patients and support group members for multiple organ types. The National Kidney Foundation (NKF) provides wide-ranging support for individuals impacted by kidney disease. Transplant Recipients International Organization (TRIO) provides similar support for transplant recipients of multiple organ types. Transplant families (TF) provides support to the transplant community, often parents of pediatric heart transplant patients. An online survey for members of these organizations was used to collect data on participant characteristics and priorities for information important to choosing a transplant program.

2 | MATERIALS AND METHODS

A study protocol for surveys with anonymous participants was approved by the human subject review board at Hennepin Healthcare Research Institute. Surveys were hosted on Qualtrics (qualtrics.com, Seattle, WA, USA). Three surveys were created, one for each organization, and each survey was accessed using a unique online link. Each organization distributed survey links using email newsletters and social media posts. Responses received within 30 days were included in the analysis.

Participants answered a total of seven demographic questions and then reviewed a short introduction (see Table S1). Surveys did not include any reference to a particular organization, for example, SRTR. Participants then answered how many centers would be “reasonable” to consider in a search “based on your ability to travel, your insurance coverage, or other factors.” Participants were shown a list of 10 program measures; four were recently displayed on the public website for the SRTR, and six were not recently displayed. The labels for measures were described in patient-friendly terminology to convey a general meaning of technical terms; for example, surveys replaced the medical terminology of “Transplant Rate” with the phrase “How fast patients move to the top of the waiting list.” Wording of survey questions and responses was informed by separate qualitative interviews and focus group studies.

Answer choices to the four recent measures included a 5-point Likert scale from “Not important at all” to “Extremely Important” to measure the strength of belief in the importance of specific measures.⁶ Answer choices for the six additional measures also included the choice “Doesn’t apply/Don’t understand this item.” A final optional question allowed open-ended responses for what additional information would be important. Feedback provided in the open-ended responses was reviewed and summarized by common themes. The text of all questions and responses is included in Table S1. The duration to complete the survey was targeted to be 5 minutes.

Likert scale ratings were summarized descriptively using the percent of participants making each choice on the 5-point importance scale. The Likert scales were also transformed to a numeric value (“Not important at all” = 1 to “Extremely Important” = 5), and linear mixed models estimated the relative rated importance of the potential metrics among participants.⁷ Two approaches were used as follows: (a) comparing the rated importance of a metric to other metrics where models adjusted for advocacy group, education level, and gender; and (b) comparing the rated importance of a metric for different respondent subgroups where models adjusted for education level and gender. For each analysis, a random patient-level intercept accounted for potentially similar responses for a given participant.

Two respondent subgroups were evaluated (recipient/nonrecipient and patient/nonpatient or support group) to determine interactions between groups and rated importance. Recipients were defined as answering Question #4 “Have you ever received an organ transplant” as “Yes”. Patients and nonpatients were defined using a combination of responses to Questions #4-7 (see Table S1). A non-patient or support group member was defined using abbreviated questions as follows: dialysis = no, waiting list = no, recipient = no, aware of friends, or family impacted by transplant = yes. The relative ratings for the four recently displayed measures were assessed separately from the six additional measures.

3 | RESULTS

Surveys were accessed 479 times and completed by 402 participants (TF = 26; TRIO = 34; NKF = 342). Eighty-two participants included an optional open-ended response about what additional information would be important. The demographics and responses across groups did not indicate overlapping participants. Table 1 describes the characteristics of participants. Figure S1 includes the US locations of respondents.

The percentage of participants indicating only one program would be reasonable to consider for a transplant ranged from 46% (TF) to 17% (NKF), as shown in Table 2. Combined, 73% indicated two or more programs would be reasonable to consider. Table 2 includes the rated importance of four program measures recently displayed on SRTR public search results. Of these four measures, survival after transplant was most frequently rated as important; responses of Extremely or Very Important ranged from 92% (TRIO) to 96% (both NKF and TF). Of these four measures, distance to center was least commonly rated as important; responses of Extremely or Very Important ranged from 42% (TF) to 50% (both NKF and TRIO). Table 3 includes estimates from the linear mixed model of these four measures. Adjusted numerical Likert ratings were equivalent for number of transplants and moving

quickly up the waiting list. Survival rate after transplant was 0.52 points higher (greater importance) than the number of transplants and moving quickly up the waiting list.

Table 4 includes the combined percentages for responses of Extremely or Very Important for six program measures not recently displayed on SRTR public search results. The two measures with consistently high (>50%) rated importance across each organization were “Survival after transplant for patients who have a deceased donor” and “Recent experience treating patients with my age or medical condition.” Table 5 includes estimates from the linear mixed model of these six measures. Adjusted numerical Likert ratings indicate survival with a living donor, survival with a deceased donor, and survival with low quality deceased donors exceeding the rated importance of other measures.

Linear mixed model estimates did not indicate a difference in Likert ratings for recently displayed metrics when comparing recipient to nonrecipients or patients to nonpatients. Estimates indicated lower ratings from recipients for the alternate metric of “Programs to help me find a living donor.” Estimates for respondent subgroups are shown in Table S2.

Table S3 includes a summary of themes described in the 82 total open-ended comments. The most common themes included information about follow-up care and the relationships or experiences interacting with providers.

4 | DISCUSSION

Transplant program measures and characteristics that are displayed on public search results are rated as important by advocacy group members even if additional information is also requested (see Table S3). The relative importance when comparing measures to each other is not reported to suggest a higher-rated measure should be viewed as more important. Rather, individual circumstances are important to individual values and behavior. While distance to a center is rated lower than other measures on average, for many patients, the distance to a center will influence decisions. These individual differences may be difficult to identify based on common demographics, such as location or socioeconomic status. For example, being turned down at a center, needing a retransplant, and the presence of high antibodies are experiences that may be independent of common demographics that creates differing needs for information and may change willingness to evaluate options.

An important component of public reporting is to help user interpret the information and reduce cognitive burden so the information can be used in a choice.⁸ There are many measures that are available and rated as important; therefore, it is important for the information sponsor to communicate how differences in a measure might impact a patient, in particular when a measure might reflect complex concepts. SRTR recently included a statement indicating the quality metric with the highest impact on patient survival.⁹ For many organ types, the metric marked as the highest impact may not align with the metric rated as most important, suggesting additional research on patient decision making is warranted.

A range of individual differences are likely to exist within any defined group (eg, transplant organ type, patient, or support group); however, the results do not indicate significant

differences across broad participant categories represented in the survey (see Table S2). A single public report should be considered as one tool and meant as a supplement to additional information sources based on individual needs and values.

Participants indicated that recently available program measures are prioritized as important for decisions. When combining “Extremely” and “Very” important, at least 77% of participants at each organization marked three of the four recently available measures as important (not including Distance). A selection of alternate measures was used to allow comparisons and inform decisions about potential new measures to include; however, the list of potential alternates was not comprehensive and was intentionally limited to create a short 5-minute survey. A waitlist mortality metric was not evaluated in this survey, but feedback has been described elsewhere.¹⁰ Open-ended requests for information about providers, research programs, patient and family housing, etc (see Table S3) were anticipated; however, alternate measures consistent with these requests were not included because data are not available to create them. Patients and family members may need to seek this information from individual programs.

Variability in ratings was evident across organizations for some measures. Kidney patients indicated the highest likelihood of choosing between two or more transplant programs (77%), a result consistent with kidney transplant centers being most common nationally; however, 50% or more participants for organizations with primarily heart and liver responses (TF and TRIO, respectively) indicated the same range of choices. Other differences may be attributed to different participant characteristics for each organization. Participants from NKF and TRIO were primarily recipients (77% and 91%, respectively). Participants from TF were predominantly impacted by heart transplant (88%), and 96% had a family member who was a recipient. These family members of heart recipients rated the lowest importance for measures related to living donation.

This study has important limitations. The results were skewed toward kidney recipients due to significantly greater responses from NKF. While sample sizes from TF and TRIO were small, responses were generally consistent across organizations for many questions. The survey does not describe the socioeconomic status of participants, and the results do not reflect how socioeconomic status may impact rated importance. However, it is unlikely that public reports would tailor information based on this factor. The locations shown in Figure S1 reflect the national distribution of participants, but locations may not reflect the area of a needed transplant center and therefore were not analyzed. The survey was limited to only text to avoid influencing responses by particular elements of a graphical display. However, some graphical elements could potentially enhance or detract from the importance of a measure as viewed on a functioning website,¹¹ suggesting separate studies are warranted to evaluate graphic displays.

This survey of multiple patient organizations indicated that transplant advocacy group members view center measures and characteristics as important to decisions about where to seek treatment, and a majority of participants indicated that more than one program would be reasonable to consider.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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TABLE 1

Characteristics of participants who completed the survey

	National Kidney Foundation	Transplant families	Transplant Recipient International Organization
Completed surveys; n	342	26	34
Age; mean (min/max)	56.2 (20/88)	35.1 (26/45)	58.0 (22/83)
Sex; % (n) ^a			
Female	58 (198)	92 (24)	59 (20)
Male	42 (143)	8 (2)	38 (13)
Education; % (n)			
Less than high school	1 (1)	7 (2)	0 (0)
High school	13 (46)	19 (5)	3 (1)
At least some college	54 (184)	54 (14)	62 (21)
Graduate education	32 (111)	19 (5)	35 (12)
Were "Impacted" by organ type; % (n)			
Heart	N/A	88 (23)	9 (3)
Kidney		0 (0)	26 (9)
Liver		0 (0)	38 (13)
Other		4 (1)	12 (4)
Any multiple organ combination		7 (2)	15 (5)
Currently receiving dialysis; % (n) ^a			
No	87 (298)	N/A	N/A
Yes	12 (42)		
Has had previous transplant; % (n)			
No	23 (79)	77 (20)	9 (3)
Yes	77 (263)	23 (6)	91 (31)
Currently on the waiting list; % (n) ^a			
No	88 (302)	96 (23)	100 (34)
Yes	9 (32)	4 (1)	0 (0)
Not sure	2 (7)	0 (0)	0 (0)
Family members needed/received transplant; % (n)			

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	National Kidney Foundation	Transplant families	Transplant Recipient International Organization
No	44 (149)	4 (1)	32 (11)
Yes	56 (193)	96 (25)	68 (23)

^aSome participants left blank responses; therefore, totals may not add up to 100%

TABLE 2

Survey responses for each organization for recently displayed measures, rated by transplant advocacy group members

	National Kidney Foundation	Transplant families	Transplant Recipient International Organization
Number of programs reasonable to consider; % (n) ^a	342	26	34
1 center	17% (59)	46% (12)	29% (10)
2-3 centers	62% (211)	42% (11)	56% (19)
4-5 centers	9% (30)	4% (1)	6% (2)
5 or more centers	6% (20)	4% (1)	0% (0)
Measures recently displayed on Scientific Registry of Transplant Recipient public website search results			
Number of transplants performed; % (n)			
Extremely important	39% (133)	27% (7)	50% (17)
Very important	44% (149)	50% (13)	41% (14)
Moderately important	13% (43)	19% (5)	6% (2)
Slightly important	4% (13)	0% (0)	0% (0)
Not important at all	1% (4)	4% (1)	3% (1)
How fast patients move to the top of the waiting list; % (n)			
Extremely important	45% (153)	19% (5)	47% (16)
Very important	37% (125)	58% (15)	35% (12)
Moderately important	13% (44)	15% (4)	18% (6)
Slightly important	3% (10)	8% (2)	0% (0)
Not important at all	3% (10)	0% (0)	0% (0)
Survival rate after transplant; % (n)			
Extremely important	74% (254)	81% (21)	68% (23)
Very important	22% (75)	15% (4)	24% (8)
Moderately important	3% (9)	4% (1)	9% (3)
Slightly important	1% (2)	0% (0)	0% (0)
Not important at all	1% (2)	0% (0)	0% (0)
Distance from where I live; % (n)			
Extremely important	22% (74)	19% (5)	29% (10)
Very important	28% (96)	23% (6)	21% (7)
Moderately important	32% (108)	38% (10)	26% (9)

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	National Kidney Foundation		Transplant families	Transplant Recipient International Organization
Slightly important	15% (50)		15% (4)	12% (4)
Not important at all	4% (14)		4% (1)	12% (4)

^dSome participants left blank responses; therefore, totals may not add up to 100%.

TABLE 3
The Likert scale difference for the recently displayed metrics estimated from a linear mixed model

	Distance	Number of transplants	Moving quickly/waitlist	Survival rate after transplant
Distance	-	-0.68 (-0.79, -0.57)	-0.69 (-0.80, -0.58)	-1.20 (-1.32, -1.09)
Number of transplants	-	-	-0.01 (-0.12, 0.10)	-0.52 (-0.64, -0.41)
Moving quickly/Waitlist	-	-	-	-0.52 (-0.63, -0.41)

The interpretation is the average Likert point difference of the row minus column metric. For example, the metric for program volume had, on average, 0.52 fewer points on the Likert scale than survival after transplant. The parentheses contain the 95% confidence interval, and the model adjusted for the effect of survey group, education, and gender.

Importance of recently displayed and potential alternative program measures displayed on Scientific Registry of Transplant Recipients (SRTR) public websites, rated by transplant advocacy group members

TABLE 4

	National Kidney Foundation	Transplant families	Transplant Recipient International Organization
	% Very or extremely important		
Measures not recently displayed on SRTR public website search results			
Recent experience treating patients with my age or medical condition	67	73	79
Programs to help me find a living donor	61	23	35
Survival after transplant for patients who have a living donor	83	27	50
Survival after transplant for patients who have a deceased donor	85	85	79
Survival after transplant for patients with donor organs that are average or lower quality	73	46	68
Center willing to use a donor organ of average or lower quality to improve patient survival or waiting time	56	38	53

TABLE 5

The Likert scale difference for the alternative metrics estimated from a linear mixed model

	Similar patients	Find a living donor	Survival with living donor	Survival with deceased donor	Survival with low quality deceased donor	Usage of low quality deceased donors
Similar patients	–	0.15 (0.03, 0.27)	–0.40 (–0.52, –0.28)	–0.49 (–0.61, –0.38)	–0.15 (–0.26, –0.03)	0.26 (0.14, 0.38)
Find a living donor	–	–	–0.55 (–0.67, –0.43)	–0.64 (–0.76, –0.53)	–0.30 (–0.42, –0.18)	0.11 (–0.01, 0.23)
Survival with living donor	–	–	–	–0.09 (–0.21, 0.03)	0.25 (0.14, 0.37)	0.66 (0.54, 0.78)
Survival with deceased donor	–	–	–	–	0.35 (0.23, 0.46)	0.75 (0.64, 0.87)
Survival with low quality deceased donor	–	–	–	–	–	0.41 (0.29, 0.52)

The interpretation is the average Likert point difference of the row minus column metric. For example, a metric for finding a living donor had, on average, 0.64 fewer points on the Likert scale than deceased donor survival metric. The parentheses contain the 95% confidence interval, and the model adjusted for the effect of survey group, education, and gender.