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CLINICAL RESEARCH

Patient and Provider Attitudes Toward Patient-Facing Kidney Organ Offer Reporting

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Introduction: In the United States (US), deceased donor kidney offers are most commonly declined by transplant centers on behalf of waitlisted candidates, without notifying them. We sought to understand patient and provider attitudes toward patient-facing organ offer reporting.

Methods: We conducted a cross-sectional survey of patients, nephrologists, and nephrology social workers on the National Kidney Foundation mailing list and the medical and surgical directors of US kidney transplant programs.

Results: Among 755 patient respondents, 64% wanted to receive organ offer reports. Patients who wanted organ offer information were younger, more likely to be of a non-White race, and more likely to be on dialysis or on the waiting list. Of the patients, 87% reported that centers should be required to tell candidates about the offers they receive, and 62% reported that candidates should be informed after every offer. Among the 107 nephrology respondents, 73% reported that candidates should be provided with organ offer information and 88% reported that they would want to receive a copy of their patients' offer reports. Among 26 transplant program director respondents, 77% reported that candidates should not be notified of offers declined on their behalf. If organ offer reports were required, most program director respondents believed that they should include the reasons offers were declined and should not include offers for kidneys that were ultimately discarded.

Conclusions: Most patients and nephrology providers, but only a minority of transplant program directors, supported the sharing of patient-facing information about individual deceased donor kidney offers that were declined on candidates' behalf.

Kidney Int Rep (2025) **10,** 1122–1130; https://doi.org/10.1016/j.ekir.2025.01.013
KEYWORDS: kidney allocation; kidney transplant; shared decision-making

In the US, deceased donor kidneys are generally allocated using an objective algorithm that prioritizes compatible waitlisted candidates based on factors including waiting time, allosensitization, and geographic proximity to the donor hospital.[1] However, most kidneys are not transplanted to the top-ranked candidate, over 99% of kidney offers are declined, and a growing proportion of kidneys recovered for transplant are discarded.[2,3] Declined offers almost all occur at the level of the transplant centers,[4] which are able to decline offers on behalf of their waitlisted candidates if they believe it is to a candidate's advantage to wait for a superior future offer. Although these decisions typically reflect concerns over organ quality,[4] they may not adequately incorporate some patients' preference for expedited transplantation; the marked heterogeneity in acceptance practices between centers directly impacts patients' likelihood of receiving a transplant.[5,6,7] Although real-time shared decision-making about individual organ offers is logistically infeasible, the development of patient-facing organ offer reports has the potential to improve patient engagement and facilitate the incorporation of patient preferences into organ offer responses; therefore, this has emerged as a potential regulatory requirement.[8,9] We aimed to understand patient and provider

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Received 23 October 2024; revised 19 December 2024; accepted 6 January 2025; published online 16 January 2025

attitudes toward informing waitlisted candidates about offers declined on their behalf.

METHODS

We conducted a cross-sectional survey of patients, nephrology providers (nephrologists and nephrology social workers), and the medical and surgical directors of kidney transplant programs in the US. This study was approved by the Institutional Review Board of Columbia University Medical Center. Written informed consent was not required because all survey responses were anonymous.

Survey Design and Recruitment

Given the lack of an existing validated survey instrument on patient-facing organ offer reports, a new survey was designed by the study team. First, the study team identified key themes to be queried in the surveys for each study group (patients, nephrology providers, and kidney transplant programs). Two authors drafted the survey items based on these themes, and the remaining authors reviewed and iteratively refined all the items. No pilot or technical tests were conducted. Final survey questions (excluding demographics questions) are presented in Supplementary Items S1 to S3. All the survey items were presented on a single page. The survey was available only in English and was electronically formatted for distribution on a Qualtrics platform (Silver Lake, UT).

Survey links were electronically disseminated via email by the National Kidney Foundation in April 2024 to patients ($n = 15{,}978$) and nephrology providers ($n = 8626$; social workers, nephrologists, and nonspecific physicians) using the National Kidney Foundation email listserv. Survey links were electronically disseminated via email by the study team in May 2024 to US kidney transplant program medical and surgical directors, as listed by the Organ Procurement and Transplantation Network (OPTN) program list (date of list review: April 17, 2024), except those at Columbia University Medical Center. Of the 452 medical or surgical directors listed, email contact information was found for 307 (68%); 32 resulted in email delivery failure notifications, yielding a total of 275 with delivered invitations to participate (61% of listed medical/surgical directors). All survey completion was voluntary, and no incentives were offered.

Analysis

Variable handling is described in the Supplementary Methods. Descriptive statistics were used to describe the demographic characteristics and survey responses of each group of respondents, using chi-square test and Kruskal-Wallis's rank sum test to compare the characteristics of patients who supported versus opposed patient-facing organ offers. Authors SAH and SM analyzed the responses entered in the survey comment boxes. First, SAH reviewed all the free responses using open coding to create a codebook. SM then reviewed all respondents' comments for agreement and identified additional themes before the inductive thematic analysis. Statistical analyses were performed using Stata/MP 17 software (College Station, TX).

RESULTS

Patient Responses

Of the 15,978 patients emailed the survey link, 933 opened the survey and completed at least 1 demographic information question. Of these, 178 did not complete any of the main survey questions and were excluded from the analysis, leaving 755 patients (5%). The included patients had a median age of 61 years (interquartile range: 52–69) and most commonly self-reported as female sex (52%) and White race (57%) (Table 1). Less than half (40%) were on dialysis at the time of survey completion, 41% had a functioning kidney transplant, and 34% were on the waiting list (Table 1).

Nearly two-thirds ($n = 483$, 64%) of the respondents reported wanting to receive organ offer information. Patients who wanted this information were slightly younger (median 59 vs. 63 years, $P = 0.002$), less likely to report as White race (50% vs. 71%, $P < 0.001$), have a functional transplant (35% vs. 50%, $P < 0.001$), and more likely to be on dialysis (43% vs. 35%, $P = 0.02$) and on the waiting list (39% vs. 24%, $P < 0.001$). Sex, educational attainment, and employment status were similar between patients who wanted and those who did not want the organ offer information. Patients who reported a preference for receiving organ offer information were more likely to agree that they preferred to be active participants in their care. Additionally, they prioritized time to transplantation but showed less agreement that transplant centers understood their preferences or values, or that they trusted their centers to make decisions on their behalf (Figure 1).

The majority of patients (87%) reported that centers should be required to tell candidates about all offers for donated kidneys they receive, whether through an opt-in or opt-out system. This includes 97% of patients who would want organ offer information, as well as 69% of patients who would not (Table 1). Most respondents suggested a high frequency of organ offer reporting if it were to be required, with 62% suggesting offer reporting after every offer that a candidate receives and 18% suggesting monthly organ offer reports.

Table 1. Characteristics of patient respondents included in the analysis

Characteristics	All	Would not want to receive organ offer information	Would want to receive organ offer information
	N = 755, 100%	**n = 272 (36%)**	**n = 483 (64%)**
Age, yrs, median (IQR) (CI)	61 (52–69)	63 (55–69)	59 (49–68)
Sex, *n* (%)			
Female	392 (52)	146 (54)	246 (51)
Male	359 (48)	123 (45)	236 (49)
Other	4 (0.5)	3 (1)	1 (0.2)
Race/Ethnicity, *n* (%)			
Asian	61 (8)	15 (6)	46 (10)
Black/African American	147 (19)	36 (13)	111 (23)
Hispanic/Latino	49 (6)	12 (4)	37 (8)
White	434 (57)	193 (71)	241 (50)
All others	64 (8)	16 (6)	48 (10)
Highest education level, *n* (%)			
High school diploma or less	114 (15)	37 (14)	77 (16)
Some college or college diploma	349 (46)	13 (50)	212 (44)
Graduate degree	251 (33)	79 (29)	172 (36)
Other	41 (5)	19 (7)	22 (5)
Employment status, *n* (%)			
Full time employment	164 (22)	56 (21)	108 (22)
Part time employment	66 (9)	21 (8)	45 (9)
Disability	171 (23)	66 (24)	105 (22)
Unemployed	89 (12)	25 (9)	64 (13)
Other	265 (35)	104 (38)	161 (33)
Currently on dialysis, *n* (%)	304 (40)	94 (35)	210 (43)
Currently on the kidney waiting list, *n* (%)	254 (34)	64 (24)	190 (39)
Currently have a functioning kidney transplant, *n* (%)	307 (41)	137 (50)	170 (35)
Prior failed kidney transplant, *n* (%)	97 (13)	38 (14)	59 (12)
Transplant centers should be required to tell patients about all offers, *n* (%)			
Yes, all patients	252 (33)	53 (19)	199 (41)
Yes, for patients who opt in	289 (38)	98 (38)	191 (40)
Yes, but patients can opt out	118 (16)	38 (14)	80 (17)
No	92 (12)	80 (29)	13 (3)
Did not answer	3 (0.4)	3 (1)	0 (0)
Offer report frequency if required, *n* (%)			
Every offer	468 (62)	136 (50)	332 (69)
Monthly	134 (18)	49 (18)	85 (18)
Quarterly	68 (9)	31 (11)	37 (8)
Yearly	23 (3)	17 (6)	6 (1)
Other/No answer	62 (8)	39 (14)	23 (5)

CI, confidence interval.

Thematic analysis of free responses in the survey's comment box indicated that although patients value transplant centers' expertise in organ selection ("I believe the transplant center knows more about the kidney's viability than I do"), many felt a right to their organ offer data ("Patients have the right to know any information that's pertaining to their health care") (Table 2). Further, they highlighted that patient preferences are heterogeneous ("For some, it would be most important to get a kidney fast even if it doesn't last as long; and for others it would be important to get one that would last"), and that they viewed greater transparency regarding organ offers as a mechanism of improving access to their own health information and as a way of improving shared decision-making to incorporate patient-specific values and preferences into organ offer responses ("Without understanding my requirements, I don't trust them to make decisions about kidney offers on my behalf"). However, some patients felt that such reporting has the risk of weakening the center-patient relationship ("It may also undermine the necessary trust between a patient and their transplant center").

Nephrology Provider Responses

Of the 8626 providers who emailed the survey link, 146 opened the survey and completed at least 1 demographic information question. Of these, 34 did not complete any of the main survey questions and were excluded from the analysis. One response from

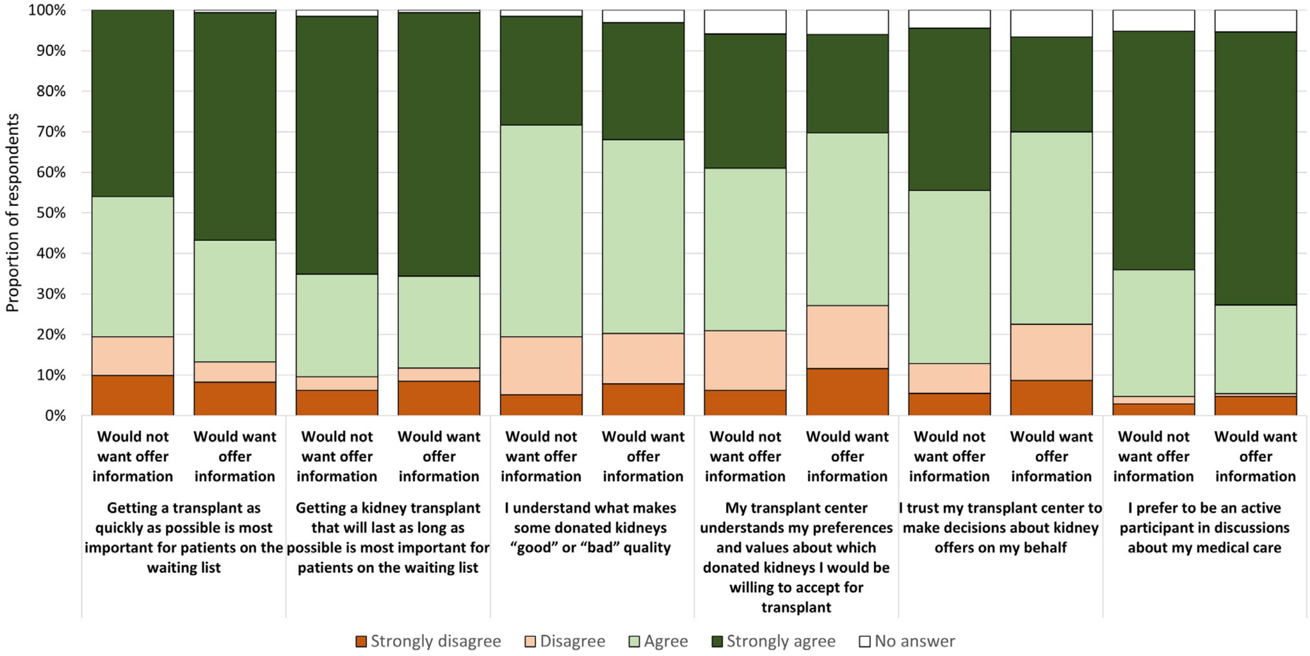

Figure 1. Patient-reported preferences and beliefs.

a transplant surgeon, 1 from a general internist, 1 from a provider whose specialty was not listed, and 2 from patients were also excluded, leaving 107 nephrologist ($n = 24$, 22%) and nephrology social worker ($n = 83$, 78%) responses for the analysis (1% of those who received a link, although the number of ineligible providers who received a link was unknown).

Among included provider responses, 78 (73%) reported that candidates should be provided organ offer information, with a plurality ($n = 41$, 38%) favoring an opt-in system (Table 3). Only 27 providers (25%) reported having been asked to help patients respond to an organ offer. Most providers (88%) reported that they would want to receive a copy of their patients' organ offer reports if they were required to send them to patients. Although almost all participants ($n = 97$, 91%) reported that they would feel comfortable contacting transplant centers with questions about organ offer reports, only 69 (64%) said that they would feel comfortable answering patient questions about such reports. Self-reported knowledge about deceased donor kidney quality assessment was similar among providers who did and did not believe that candidates should be notified about declined organ offers. However, familiarity with the kidney donor profile index was lower among those who believe that candidates should be notified about organ offers ($P = 0.04$) (Table 3).

Thematic analysis of the small number of free responses in the survey's comment box revealed a desire for increased nephrology provider education on aspects related to organ quality.

Transplant Program Director Responses

Of the 275 transplant program directors with a delivered invitation, 29 opened the survey; however, 3 did not answer any questions, resulting in 26 responses for the analysis (9% response rate; 6% of listed medical or surgical directors) (Table 4). Responses represented all OPTN regions except region 6, and most respondents were nephrologists or pediatric nephrologists ($n = 16$, 62%) and reported receiving organ offer calls ($n = 20$, 77%).

Twenty-four respondents (92%) reported that their transplant center did not inform patients about declined organ offers, whereas the remaining 2 reported that they only informed patients about select declined offers. The majority ($n = 20$; 77%) reported that candidates should not be notified of offers that have been declined on their behalf. However, if organ offer reports were required, most respondents believed they should include the reason an offer was declined ($n = 21$, 81%), whereas only 10 (38%) thought they should also include offers for kidneys that were ultimately discarded. Approximately half of the respondents believed that these reports should be the responsibility of transplant centers rather than the OPTN (Table 4).

Thematic analysis of free responses in the survey's comment box showed that centers' concerns about organ offer reports centered on the large burden of work to create these reports ("This process, while potentially well-intended, will likely overwhelm centers with work") and that most patients lack the knowledge to appropriately contextualize organ offer

Table 2. Key themes in patient free responses in comment box

Key themes	Illustrative patient comments
Heterogeneity in patient preferences	*For some, it would be most important to get a kidney fast even if it doesn't last as long and for others it would be important to get one that would last.
	*They assume that everyone is the same ... Take a minute and try to understand the person and what they are dealing with.
Patients' right to organ offer information	*Patients have the right to know any information that's pertaining to their health care, even if it's bad or good.
	*I believe that a transplant patient should be FULLY informed about EVERY aspect relating to their health care decisions.
Need for shared decision-making	*The word "Team" in my opinion means I should be an active participant in this process. I'd like to have more discussions with my transplant coordinator and more involvement in this process.
	*My transplant center has never talked to me about which kidneys I would be willing to accept. I do believe they could do a good job selecting a good kidney, but without understanding my requirements I don't trust them to make decisions about kidney offers on my behalf.
Benefit of transparency	*The transparency of informing patients would require more education for patients but also improve trust between the patient and the transplant center.
	*More transparent information by centers and providers is needed to make better decisions…
	*It would also be helpful to understand the reasoning behind their decision… The transparency could help the patient better understand why the decision was made and increase the patient's education…
	*If a patient knows how many offers there were and have been turned down, they would want to know why… The transplant team will have to explain why the kidney wasn't a good fit for them.
Lack of candidate counseling	*When going through the transplant process, I was very disappointed with the very limited information and education I received about what factors influence the quality of kidney … I definitely did not think it was a fully informed decision.
	*I think potential transplant patients need a much better explanation and understanding of how the UNOS system works … This entire realm of kidney transplantation is a total mystery to the average CKD transplant candidate.
Trust in transplant center expertise	*Being on the list can be a hard place because of not knowing. I believe the transplant center knows more about the kidney's viability than I do.
	*I realize they are not infallible, but they have been trained on what constitutes a good kidney for a specific patient, whereas I have not.
	*My transplant team chose one that was right for me ... I could not have made that decision myself as to what was a good kidney for me or not.
	*Although I wanted a kidney transplant as soon as possible I trusted my transplant center with their knowledge and expertise to choose the best donor kidney for me.
Potential negative impacts of organ offer reports	*[I] do think there's the risk of offer reports complicating things because the patient may not agree with the center's decision, or they may want a kidney the center rejected just out of desperation and not sound decision making.
	*Getting a report with a list of declined offers after the fact could be upsetting to patients, particularly if there was an offer they would have liked to have been able to consider with their care provider.
	*It may also undermine the necessary trust between a patient and their transplant center. Personally, I'm glad I didn't know about offers
	*In some ways the patient, maybe, should not know some of the things that go on with the organ referral and transplant process so the medical people can make the objective decisions, not the emotionally charged decisions and desires by patients eager to get off dialysis.

CKD, chronic kidney disease; UNOS, United Network for Organ Sharing.

decisions ("[This] will inundate patients with information that many may be ill-equipped to process") (Table 5).

DISCUSSION

In this cross-sectional US survey, we found that most patients wanted to be informed about deceased donor kidney offers that were declined on their behalf and were more likely to have a non-White race, be on dialysis, or be on the waiting list. Furthermore, though a large majority of patients and nephrology providers felt that all or some patients should be informed about organ offers, only 23% of transplant program directors agreed with this approach. This discrepancy indicates the need to develop patient-facing organ offer reports that satisfy patients' desires to be engaged in their care while better understanding center concerns about sharing these data.

Over 99% of primary deceased donor kidney offers are declined in the US, largely because of organ quality concerns compounded by worsening inefficiency in the allocation system for deceased donor kidneys.[2,10] Even among kidneys that are accepted for transplant, fewer than 1 in 7 are accepted without any declined offers.[4] Further, about 30% of kidneys recovered for the purpose of transplant are now discarded after not being accepted by any center.[3] The large number of declined offers reflects both the challenges of reliably assessing donor organ quality, as well as suboptimal use of organ offer filters, thereby leading to the frequent generation of a large number of avoidable kidney offers for organs that a given center on the match run is predictably unwilling to accept based on donor or organ characteristics.[11,12,13,14] Transplant centers typically decline organ offers on behalf of a patient when they believe that transplantation with a given organ is not superior to continuing to wait for a better offer. This assessment is most often because of low perceived donor or organ quality, although factors such as immunologic barriers, logistical hurdles, or recipient factors also occasionally contribute to the decision.[4] However, most patients who die or are delisted before transplant have typically received multiple offers for kidneys that were declined

Table 3. Demographics and responses of nephrology providers included in the analysis

Survey response	All	Candidates should not be notified of declined offers	Candidates should be notified of declined offers[a]
	N = 107, 100%	*n* = 29 (27%)	*n* = 78 (73%)
Specialty, *n* (%)			
Nephrology	24 (22)	10 (34)	14 (18)
Social worker	83 (78)	19 (66)	64 (82)
Years in practice, *n* (%)			
0–5	38 (36)	12 (41)	26 (33)
6–10	15 (14)	5 (17)	10 (13)
≥ 11	54 (50)	12 (41)	42 (54)
Frequency of care for patients who need a kidney transplant, *n* (%)			
Never or infrequently	8 (7)	2 (7)	6 (8)
Often	23 (22)	9 (31)	14 (18)
Very often	76 (71)	18 (62)	58 (74)
Should candidates be notified of all primary offers declined on their behalf, *n* (%)			
Yes, all patients	11 (10)	–	–
Yes, for patients who opt in	41 (38)	–	–
Yes, but patients can opt out	26 (24)	–	–
No	29 (27)	–	–
Would want to receive a copy of organ offer reports, *n* (%)	88 (82)	18 (62)	70 (80)
Would feel comfortable if patient asked questions about organ offer report, *n* (%)	69 (64)	17 (57)	52 (67)
Would feel comfortable reaching out to transplant center with questions about organ offer report, *n* (%)	97 (91)	23 (79)	74 (95)
Ever been asked to help a patient make an organ offer decision, *n* (%)	27 (25)	4 (14)	23 (29)
Knowledge about deceased donor kidney quality assessment, *n* (%)			
Not knowledgeable	40 (37)	10 (34)	20 (38)
Somewhat knowledgeable	50 (47)	13 (45)	37 (47)
Very knowledgeable	11 (10)	4 (14)	7 (9)
Not sure	6 (6)	2 (7)	4 (5)
Familiarity with kidney donor profile index, *n* (%)			
Not familiar	30 (28)	5 (17)	25 (31)
Somewhat familiar	59 (55)	15 (52)	44 (56)
Very familiar	18 (17)	9 (31)	9 (12)

[a] Includes those who selected all patients, opt-in, or opt-out in response to question about whether candidates should be notified of offers declined on their behalf.

and ultimately transplanted into a lower-priority recipient, suggesting that declined offers frequently represent missed opportunities for transplant.[4] The very small proportion of offers that are declined by patients and the large number of offers to patients who remain active on the waiting list after their death would suggest that patients are not typically engaged in discussions regarding declined organs, even retrospectively.[15] Correspondingly, all but 2 transplant program directors responding to our survey reported that their programs do not share information about declined organ offers with waitlisted candidates.

Approximately one-third of the patients in our survey reported that they would not want to be informed of the declined organ offers. These patients were older and more likely to be of White race, reported a higher degree of trust in their transplant centers to make decisions on their behalf, and a higher degree of agreement that their transplant centers understood their values and preferences. Nevertheless, 87% of patient respondents—including the majority of those who would not want organ offer information themselves—reported that patients should have access to this information. This finding is consistent with a greater demand for health information access more broadly, as reflected by an effort to improve patients' access to their health data via the 21st Century Cures Act, which included several provisions related to "patient access to health information in a convenient form."[16] The majority of patients with access to their health records reported accessing them, with an increased frequency of accessing records over time.[17] In light of the fact that clinical data, including laboratory results, radiology images and reports, and clinical notes are all currently made readily available to patients, withholding organ offer data is inconsistent with other areas of medical practice, especially because 90% of patient respondents in our analysis reported agreement or strong agreement that they prefer to be active participants in discussions about their medical care. In addition, physicians' concerns about sharing clinical data with patients in other scenarios are typically replaced by positive views after the rollout of such data sharing.[18–21]

Table 4. Demographics and responses of transplant center program directors included in the analysis

Survey response	All *N* = 26, 100%
Specialty, *n* (%)	
Nephrology	16 (62)
Surgery	10 (38)
Years since completing training, *n* (%)	
0–5	2 (8)
6–10	3 (12)
≥11	21 (81)
Take donor kidney offer calls, *n* (%)	
Yes	20 (77)
No	6 (23)
Center currently informs patients about declined offers, *n* (%)	
Yes, but only for select offers	2 (8)
No	24 (92)
Should candidates be notified of all primary offers declined on their behalf, *n* (%)	
Yes, all patients	1 (4)
Yes, for patients who opt in	4 (15)
Yes, but patients can opt out	1 (4)
No	20 (77)
Offer report frequency if required, *n* (%)	
Every offer	1 (4)
Monthly	2 (8)
Quarterly	10 (42)
Yearly	8 (31)
Other	4 (16)
Offer report should include reason offer was declined, *n* (%)	21 (81)
Offer report should include discarded kidneys, *n* (%)	10 (38)
Who should be responsible for sending offer reports, *n* (%)	
Organ Procurement and Transplantation Network	12 (46)
Transplant center	13 (50)
Other	1 (4)

Table 5. Key themes in center free responses in comment box

Key themes	Illustrative center comments
Insufficient patient knowledge to understand organ offers	*[This] will inundate patients with information that many may be ill-equipped to process.
	*This is an added burden to patients without the appropriate context to understand why a particular offer is not correct for a particular recipient.
	*It is frequently a complex multifaceted decision that most patients will lack the knowledge to fully comprehend why an offer was declined.
Large workload to provide offer reports	*I think will be a burnout to the transplant center to provide this information, [e]specially with the new allocation system you received around 15 to 20 offers per week or more.
	*The amount of increased workload this initiative would create is substantial. If a kidney is turned down for quality and 200 recipients are on the match run, would they all require notification? This process, while potentially well-intended, will likely overwhelm centers with work.
	*Another unfunded mandate.
Patient empowerment	*Although a lot of work, I think it will go a long way to empower patients to be part of their health care decisions.

Patients have differing preferences regarding waitlist time versus risks associated with inferior allograft outcomes from marginal organs.[5,22] Consistent with this, we found heterogeneous patient responses to our questions about the prioritization of expedited transplant or optimizing allograft longevity; as well as that a sizeable minority of patients believe that their centers do not appreciate their preferences. Given this combination of findings, patient engagement in the organ offer process through patient-facing organ offer reports has the potential to help patients ensure that offer responses made on their behalf truly reflect their preferences by stimulating meaningful conversations with their transplant centers about risk thresholds.[8,9] Criticisms of patient-facing organ offer reports often center on operational feasibility, given the impracticality of real-time shared decisions arising from the time-sensitive nature of organ offer responses and the massive number of offers that occur.[9,10] However, automated patient-facing reports can be used to asynchronously inform patients of declined offers without affecting the offer response workflow. Further, the burden on the part of the transplant center staff to have related conversations can be mitigated by engaging the patient's primary nephrology care team, such as the clinic or dialysis unit nephrologists and staff. Importantly, given some patient respondents' concerns regarding the negative emotional consequences of receiving this information, a clear opt-out system must be developed to respect individual patient preferences for not receiving organ offer reports.

Increased transparency regarding organ offers may help maintain equity and objectivity in the allocation system at a time where deviations from codified allocation priority are increasing and many Americans report distrust in the fairness of the transplant system.[23,24] Currently, an increasing proportion of deceased donor kidneys are transplanted after being allocated "out-of-sequence," a strategy by which the recovering organ procurement organization skips the allocation priority for a given organ to place it with a transplant center of the organ procurement organization's choosing, ostensibly for the sake of expediting placement of kidneys at a high risk of nonutilization.[25] In addition, centers sometimes engage in a practice colloquially known as "list diving," where kidneys are allocated to candidates with lower priority despite being suitable for a higher-priority candidate.[26] Given recent recommendations from the OPTN's "Expeditious Task Force" to increase the use of out-of-sequence placement in particular as a method of improving allocation efficiency,[27] informing higher-priority candidates about the occurrences of these events can serve as a check to ensure that these nonstandard allocation practices only occur when most appropriate.

Based on the responses to our surveys regarding patient preferences for information and center concerns about the workload of creating offer reports, it seems reasonable that the OPTN should be mandated to disseminate organ offer reports to patients and their referring providers with an opt-out option. The OPTN has the information technology infrastructure to manage such a task, and as the organization that oversees all transplant activity, is the only stakeholder that will have all necessary data about the organ offers, final disposition, and the offer refusal codes provided by centers as well as the growing number of out-of-sequence placements and offers that are declined using automated bypass filters.[11,12] Importantly, the Centers for Medicare and Medicaid Services' recently finalized Increasing Organ Transplant Access model eliminated a mandate for monthly center-generated patient-facing organ offer reports that was present in the initial model proposal.[28] In the absence of such a mandate, this discrepancy between patients and center attitudes toward organ offer transparency can also only be resolved at the OPTN level. Further research to establish the optimal content and layout of organ offer reports—which, based on patient and center responses, should include information on organ quality, reasons for declining the offer, and eventual organ disposition—may include human-centered designed initiatives involving key stakeholders from candidates and transplant centers to provide the correct context of declined offers. The development of a personal offer portal for waitlisted candidates might be an ideal method of serving different patient preferences for the frequency of receiving organ offer information and the types of data included in the same way that patients can set notification preferences for other health record applications. Dissemination of this information should also include patients' current nephrology care teams.

The limitations of our study include the possibility of selection bias in survey respondents, particularly in the nephrology provider and transplant program director analyses, because of the low response rate. Furthermore, given that the survey was only administered in English, these results may not be generalizable to non-English-speaking patients and providers or to non-US transplant systems. Nevertheless, these data provide a foundation for the development of policies related to transparency in the deceased donor kidney offering process.

In conclusion, we found that the majority of patients and nephrology providers supported a mandate for patient-facing information about individual deceased donor kidney offers that are declined on a patient's behalf. This is consistent with the transparency requirements outlined in the initial proposal for the Increasing Organ Transplant Access care model, which were later eliminated. Patient-facing organizations that offer reports incorporating patient preferences for information delivery should be developed with broad stakeholder input.

DISCLOSURE

SM received grant funding from the NIH (DK114893, DK116066, DK126739, DK130058, and MD014161) and personal fees from the Kidney International Reports, Sanofi, Specialist Direct, and Health Services Advisory Group outside of the submitted work. SAH received fees as an editorial fellow for the Journal of the American Society of Nephrology outside of the submitted work. AMH received funding from the NIH grants DK1289980, DK126654, and PCORI CER 26300 and the Kidney Transplant Collaborative and serves on the advisory boards for the Cleveland Minority Organ and Tissue Transplantation Education Program (MOTTEP) and ESRD Network 9 of the Ohio River Valley. All the other authors declared no competing interests.

ACKNOWLEDGMENTS

The authors thank the National Kidney Foundation for their assistance in conducting this research through survey dissemination. The authors also thank the patients, nephrology providers, and transplant program directors who completed the surveys.

Funding

This study was funded by a grant from the Kidney Transplant Collaboration (SM). SAH was supported by the NIDDK grant K23DK133729. The funders had no role in the design of the survey, collection or analysis of data, or preparation or approval of the manuscript.

SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Supplementary Methods.

Item S1. Questions included in patient survey.

Item S2. Questions included in nephrology provider survey.

Item S3. Questions included in transplant program director survey.

CHERRIES Checklist.

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