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Organ Offer Review Cards: Improving Transparency on the Kidney Transplant Waitlist

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ABSTRACT

Introduction: The 2022 National Academy of Sciences, Engineering, and Medicine report on equity in organ transplantation highlighted limited transparency and accountability for organ offer declines and recommended prioritizing patient engagement in decisions regarding organ offers. Yet, there is no guidance on how to incorporate patients in organ offers. We elected to study the experiences of patients on the waitlist and their perception of a novel Organ Offer Review Card (OORC).

Methods: A prototype OORC was created using Donornet refusal codes. Sixty randomly selected kidney waitlist patients at a single center were asked to participate in a web-based survey focusing on current medical decision-making preferences and perceptions of the prototype OORC.

Results: Among the 43 patients reached, 17 (39.5%) completed the survey. Most participants (88.2%) expressed it was important to be involved in the decision-making about organ offers, with 100.0% of respondents wanting to know why an organ was declined. Regarding the prototype OORC, 94.1% thought it helped them understand the factors and priorities considered when selecting an organ, and 88.2% said it increased their belief that their team was acting in their best interest.

Conclusion: An OORC could increase transparency and communication during the waitlist process while enhancing trust in the transplant team.

1 | Introduction

Kidney transplantation is the preferred treatment of end-stage renal disease as it prolongs survival, improves quality of life and reduces cost compared to chronic dialysis [1–5]. Yet there remains a wide gap between the demand and supply of kidneys for transplant [6]. Three years after wait-listing, about a quarter of candidates have received a deceased donor kidney transplant (DDKT) and a third are still waiting [7]. Throughout this time, there is minimal communication to waitlisted patients surrounding organ offers, with the majority of communication regarding either what the candidate needs to remain active or when the transplant provider intends to accept an offer.

In 2022, The National Academy of Sciences, Engineering, and Medicine (NASEM), released a report entitled *Realizing the*

Abbreviations: DDKT, deceased donor kidney transplant; NASEM, National Academy of Sciences, Engineering, and Medicine; OORC, Organ Offer Review Card; OPTN, Organ Procurement and Transplantation Network; UNOS, United Network for Organ Sharing.

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Promise of Equity in the Organ Transplantation System. One recommendation was to "increase transparency and accountability for organ offer declines while prioritizing patient engagement in decisions regarding organ offers," specifically urging transplant centers be required to share the number and context of organ offer declines with patients [8]. Furthermore, the NASEM report recommends that the Organ Procurement and Transplantation Network (OPTN) contract be modified "to require transplant center accountability for patient engagement and partnership between transplant center professionals and patients in deciding whether to accept or reject an offered organ."

Currently, there is limited data directing transplant centers on how to achieve this goal—leading to questions surrounding what information patients desire, how to share it in an understandable way, what reactions patients might have, and how this might affect patient-provider relationships. Initially, transplant centers might balk at NASEM's recommendations because of the resources and manpower required to accomplish it. Therefore, we sought to develop an Organ Offer Review Card (OORC) summarizing the last 6 months of a waitlisted patients' organ offers and the reasons for organ decline. Our primary objective was to understand patients' perceptions, attitudes, and feedback on the OORC. Additionally, we sought to understand patients' perspective regarding shared decision-making for organ offers.

2 | Methods

We randomly selected 60 patients age ≥18 that were active on the kidney waitlist with ≥6 months of wait-time at the University of Michigan. Non-English-speaking patients were excluded. From July to August 2022, patients were recruited via phone and sent an online survey (Qualtrics, Provo, UT). We attempted contact via phone and/or sent email reminders to complete the survey a minimum of three times each. This study was deemed exempt from review by the University of Michigan's institutional review board (HUM00219420).

The online survey consisted of two parts (Appendix 1). Part 1 asked questions about patients' preferences regarding medical decision making and involvement in the organ offer process as well as current level of trust with the transplant center. Next participants digitally viewed the prototyped OORC. After reviewing the OORC, participants completed part 2 of the survey which asked questions about patients' reactions to the card. The questionnaire utilized Likert scale and free response questions. The readability of the survey was assessed at a high-school or less level using the Flesch Reading Ease scale.

The prototyped OORC has four sections (Figure 1A). Section 1 includes patient-specific data that affects DDKT prioritization (wait-time and panel reactive antibody) and the number of offers over 6-month. Section 2 describes patient-specific considerations for DDKTs, determined by the transplant team. Section 3 reviews the reason why offers were declined based off the United Network for Organ Sharing (UNOS) refusal codes and how many of the kidneys declined for that patient were transplanted. Section 4 shares potential avenues to accelerate access to transplant.

We utilized the updated UNOS organ refusal codes that went into effect December 2, 2021 [9]. For ease of patients understanding, we did not individually use all 42 UNOS refusal codes with their full description. Appendix 2 demonstrates how we consolidated and rephrased the refusal codes using nonmedical jargon. The OORC was developed by a team of transplant surgeons and underwent multiple iterations after seeking feedback from transplant providers not on the research team.

3 | Results

Of the 60 randomly selected individuals, 43 patients were reached by phone and 17 (response rate: 39.5%) completed the survey. Patient demographics are listed in Table 1.

3.1 | Pre-OORC Medical Decision Making Survey

When it comes to making general medical decisions, 52.9% of participants ($n = 9$) preferred to make the final decision themselves but seriously consider their doctor's recommendation and only 5.9% ($n = 1$) preferred to leave all decisions regarding medical treatment to their doctor. All participants ($n = 17$) had some level of trust in our physicians to decide what kidneys to transplant. Of the participants, 88.2% ($n = 15$) expressed it was important to be involved in the decision-making about organ offers, 94.1% ($n = 16$) found it important to have information about all organs offers they received, and 100.0% ($n = 17$) of respondents wanted to know why an organ was declined. Participants listed various donor details about they would like to know including lifestyle, age, medical history, and cause of death. Participants wanted information regarding prior offers weekly (35.3%), monthly (23.5%), quarterly (23.5%), semiannually (11.8%), and annually (5.9%).

3.2 | Post-OORC Viewing Survey

After viewing the prototype OORC, 94.1% ($n = 16$) of patients felt an increased understanding of the factors and priorities considered when selecting an organ, and 88.2% ($n = 15$) felt an increased belief that their team was acting in their best interest (Figure 1B). Only 29.5% ($n = 5$) found the information in the prototype OORC too complex and confusing. Among participants, 41.2% ($n = 7$) reported that they might feel angry or frustrated about learning about offers the transplant team has turned down on their behalf, whereas 35.3% ($n = 6$) disagreed and 23.5% ($n = 4$) neither agreed nor disagreed. Despite this, 94.1% ($n = 16$) wanted to see an OORC with individualized data and believed this intervention would increase their trust in the transplant center. Overall, the majority of participants, 82.4% ($n = 14$), were satisfied with receiving an OORC. (Tables S1 and S2 for comprehensive survey data).

The free responses illustrated some additional feelings about the current system: "This process does need to be more transparent…People often lose hope if there is no update or even a follow up…It makes me question what the center is doing for me" and the uplifting potential of receiving the OORC: "Showcasing that a patient did receive offers, it provides hope." (Table S2).

(A)

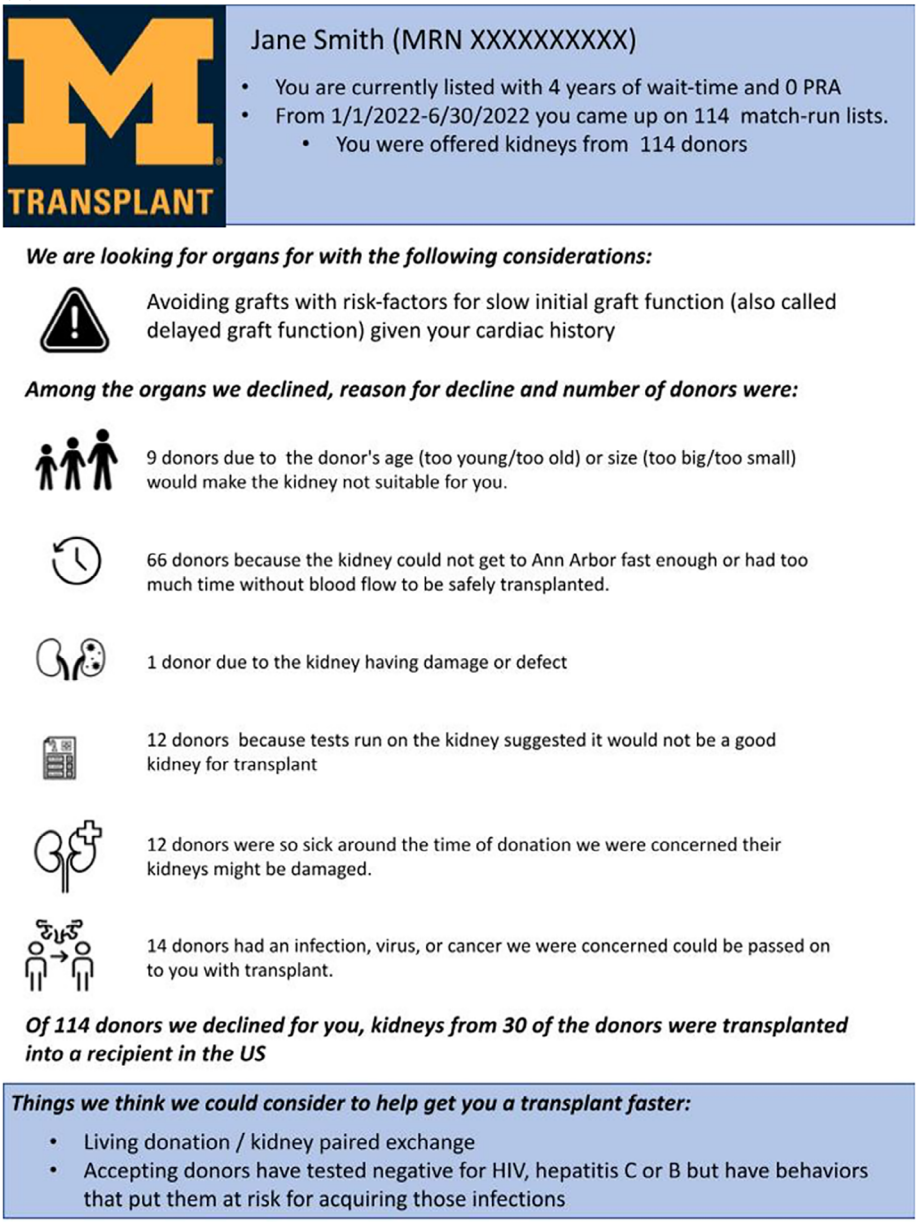


FIGURE 1 | (A) Prototype OORC. (B) Bar graph of participants' reactions to OORC. OORC, Organ Offer Review Card.

4 | Discussion

In this patient-centered study, participants were optimistic about the Organ Offer Review Card's ability to convey the factors that gave them priority on the waitlist, clarify the transplant team's considerations in accepting an organ, and enhance their trust in the transplant team. The aim of this study was to create a tool that fulfills the 2022 NASEM recommendations to increase transparency and accountability for organ offer declines to transplant candidates. Specifically, the NASEM report recommends that the OPTN contract be updated to require transplant centers to share with patients the number and context of organ offer declines. Our OORC provides a reproducible and efficient tool for transplant centers to directly fulfill this requirement. Furthermore, our findings validate the importance of transparency regarding organ offers, with 94.1% of participants reporting it was important to have information about all organ offers and all participants wanting to know why an organ was declined.

The OORC may facilitate communication and a periodic update with waitlisted patients. First, as simple as it is, transplant candidates have described an "eligibility enigma" of not knowing if they are in the evaluation, active or inactive on the waitlist [10]. Other candidates describe "spiraling doubt and disappointment" remaining on the waitlist and some patients express feeling forgotten [10]. Our participants echoed these findings complaining about the lack of transparency and communication (Table S2). Other studies that examined transplant candidates' knowledge and perspective on decision-making have called for increased transparency on the waitlist process and allocation-related concepts [11–14]. The OORC directly serves these needs.

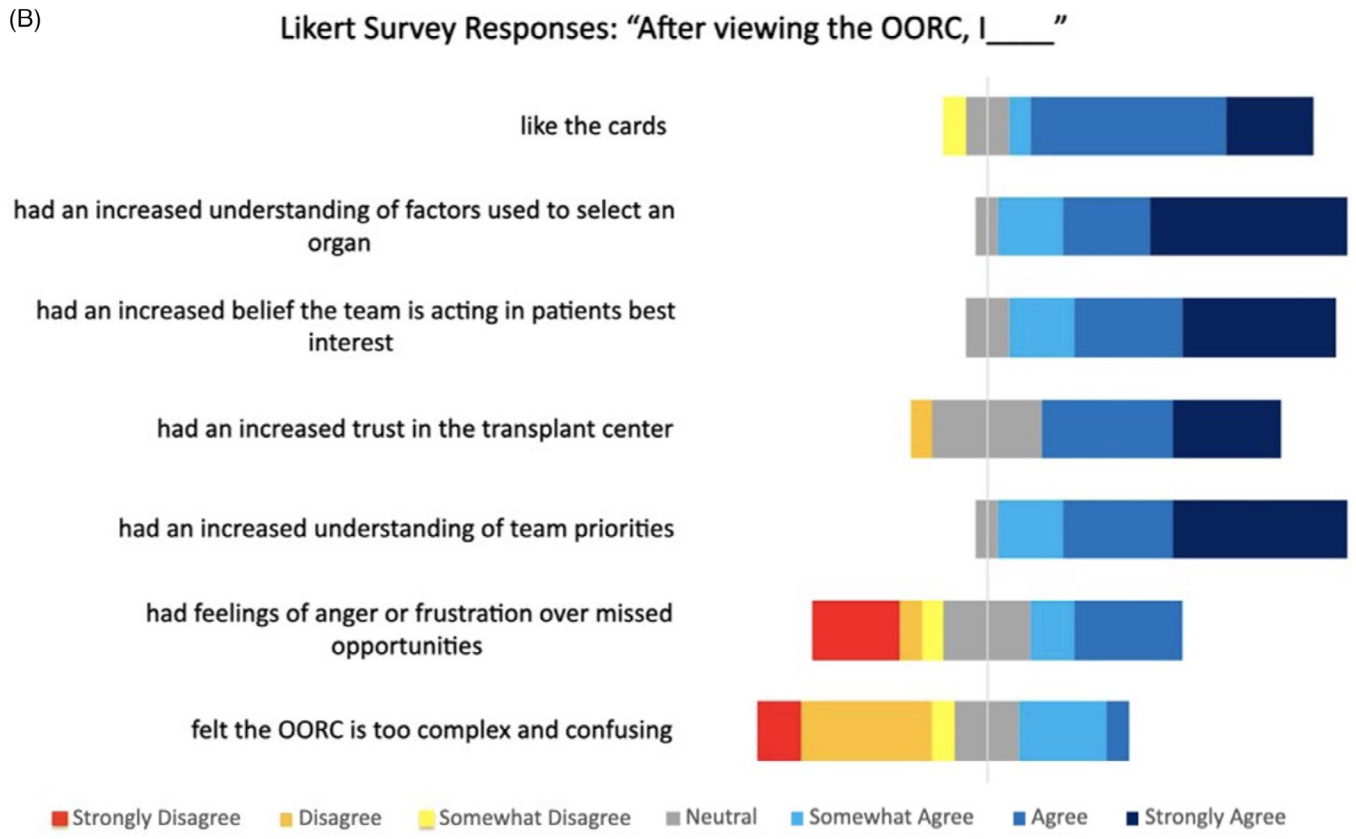


FIGURE 1 | *Continued*

While the OORC is a good start to fulfill NASEM's recommendations, we recognize that retrospectively informing patients about organ offers may be insufficient for shared decision-making as previously described by Gordon et al. [15]. As we implement individualized cards, we envision that the Organ Offer Review Card may facilitate more knowledge and discussions for candidates regarding individual priorities. For example, some patients might prefer enduring dialysis for the optimal outcomes whereas others might prioritize earlier transplant with lower quality kidneys—and patient preferences might relate to their experience on dialysis, family considerations, and current health status [10, 16, 17]. An enhanced understanding of prior offers may promote patients' input when accepting an organ with some risk (i.e., donor-derived disease, prolonged delayed graft function, etc.)—as a lack of knowledge has previously been described by transplant candidates as a barrier to shared-decision making [17, 18]. Furthermore, periodic updates might encourage transplant providers and patients to reconsider other avenues to increase the potential donor pool (e.g., high kidney donor profile index donors, living donors, hepatitis C donors, desensitization, etc.). Although the OORC may be a tool for initiating these conversations, we expect that transplant centers may need to employ a variety of resources, such as mobile applications and animated videos, to explain the complexity of allocation system and risks/benefits of different donors [19, 20].

Although participants generally had a positive review of the prototyped OORC, we acknowledge that learning retrospectively of an organ refusal might have detrimental consequences. About 41.2% of participants anticipated that they might feel angry or frustrated learning an organ for them was declined. Despite this, most participants wanted to receive the OORC and said it would enhance their trust in the transplant center. We believe that if OORCs are implemented thoughtfully, the card might be a *means* to define and refine an individual patient's preferences, rather than an *end* of a static report, but further studies are necessary to understand its impact.

The Organ Offer Review Card presents operational challenges as dispersing these reports will require administrative support, provider time, and funding. A strength of the OORC is that most of the data exists in DonorNet, so if an automated computer program that extracts the relevant data was developed, there would be minimal resources required to generate the OORC reports. The only input not in DonorNet is recipient considerations (Section 2), but many centers already keep similar notes to streamline reviewing offers real-time. We have provided an OORC templating guide that can serve as a framework for transplant centers (Appendix 3, Supplemental Materials). In terms of resources required to distribute the OORC, we envision this data could be shared with candidates by pretransplant coordinators and/or transplant nephrologists or advanced practice providers. Distribution could occur either electronically or in conjunction with annual pretransplant visits, where there would be a discussion of the candidates' preferences. Alternatively, since some decisions about organ acceptance are nuanced, larger centers might choose to centralize this role with one coordinator who has more dedicated training and, perhaps, has experience as a procurement coordinator. The NASEM report called upon the Department of Health and Human Services to update the

TABLE 1 | Participant demographics.

Characteristics	Number of participants (%): (unless noted otherwise)
Sex (female/male)	8 (47.1)/9 (52.9)
Median age in years, (IQR)	57 (51, 64)
Race	
Black or African-American	5 (29.4)
White	11 (64.7)
Prefer not to say	1 (5.9)
Education	
Some high school or less	1 (5.9)
High school diploma or equivalent	5 (29.4)
Associates or technical degree	3 (17.6)
Bachelor's degree	5 (29.4)
Graduate or professional degree	3 (17.7)
Employment	
Employed	4 (23.5)
Self-employed	2 (11.8)
Retired	7 (41.2)
On Disability	4 (23.5)
Household Income	
Less than $49 999	6 (35.3)
$50 000–99 999	7 (41.2)
Above $100 000	4 (23.5)
Median waitlist time in days, (IQR)[a]	641 (470, 1074)
Median dialysis duration in days, (IQR)[a,b]	501 (200, 1129)
Dialysis type	
Peritoneal	4 (23.5)
Hemodialysis	10 (58.8)
None	3 (17.6)

[a]Waitlist time and dialysis vintage was defined as the period between the date of waitlist or dialysis initiation and the date of study entry (January 7, 2022).
[b]Median dialysis duration is limited to only participants on dialysis.

OPTN contract, however, it did not outline financial support or incentives. We would advocate for some financial incentive or compensation as this will require additional provider or coordinator time and effort.

Our study has some limitations. First, we had a small sample size at a single institution, which limits its generalizability. Moreover, the sample may be subject to a nonresponse bias, as the participants who responded to our recruitment may be inherently more interested in being involved in organ offers and may skew the results towards positive responses. Second, we showed patients a prototyped OORC; a response to personalized data might be different. However, we deliberately chose an OORC with multiple offer declines, as the prototype OORC had over 100 offers declined and over 25% of those organs were transplanted. Third, UNOS organ refusal codes may lack specificity and/or providers may decline for a culmination of multiple factors. Additionally, DonorNet refusal codes are dependent on the accuracy of documentation by the transplant center, so centers implementing OORCs might want to discuss amongst the providers and procurement coordinators to establish uniformity in documentation. Lastly, we do not address—nor was it our aim to address—the uncertainties inherent in whether an organ should be refused, for example, how much cold ischemia time and how much donor comorbidity is prohibitive for transplant, and there is variability in practice [21].

Next steps include implementing and understanding transplant candidates' reactions to individual OORCs, with special attention to recruit candidates from all blood types reflecting the full spectrum of wait-time, dialysis duration, age, education, and other factors impacting access. A parallel study could examine if providers decision-making changes when enhancing transparency and compiling refusals by the patient-unit (i.e., knowing a candidate has had 100 organ offers refused and a quarter of those organs were transplanted vs. a patient's first or second kidney offer), as a different intervention that paired offers with patient-specific predictions improved decision quality, confidence and organ utilization [22].

In conclusion, we made a prototype of an innovative, personalized report of organ offers and reasons for turndowns based on DonorNet data. We found Organ Offer Review Cards were desired by participants and enhanced participants' trust in the transplant team, although the generalizability of our positive results must be interpreted with caution given the small sample and potential nonresponse bias. We have presented how an individualized Organ Offer Review Card will increase transparency and may facilitate nuanced communication regarding patient preferences and patient-centered decision-making in the organ acceptance process.

Author Contributions

Research idea and study design: Elizabeth M. Sonnenberg, Meredith Barrett. Data analysis/interpretation: Elizabeth M. Sonnenberg, Meredith Barrett, Husain A. Rasheed, Meridith Pensler, Sarah Diaz, Emily Roney. Statistical analysis: Husain A. Rasheed, Meridith Pensler, Sarah Diaz, Emily Roney. Drafting article: Elizabeth M. Sonnenberg, Meredith Barrett, Husain A. Rasheed, Meridith Pensler, Sarah Diaz, Emily Roney. Critical revision of article: Elizabeth M. Sonnenberg, Meredith Barrett, Husain A. Rasheed, Meridith Pensler, Sarah Diaz, Emily Roney. Supervision or mentorship: Elizabeth M. Sonnenberg, Meredith Barrett. 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.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

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