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Patient and Clinician Perceptions of Informed Consent and Decision Making About Accepting KDPI > 85 Kidneys

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Background. Although the impact of the kidney donor profile index (KDPI) on kidney discard is well researched, less is known about how patients make decisions about whether to give consent for KDPI > 85 kidney offers. **Methods.** We conducted in-depth, semistructured interviews with 16 transplant recipients, 15 transplant candidates, and 23 clinicians (transplant surgeons, nephrologists, and nurse coordinators) to assess and compare perceptions of transplant education, informed consent for KDPI > 85 kidneys, and the decision-making process for accepting kidney offers. Thematic analysis was used to analyze qualitative data. **Results.** Four themes emerged: (1) patients reported uncertainty about the meaning of KDPI or could not recall information about KDPI; (2) patients reported uncertainty about their KDPI > 85 consent status and a limited role in KDPI > 85 consent decision making; (3) patients' reported willingness to consider KDPI > 85 kidneys depended on their age, health status, and experiences with dialysis, and thus it changed over time; (4) patients' underestimated the survival benefit of transplantation compared with dialysis, which could affect their KDPI > 85 consent decision making. **Conclusions.** To better support patients' informed decision making about accepting KDPI > 85 kidneys, centers must ensure that all patients receive education about the trade-offs between accepting a KDPI > 85 kidney and remaining on dialysis. Additionally, education about KDPI and discussions about informed consent for KDPI > 85 kidneys must be repeated at multiple time points while patients are on the waiting list.

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INTRODUCTION

Between 2015 and 2018, nearly 20% of the patients on the waiting list for a kidney transplant in the United States died or were removed from the waiting list because they became too sick to transplant.¹ Despite the shortage of kidneys for transplantation, approximately 20% of the

deceased donor kidneys recovered in the United States are discarded.¹ The kidney donor profile index (KDPI) was implemented in 2014 to allocate the kidneys with the greatest expected graft longevity to patients with the highest expected posttransplant survival. KDPI is a calculation that predicts a kidney's relative risk of graft failure

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based on donor factors including age, history of hypertension and diabetes, height and weight, race, hepatitis C status, serum creatinine, cause of death, and donation after circulatory death. A kidney with a KDPI of 85 has a higher expected risk of graft failure than 85% of kidneys.^{2,3} Kidneys in the lowest KDPI range (KDPI < 20) are only allocated to patients with an expected posttransplant survival score in the top 20%. Kidneys with KDPI > 85 are only offered to patients who have provided informed consent to be listed for KDPI > 85 kidney offers.⁴ The use of KDPI in kidney allocation may be exacerbating kidney discard.⁵⁻⁷ Over 50% of kidneys with KDPI > 85 are discarded.⁷ Meanwhile, <50% of patients nationally have granted consent to be listed for KDPI > 85 kidneys¹; however, even a KDPI = 99 kidney confers a survival advantage over remaining on dialysis for most patients.⁸ Using more KDPI > 85 kidneys could provide significant benefit to patients in terms of survival and quality of life.^{8,9}

Receiving education about kidney transplantation influences whether end-stage kidney disease patients pursue evaluation at a transplant center, complete the evaluation process, and eventually receive a transplant.¹⁰⁻¹³ Education is also critical in ensuring that patients understand treatment options, such as consenting for KDPI > 85 kidneys. Although the Organ Procurement and Transplantation Network (OPTN) requires transplant programs to relay specific content, transplant programs vary in the depth of information provided and delivery modality.^{14,15} Studies show that patients' understanding of kidney quality in general, and KDPI in particular, is limited.^{16,17} Additionally, patients lack information about their chances of survival on the waitlist.¹⁸ The present study builds upon these findings, focusing specifically on the informed consent process for KDPI > 85 kidneys. This study assesses and compares patients' and clinicians' perceptions of transplant education and KDPI > 85 informed consent and kidney offer acceptance decision making, with the goal of ensuring that patients have the ability to make informed KDPI > 85 consent decisions.

MATERIALS AND METHODS

This is a qualitative, cross-sectional study. The standards for reporting in qualitative research checklist was used to ensure appropriate reporting of this qualitative research.¹⁹

Sample and Recruitment

Patients were eligible if they were 21 y or older, English-speaking, and were waitlisted for a kidney transplant, or had received a deceased donor kidney transplant between 2015 and 2020. A cutoff of 2015 was used to ensure that patients did not receive a kidney transplant before the adoption of the kidney allocation system in 2014. Clinicians (surgeons, nephrologists, and nurses) were eligible if they were directly involved in the clinical care of kidney transplant candidates.

Patients were recruited through the American Association of Kidney Patients (AAKP) and Northwestern Comprehensive Transplant Center. Demographic information and approximate date of wait listing and date of transplant surgery were provided by AAKP and the Northwestern Electronic Data Warehouse. Patients were screened for eligibility using the data provided by AAKP and the Electronic Data Warehouse, then intentionally selected to obtain a diverse sample by age, sex, race, ethnicity, geographic location, and waiting time. The selected patients were invited to participate in an interview

via email. Those who expressed interest in participating were then contacted by telephone to schedule interviews. All patient interviews were conducted by telephone.

Surgeons and nephrologists were recruited from a national list of OPTN committee members and transplant center medical directors and were selected to obtain a diverse sample by sex, race, ethnicity, and geographic location. Nurses from 5 different transplant centers were identified by the study's scientific advisory board. These 5 nurses participated in an interview and then were asked to identify additional nurses at other transplant centers to participate in the study. Five additional nurses were identified, 3 of whom completed an interview. All interview invitations were sent via email. Interviews were conducted over the phone or using video conferencing depending on participant preference. Institutional review board approval was obtained from Northwestern University (STU00208614), and all participants gave verbal informed consent.

Data Collection Methods

A research associate/project coordinator (K.S.) conducted semistructured, in-depth interviews with transplant recipients, candidates, surgeons, nephrologists, and nurse coordinators. Interviews were conducted during April through December 2020.

Interview guides for transplant candidates, recipients, surgeons, nephrologists, and nurses were developed based on literature on the kidney allocation system, KDPI, and kidney discard and formative interviews with 4 patients and 10 transplant clinicians and administrators.^{4-6,20,21} The interview guides were pilot tested through cognitive "think-aloud" interviews with 3 surgeons, 3 nephrologists, 4 nurses, 3 candidates, and 3 recipients. Cognitive interview participants were asked to explain their thought process as they interpreted and responded to the questions; their feedback was used to enhance question clarity and order.²² Topics covered in the patient interview included information patients received about kidney quality, understanding of KDPI, decision making regarding giving consent to be waitlisted for KDPI > 85 kidneys and accepting KDPI > 85 kidneys, and perceptions of the risks of dialysis compared with the risks of transplantation. KDPI > 85 consent was an area of particular focus because patients only appear on the match run for KDPI > 85 kidney offers if they have already given consent. After covering these topics, the interviewer provided additional information on KDPI; then, patients were asked a hypothetical question about how they would decide if they could accept a KDPI > 85 kidney today or wait 2 additional years for a KDPI < 85 kidney. Patients were also asked how they would make a decision if their transplant team offered them a kidney that was expected to last for 5 y. Demographic information was collected at the end of the interview.

Topics covered in the physician interview included how transplant teams educate patients about kidney quality and KDPI, which patients benefit the most from accepting KDPI > 85 kidneys, which patients are encouraged to consent for KDPI > 85 kidneys, and why patients decline kidney offers. Topics covered in the nurse interview included how patients are educated about kidney quality and KDPI and what information patients are provided with at the time of organ offer. Demographic information was collected at the end of the interviews. The duration of the interviews was approximately 40 min to 1 h. All interviews were audio recorded. Participants were compensated 100 USD. Interview guides are available in the Supplemental Digital Content, <http://links.lww.com/TXD/A386>.

Analysis

Audio recordings were transcribed, and transcriptions were analyzed thematically, using inductive and deductive coding methods.²³ The analysis team was composed of K.S. (a research associate/project coordinator) and U.L. and M.R. (undergraduate students with training in qualitative research methods). The analysis team engaged in reflexivity by identifying how personal areas of subjectivity, potential sources of role conflict, and interests of gatekeepers in the field could influence data collection and analysis.²⁴ We reached the point of no new themes identified, following guidance on data saturation published by Guest et al.²⁵ The analysis team developed initial deductive codebooks for patients, physicians, and nurses based on interview questions. After coding the first set of transcripts, the analysis team revised the codebooks, adjusting for new responses. All transcripts were thereafter independently coded by 2 research team members using NVivo qualitative analysis software (version 12; QSR International). Coders met to resolve discrepancies and achieved an interrater reliability of Kappa > 0.9. The analysis team then reviewed codes to identify emergent patterns within the data and generated themes.²⁶

RESULTS

Thirty-one patients (15 transplant candidates and 16 transplant recipients) participated (38% participation rate). Thirteen were patients at Northwestern Comprehensive Transplant Center, and 18 were AAKP members. The median age was 54 y old, and the sample was evenly divided by gender (Table 1). Most identified as White (n = 12) or Black (n = 12). Candidates had been waitlisted for a median of 4 y. Recipients had received their transplant a median of 3 y prior and reported a median waiting time of 4 y.

Clinicians included 15 physicians (9 surgeons and 6 nephrologists) and 8 nurses. The participation rate for physicians was 26%. Participation rate was not calculated for nurses, as they were identified through snowball sampling. Clinicians from all 11 OPTN regions participated. Clinician demographics are presented in Table 2.

Four major themes emerged: (1) Patients reported uncertainty about the meaning of KDPI or could not recall information about KDPI; (2) patients reported uncertainty about KDPI > 85 consent status and a limited role in KDPI > 85 consent decision making; (3) patients' reported willingness to consider KDPI > 85 kidneys depended on age, health status, and experiences with dialysis and changed over time; and (4) patients underestimated the survival benefit of transplantation over remaining on dialysis. Representative illustrative quotations are presented in Table 3.

Patients Reported Uncertainty About the Meaning of KDPI or Could Not Recall Information About KDPI

Patients identified donor age and health as factors that could affect kidney quality and recognized that a higher quality kidney might survive longer or function better than a lower quality kidney; however, patients had limited knowledge about KDPI, especially transplant candidates. Only 3 of the 15 transplant candidates interviewed could provide a description of KDPI. Thirteen of the 16 transplant recipients interviewed could provide some, albeit incomplete, description of KDPI. KDPI knowledge was similar among Black and

TABLE 1.
Patient demographics

Category	N (%)
Patient type	
Transplant recipient	16 (52)
Transplant candidate	15 (48)
Gender	
Male	16 (52)
Female	15 (48)
Race	
White	12 (39)
African American or Black	12 (39)
Other	5 (16)
Asian	0 (0)
Native Hawaiian	1 (3)
Mixed or multiple races	1 (3)
Ethnicity	
Not Hispanic or Latino	25 (81)
Hispanic or Latino	6 (19)
Age	
Under 50	12 (39)
50–70	17 (55)
Above 70	2 (6)
OPTN region	
Region 1	0 (0)
Region 2	2 (6)
Region 3	3 (10)
Region 4	5 (16)
Region 5	1 (3)
Region 6	0 (0)
Region 7	13 (42)
Region 8	1 (3)
Region 9	1 (3)
Region 10	3 (10)
Region 11	2 (6)
Education level	
High school or equivalent	4 (13)
Some college but no degree	4 (13)
Technical or Associate's degree	2 (6)
4-y college degree	12 (39)
Graduate or professional degree	9 (29)
Primary insurance type	
Medicare	19 (61)
Private	12 (39)

OPTN, Organ Procurement and Transplantation Network.

White patients; 9 patients who were able to provide a description of KDPI identified as Black, and 7 identified as White.

Patients who were unable to describe KDPI commonly reported having heard or seen the term before but did not remember or understand what it meant:

I haven't heard it but I did see it in my paperwork. Not really clear exactly what that is and how that works for me. (participant 21; 44-y-old, female transplant candidate)

Patients who could provide a description of KDPI were aware that it is a measure of kidney quality but were often unsure about the factors that comprise KDPI. Patients confused KDPI with Public Health Service previously designated "increased risk" donor kidneys or related KDPI to the quality of the organ match:

TABLE 2.
Clinician demographics

Category	N (%)
Specialty	
Surgeon	9 (39)
Nurse	8 (35)
Nephrologist	6 (26)
Gender	
Male	12 (52)
Female	11 (48)
Race	
White	16 (70)
African American or Black	2 (9)
Other	1 (4)
Asian	4 (17)
Native Hawaiian	0 (0)
Mixed or multiple races	0 (0)
Ethnicity	
Not Hispanic or Latino	19 (83)
Hispanic or Latino	4 (17)
Years of experience	
<10	6 (26)
10–20	10 (44)
>20	7 (30)
Transplant center volume	
<100	3 (13)
100–199	7 (30)
200+	13 (57)
OPTN region	
Region 1	2 (9)
Region 2	1 (4)
Region 3	3 (13)
Region 4	2 (9)
Region 5	2 (9)
Region 6	1 (4)
Region 7	4 (17)
Region 8	2 (9)
Region 9	2 (9)
Region 10	2 (9)
Region 11	2 (9)

OPTN, Organ Procurement and Transplantation Network.

Well the higher the number, the... less compatible it may be, the lower the number the more compatible a kidney is what my understanding is. (participant 27; 65-y-old, male transplant recipient)

Clinicians explained that patients typically receive information about KDPI as a part of the education provided during their initial evaluation. Although some nurses and physicians said that they review information about KDPI with candidates during follow-up visits, not all clinicians reported doing so. Physicians commonly felt that information about KDPI should be repeated more frequently. Nurses reported having to reeducate patients about KDPI when contacting them about kidney offers.

Clinicians also experienced difficulty conveying that a high KDPI does not necessarily mean a “bad kidney”:

It’s very difficult to sell a high KDPI kidney to patients. Like, “Mrs. Jones, I have a wonderful kidney for you.” “Oh, that’s great, Doctor. How good is this kidney?” “Well, it’s really

good, but 95 percent of the kidneys are better....” (participant 43, male surgeon)

Thus, some clinicians, particularly nurses, emphasized the need to better tailor information about KDPI to patients’ health literacy levels and to establish trust during education sessions; however, this can be difficult given time constraints:

... we move fast and everything makes sense to us because we do it every single day. But when somebody is hearing this for the first time and then we want them to sign a piece of paper 15 min later, you know what I mean? Like it’s just, you know I think sometimes people just have to rest with the information and then we’ll be able to circle back and then we’ll add another layer of education and another layer of trust, and sometimes the system doesn’t always allow for that. (participant 52, female nurse)

Patients Reported Uncertainty About Their KDPI > 85 Consent Status and a Limited Role in KDPI > 85 Consent Decision Making

Only 2 of the 15 transplant candidates interviewed knew their KDPI > 85 consent status. Ten of the 16 transplant recipients interviewed recalled if they had given consent to be waitlisted for KDPI > 85 kidneys. Awareness of KDPI > 85 consent status was similar for Black and White patients. Some candidates and recipients who were unsure of their KDPI > 85 consent status recalled discussing kidney quality with their transplant team but could not confirm if they had given informed consent to be waitlisted for KDPI > 85 kidneys specifically; however, some candidates did not remember their transplant team discussing kidney quality or KDPI:

I don’t recall anything that they talked to me about kidneys that were lower quality or anything. (participant 25; 67-y-old, male transplant candidate)

Interviews with clinicians revealed a range of practices for educating patients about KDPI and obtaining consent for KDPI > 85 kidneys. Some clinicians reported that they provided general information about KDPI but did not consistently engage in detailed conversations about KDPI > 85 consent:

... we have a very, I would say, superficial way of describing it to most people and then if they have more questions, we have more... if we think that they are a good candidate for a high KDPI kidney, then we bring out the consent form and we go into it with them in a little bit more detail. (participant 41, female nephrologist)

Criteria for which patients were offered the option to consent for KDPI > 85 were generally based on age, comorbidities, and expected waiting time; age was a particularly salient consideration:

... it’s mainly the age that I look at when I look at high KDPI kidneys and the one that I’ll put them into. (participant 45, female surgeon)

By contrast, some physicians reported that they discuss the option to be waitlisted for KDPI > 85 kidneys with all patients at their center. Physicians in this group did not necessarily recommend that all patients give consent for KDPI > 85, but they believed everyone should be informed:

TABLE 3.**Representative quotations****Theme 1: Knowledge gaps and misperceptions about KDPI****Patient quotes**

- "I saw those paper, any, sometime in the process they explained me, but I don't remember completely what is involved in KDPI." (participant 19; 65-y-old, male transplant candidate)
- "Well I know that they, I've heard the term but I'm not sure if I remember the whole aspect of what it is. I mean I know I know it's an index, well actually I might've forgotten about what it is. I remember in 2009 hearing about that for the first transplant. I might've heard about it in 2017 but it was so fast." (participant 18; 46-y-old, female transplant recipient)
- "It's basically a number based upon the donor's activity before death or, as a living donor, at that moment. Whether or not he is a high risk. Those variables can be age, how they died, whether they had spent any time in prison, that sort of stuff. Did they have any blood pressure, or heart disease, or a possibly diseased kidney that they are trying to donate as well. So all that good stuff." (participant 11; 50-y-old, male transplant recipient)

Clinician quotes

- "... often even though we actually educate these patients you know during their initial intake process, many patients don't remember and then tend to just be focused on the, well you know, having the best quality kidney. So it takes up a lot of you know saying the same thing 3, 4, 5 times, and sometimes it sticks and sometimes it doesn't." (participant 37, male nephrologist)
- "...on the spot, in real time they do have education sessions. But when these folks get listed, get educated and then the time that I call them, or my coworkers call them, there, you know, could have been a huge amount of time lapse." (participant 34, male, nurse)
- "... the language surrounding it, like trying not to make it so scary. Like right off, so they're not, they're not uninterested right off the bat. That I think, that's the probably the hugest thing for me." (participant 53, female nurse)
- "... that, you know, is a complicated process to get your patients to understand the level of granularity that, that comes with high KDPI and the concept of EPTS." (participant 70, male nephrologist)

Theme 2: Limited awareness of consent status and limited role in decision making**Patient quotes**

- "I'm really not sure [about KDPI > 85]. The thing that we talked about, what makes a kidney lower quality was the difference in the cadaver and the live donor. So it was that, that's the thing that we talked about, that having a live donor, all of those kidneys are of better quality than the cadaver. That's all I understand about that." (participant 35; 67-y-old, female transplant candidate)
- "...well the team that I'm with they didn't offer that as an option. So they didn't say much." (participant 21; 44-y-old, female transplant candidate)

Clinician quotes

- "... I'm calling some patients who are literally like surprised that they're listed." (participant 57, female nurse)
- "We have an internal criteria for who would qualify for those [KDPI > 85]. So we talk about the kidneys being at increased risk for delayed graft function, and the potential to have a shortened graft life, but in general what we do is see the patient, briefly review them, and then determine if they meet criteria for those organs based on our center criteria." (participant 55, female surgeon)
- "If they're a suitable candidate we would offer them to be patients who we believe are candidates for high KDPI kidneys. We don't offer them to everybody." (participant 32, male surgeon)

Theme 3: Consent preferences change over time and depend on health status, age, and experiences on dialysis**Patient quotes**

- "I would have to decide on how I feel at the time. So it would, if I think that I need... if at that moment, I have to decide, um, my quality of life and being a candidate for a different kidney if I wait for 2 y, that all depends on how I'm feeling at that moment. That's all I can say." (participant 60; 56-y-old, male transplant candidate)
- "You know I mean I can say that when I first went on dialysis or back on dialysis when my kidney rejected, I might've been a little more likely to um you know turn a higher risk kidney down, but as time has kind of gone on, it's kind of like wait a minute I've been waiting 17 y at this point, I'll take whatever I can get." (participant 20; 37-y-old, male transplant candidate)

Physician quotes

- "... If they're running out of dialysis access, if they got advancing comorbidities, you know, those patients who would certainly benefit from shorter waiting time" (participant 70, male nephrologist)
- "... when they are on the list, they come in once a year as waitlist candidate to be seen, and then that whole consent process is repeated." (participant 36, male surgeon)

Theme 4: Patients underestimate the survival benefit of transplantation over dialysis**Patient quotes**

- "... Well one of the things that I'd like to say is this, keeping it in mind that transplant is a form of dialysis. You're not cured when you are transplanted. It's another modality that you've chosen to respond to your chronic kidney disease." (participant 16; 55-y-old, female transplant recipient)
- "You know what, I personally believe it's either could work depending on the person. I, I have seen it from both ends you know. People thrive very well with the transplant and those with dialysis thrive just as well. So, I personally believe it could be either way, depends on the person." (participant 21; 44-y-old, female transplant candidate)

Physician quotes

- "... I think what some of the patients don't understand is how bad is dialysis, to stay on dialysis, how detrimental it is to, that is to your health over getting any kidney, you know... If you have an effective kidney that's working, you know, 3 y, 5 y, 10 y, that's, any number of years is better than being on dialysis, and I think getting that point across to community nephrologists, the patients themselves is the most important." (participant 45, female surgeon)
- "... so like the average person who gets a 99% KDPI kidney has a 60 plus percent 5-y survival, and the average person who stays on dialysis for that 5 y has a 40% life expectancy at 5 y. It's a reasonably large difference. And I think by, by creating this comparison that says my kidney is better than yours we have set up, we have essentially created a reference framework that encourages transplant centers and patients to decline kidneys." (participant 51, male nephrologist)

...we believe that we have an obligation to tell them that. We at the same time tell people that it isn't right for everybody. (participant 31, male surgeon)

Patients' Reported Willingness to Consider KDPI > 85 Kidneys Depended on Age, Health Status, and Experiences With Dialysis and Changed Over Time

Patients' preferences on granting consent for lower-quality or KDPI > 85 kidneys depended on their health status and could change over time. For example, a candidate who was listed at multiple transplant centers reported that she was initially advised to consider only high-quality kidneys; however, the amount of time she had been waiting and her declining health motivated her to consider lower-quality kidneys when she was later evaluated at a different center:

... because of all the time that has passed with me being on the list, so like I said, I've been on one at least 7 y, and my health is, um, getting progressively worse. (participant 29; 57-y-old, female transplant candidate)

Patients also reported that their experiences on dialysis motivated them to consider KDPI > 85 kidneys to receive a transplant sooner:

... You know, I really wanted to be active, or more active, in my grandchildren's life. So at that time, I was just willing to do anything just to get off of dialysis and have some form of normalcy in my life. (participant 13; 56-y-old, male transplant recipient)

In response to hypothetical questions about whether to accept a KDPI > 85 kidney today or wait for a higher quality kidney, patients said the decision would depend on their age, health in general, and how they are faring on dialysis. Although younger patients often cited their age as a reason to wait for a higher-quality kidney, some expressed willingness to consider KDPI > 85 kidneys because of the complications they had suffered on dialysis:

... there's nothing that you could really say, that would tell me, Okay, wait 2 y and you'll have a perfect kidney. I would just say go ahead and give me this one now because I have a life to live. (participant 23; 48-y-old, female transplant recipient)

Although physicians commonly emphasized patient age when discussing who should consider KDPI > 85 kidneys, many also noted the importance of experiences on dialysis. Some physicians made a point of discussing the option to consent for KDPI > 85 kidneys again with patients after they had been waitlisted:

...if they have been waiting for 3–4 y and nothing's coming, they may decide to sign for something else. (participant 42, male nephrologist)

However, this was not the case at every center represented in our sample. Some clinicians noted that patients who had not granted consent at their initial evaluation may not have an opportunity to change their consent status. Thus, some physicians encouraged most, or even all, patients at their centers to consent for KDPI > 85 during their initial education sessions:

... Somebody may be completely healthy, a healthy 45-y-old other than the fact that they have end stage renal disease. You

say you shouldn't sign up for any of that, and they wait 7 or 8 y on the waitlist, then during that 7 or 8 y, they've grown frail, they've had 2 arterial infarctions, they've had a hip fracture, you know, and they're doing terribly on dialysis. And if you haven't listed them for the high KDPI organs, even though they may be, at that point, candidates who would benefit from even high KDPI kidneys, you don't have that opportunity. (participant 51, male nephrologist)

Patients Underestimated the Survival Benefit of Transplantation Over Dialysis

Patients preferred transplant over dialysis because it confers a better quality of life; however, nearly one-third of patients (n = 11) were not sure if transplant helps patients live longer than dialysis:

I think persons live as long on either treatment because, well, you actually can live long on dialysis because you've got someone cleaning your blood. (participant 30; 52-y-old, male transplant candidate)

The majority of the patients who expressed uncertainty about whether patients live longer with a transplant or thought that patients survive the same amount of time with either treatment identified as Black or Hispanic (n = 9).

Clinicians commonly noted that dialysis mortality needs to be better incorporated into transplant education:

... we require consenting for so many things that are way outside of their healthcare literacy state, you know... and they don't even understand what their own mortality is on dialysis. (participant 47, female nurse)

Clinicians expressed concern that patients who do not fully understand the risks of dialysis are less willing to consider KDPI > 85 kidneys. Clinicians worried that patient education comparing high KDPI kidneys against average KDPI kidneys makes patients think in terms of good versus bad organs instead of considering the benefit of potentially getting a transplant sooner compared with the risk of staying on dialysis. Although patients would prefer a standard kidney, clinicians reported that patients are willing to consider KDPI > 85 kidneys when they understand their mortality risk on dialysis:

I mean most patients, if they had a choice, they would rather get a standard or normal kidney rather than a high KDPI or marginal kidney. But it's only when they realize that they do have survival advantage by selecting the high KDPI kidneys when they compare their mortality rate if they remain on dialysis. (participant 37, male nephrologist)

DISCUSSION

In our interviews with transplant patients and providers, we found that transplant candidates were generally unfamiliar with KDPI and did not recall whether they had given consent to be waitlisted for KDPI > 85 kidneys. Transplant recipients were more familiar with KDPI than the transplant candidates in the sample; however, they commonly expressed confusion about the factors that comprise KDPI. The lack of awareness of KDPI, particularly among transplant candidates, is problematic because of the implications for informed consent. Our findings are also disconcerting given research demonstrating the frequency with which offered organs are declined

on behalf of patients without their knowledge, with patients who died on the waiting list receiving a median of 16 offers.²⁷ Patients have a right to education about the types of offers available so they can make informed treatment decisions.

Clinicians commonly expressed concern that patients do not understand or remember information about KDPI and reported difficulty explaining KDPI in plain language. Some physicians discussed KDPI > 85 consent in detail only with patients who fit specific center-level criteria to be recipients for high KDPI kidneys at the time of their initial evaluation. A national program to standardize transplant center education about the option to consent for KDPI > 85 kidneys is needed to ensure all patients have an understanding of KDPI and know that they have the option to be waitlisted for KDPI > 85 kidneys. This is critical because patients' reported willingness to consider KDPI > 85 kidney offers depended on age, health status, and experiences with dialysis and could change over time. These findings align with previous research on patient willingness to accept hepatitis C positive organs and organs subjected to intervention research.^{28,29} The education gaps we identified also align with previous findings regarding patient education and HCV. A majority of patients express willingness to consider HCV-positive kidneys when informed of high HCV cure rates, yet a survey found that 40% of patients were unaware that HCV is curable.^{28,30}

Additionally, our findings align with previous studies showing that end-stage kidney disease patients are often unaware of or underestimate their dialysis mortality.^{18,31} Clinicians perceived that it is difficult for patients to make informed decisions about KDPI > 85 kidneys when many do not fully understand their own mortality risk on dialysis. Although our study is not large enough to draw conclusions regarding racial or ethnic disparities in transplant education, it is also concerning that Black and Hispanic candidates were particularly likely to underestimate the risks of dialysis compared with transplantation. Transplant center education should address dialysis mortality and the relative risks of transplantation with a lower-quality kidney versus remaining on dialysis.

This study has strengths. Our qualitative interviews provided novel insights into both patients' and clinicians' perceptions of transplant education and the KDPI > 85 kidney consent process. Surgeons, nephrologists, and nurses were represented in our sample of clinicians, and patient participants included both candidates and recipients. Our national recruitment efforts resulted in a geographically and racially/ethnically diverse sample.

The study also has limitations. Recall bias may have limited participants' reports of prior discussions about KDPI. Recruitment occurred during the Covid-19 pandemic, which may have contributed to lower participation rates and increased the potential for participation bias. Patients with a college degree were overrepresented. The knowledge gaps and misconceptions discussed here could be more pronounced in the general population of transplant candidates and recipients. The majority of clinicians in the sample were from medium- or high-volume transplant centers. The education and consent practices reported may not reflect all US transplant centers.

In summary, patients have limited understanding of KDPI and are unsure of their KDPI > 85 consent status. This can result in missed opportunities for patients to make informed consent decisions that could increase their chances of receiving

a kidney transplant sooner. Transplant centers should revise their educational processes to ensure that patients understand the risks and benefits of accepting high KDPI kidneys and are aware of their own mortality risk on dialysis. All patients should be informed of the option to grant consent to be waitlisted for KDPI > 85 kidneys, and patients should have the opportunity to periodically review and update their consent status. Future research should focus on designing and implementing educational strategies to better support patient decision making about KDPI > 85 consent. Further research is also needed to quantitatively evaluate the association between education to support patients' KDPI > 85 consent decision making and centers' KDPI > 85 consent rates, kidney offer acceptance patterns, and waiting times.

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