Getting a Kidney: Where Is Patient Choice?

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Introduction
As a lifelong patient with kidney disease and threetime kidney transplant recipient, I would first like to applaud the authors of “Patient Preferences for Waiting Time and Kidney Quality” for undertaking such an important research study and submitting the resulting manuscript for publication in CJASN (1). The topic of patient preferences and the inclusion of them in care decisions is deeply personal to individuals living with kidney disease, and it is truly an honor to review a manuscript on the topic, specific to transplant and organ allocation.

As a professional who has spent the first 11 years of their career in health care, specifically kidney care, including time in transplant administration, I am unfortunately left with a few more questions than answers after reviewing the article. Specifically, when I consider a transplant center, I am hard-pressed to identify any immediate action items an individual program might feel emboldened to implement as a result of the study.

The authors position the results of the study as factors to address the deceased donor kidney discard rate, which, of course, is a very important gap to fill. More broadly, however, the study can serve as a vehicle to discuss much-needed innovation in creating a more transparent and patient choice-driven organ allocation system. Specifically, I imagine a future in which each transplant candidate on the deceased donor kidney registry waitlist is notified of every organ offer and, in partnership with the medical team, determines the best therapy choice, incorporating the candidate’s unique preferences at that specific time in their kidney journey.

Understanding the Study and Driving Innovation
The study, through its design and results, provides significant considerations to ponder in moving toward a more transparent and patient-centric organ allocation system. There are too many discussion points to cover here in great detail, such as how to account for care partner preferences (particularly in the pediatric population), how and at what frequency patient preferences should be captured, how transplant centers will be “graded” by regulatory bodies and payors in transplant decisions that include patient preference for low-quality (Kidney Donor Profile Index >85) kidneys, and what infrastructures must exist for patients to be partners in their kidney offer or possible acceptance process. The below commentary focuses on three critical considerations that stem directly from the design and results of the study and will help the nephrology community move toward the long-term vision suggested above.

Certainty versus Uncertainty
In the discreet choice experiment design, participants are presented with options of deceased donor kidney offers in which all data are known across the key factors of wait time and kidney quality (expressed as kidney longevity). The authors self-report that the certainty in which the scenarios are described is a limitation of the study and does not mimic the real world in which uncertainty is extremely prevalent within the system.

Patients want to be in the loop on kidney acceptance decisions, understand the nuances and uncertainties in each situation, listen to the clinical team’s rationale for an accept or decline recommendation, and ultimately have a voice in the decision. To achieve that, there needs to regular and transparent communication, which could start with patients being notified of each organ offer.

Preferences Now versus Preferences Over Time
The study includes >600 participants who were presented with the discreet choice experiment (1). But each participant was given the scenarios only once and was influenced by their personal experience with kidney disease at that point in time. A more robust analysis of the rationale or factors driving patient preferences should be evaluated. Existing time on dialysis, dialysis modality, current clinical outcomes, current quality of life, living situation, and work situation are just some hypothesized factors that might cause a change in a patient’s preference to accept an offer of a lower-quality kidney now versus waiting for a possibly normal kidney in the future.

To meaningfully include patient preferences in kidney acceptance decisions, clinician insights and the dynamic patient preferences need to be aligned and refined regularly, starting with every offer of a kidney with a Kidney Donor Profile Index >85.

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Attributable Preference Findings versus an Individual Patient

Finally, the study found that participants preferred accepting a lower-quality kidney in return for shorter waiting time (especially those who were older and had lower functional status) (1). Additionally, the study was further able to identify meaningful differences between patient groups, described as classes 1, 2, and 3. Although these attributable findings are important, when incorporating patient preferences into the organ allocation process, an individual patient’s unique circumstances and resulting preferences need to take precedence over the broader findings.

Conclusions

There are many obstacles in moving toward the long-term vision proposed in the introduction; however, as long as studies, such as “Patient Preferences for Waiting Time and Kidney Quality,” are pursued and push the bounds on what is known about patient preferences in the organ allocation system, and stimulate robust discussion and communal action on continued unmet needs, the goal can be reached much sooner than imagined.

Disclosures

M.J. Lennon reports employment with CVS Kidney Care; having contractor agreements with Talaris Therapeutics; and serving in an advisory or leadership role for The Improving Renal Outcomes Collaborative Board of Directors and The Kidney Health Initiative Patient and Family Partnership Council.

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Author Contributions

M.J. Lennon wrote the original draft

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See related article, “Patient Preferences for Waiting Time and Kidney Quality,” on pages 1363-1371.