

Kidney News

March 2023 | Vol. 15, Number 3

Improving Transplantation Education Requires a Multipronged Approach

By Melanie Padgett Powers



Although kidney diseases affect an estimated 37 million people in the United States, most people are unaware and may not be diagnosed until they reach kidney failure, or end stage kidney disease (ESKD). More than 786,000 people in the United States have kidney failure, with more than 61% receiving in-center dialysis (1).

Transplant is the gold standard for most of these patients, but getting to that stage can be a confusing, complex path with several barriers along the way. Multiple strategies are needed to improve kidney transplantation rates, experts say, including better patient education, engagement, and choice.

“One goal of ESKD treatment is to skip dialysis and aim for a preemptive transplantation, as this strategy provides the optimum benefit,” said Vineeta Kumar, MD, professor of medicine and medical director of the Incompatible Kidney Transplant Program at The University of Alabama at Birmingham (UAB). “Every year you spend on dialysis, you are chipping away at that benefit of transplantation,” Kumar said. “So preemptive transplantation is the way we

want to go.” However, in the United States, fewer than 10% of all kidney transplants are preemptive, she said, even after changes in the kidney allocation system to increase access to organs (2).

This is because “the care of the patient in the journey from kidney disease[s] to transplantation is very siloed,” Kumar said. Patients may start with a primary care physician managing their early kidney diseases, then be referred to a nephrologist at a later stage, and ultimately reach a health care team at a dialysis center. If patients are connected to a transplant center, they will have a new transplant team and a transplant nephrologist. These multiple transitions of care oftentimes lead to missed opportunities, Kumar said. Plus, she added, they can exacerbate existing health care disparities among vulnerable populations.

Empowering patients with information

Although nephrologists should play a key role in patient education, oftentimes the education needs to start much

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Glucose Absorption May Drive Cyst Formation in Polycystic Kidney Disease

By Tracy Hampton

Researchers have identified many of the genes that cause autosomal-dominant polycystic kidney disease (ADPKD) and other forms of PKD, which are characterized by fluid-filled cysts that arise from tubules in kidneys and other organs. They have developed human kidney organoids to model these conditions, but very little is known about the mechanisms underlying cyst formation in affected patients. By applying a microfluidic chip to the organoids, investigators recently uncovered new insights into how the flow of fluid within the kidney contributes to PKD. The work, which is published in *Nature Communications*, points to the importance of aberrant glucose absorption in cyst formation (1).

“The results...are significant because there is a whole

class of molecules that block sugar uptake in the kidneys and are attractive therapeutics for a number of conditions,” said co-senior author Benjamin Freedman, PhD, an assistant professor of medicine in the Division of Nephrology at the University of Washington School of Medicine in Seattle.

Combining kidney organoids with microfluidic chips allowed a mixture of water, sugar, amino acids, and other nutrients to flow over the organoids, which were derived from human pluripotent stem cells and contained podocyte, proximal tubule, and distal tubule segments in contiguous, nephron-like arrangements. In organoids that had been genetically edited to mimic PKD, the process of cyst swelling

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Inside

Infectious diseases and the kidney

From *P. vivax* to norovirus, the spectrum of infections affecting the kidney varies widely around the world.



Anti-GBM disease

Can we do better at predicting it?



Findings

Dapagliflozin reduces hospitalizations in patients with CKD.



Improving Transplantation Education

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earlier, Kumar said. Patients, particularly those with diabetes or a family history of kidney diseases, should have their kidney function measured regularly and be taught what their numbers mean—their serum creatinine value, random urine albumin-to-creatinine ratio, and blood glucose number. This early detection could help prevent or slow progression of loss of kidney function. “It’s empowering our patients with information as it applies to their condition so that they have the chance to be more active participants in the trajectory of their own care,” Kumar said.

Kumar recognizes, however, that there are barriers to the ideal version of early, ongoing, effective education, especially for individuals who face negative social determinants of health, such as low income, lack of transportation, no health insurance, or interpersonal and structural racism. Racial and ethnic minorities in the United States are less likely than people who are White to receive kidney care before kidney failure, to receive a kidney transplant, and to go on home dialysis. Individuals who are Black in the United States, in particular, are less likely to be placed on the kidney transplant waitlist when compared with people who are White (3).

In addition, there are no standardized, evidence-based guidelines that tell health care providers how to educate a patient about transplant options, said Tanjala S. Purnell, PhD, assistant professor at the Johns Hopkins Bloomberg School of Public Health in Baltimore, MD, who researches ways to improve equity in access to kidney transplantation.

Medicare ESKD Form 2728 asks whether a patient has been informed of transplant options, but it does not go into details about that education. The form does not ask “exactly which components about transplant were they informed about or how long was the conversation, the timing of the conversation, none of that,” Purnell said.

Furthermore, transplantation is an evolving field. Purnell wonders: “Are patients being told about innovative options beyond a living donor they know or beyond being placed on the deceased donor waiting list?” For example, studies have shown positive results in patients who have received kidneys from donors who have hepatitis C, now that more effective and tolerable, direct-acting antivirals are available to cure hepatitis C (4).

Another challenge is that physicians are often not taught in medical school and residency about how to engage a patient based on his or her individual learning style or culture. “Care isn’t cookie cutter,” said Quin Taylor, a 2015 kidney transplant recipient and patient advocate on ASN’s Excellence in Patient Care Advisory Committee. “You can’t approach every patient the same way and expect [him or her] to understand and be proactive in the same way, especially culturally. Patients have a care team for a reason, and I think each partner in that care team needs to take the time to find an effective way to help patients understand not only why transplantation is important but also to address their concerns.”

As a child, Taylor watched her father go through years of dialysis before getting a transplant. But because of complications he went through, when Taylor was first told she needed a transplant, she wanted no part of it. She planned to stick with dialysis at first. “There were certain things that I had to learn for myself, and one of the biggest things was that transplantation isn’t a cure. . . . Once I was able to understand that, it helped me on the journey.”

Taylor switched from in-center dialysis to at-home dialysis and became very proactive in the transplantation process. She worked through barriers, such as needing to lose weight first. “I was very self-motivated, but not all patients are.”

Like with Taylor, it can take time for patients to choose or accept the decision their health care team believes is the best one for them. Having these conversations early and often

“gives patients the opportunity to figure out what this is [because] a lot of times patients crashed into dialysis because they didn’t know they had kidney disease[s],” Taylor said.

Including patient goals in decision-making

Patient choice and decision-making need to be a part of the educational process, Taylor added. A 2022 *CJASN* study (5) showed that those on the kidney transplant waitlist would be willing to have a kidney with fewer years of quality if it meant they could get the transplant now, rather than spend 2 more years on the waitlist for a better kidney. Approximately 20% of deceased donor kidneys are discarded in the United States each year. Could some of those kidneys benefit patients?

In the *CJASN* study of 605 participants (5), the average respondent said he or she would accept a kidney today that had 6½ years of expected graft survival rather than waiting 2 more years for a kidney with 11 years of expected graft survival. Those less willing to accept increases in wait time for improvements in kidney quality were more likely to be older, Black, not have a college degree, and have a lower Karnofsky Performance Status score, which assesses a patient’s ability to handle activities of daily living.

Health care providers “don’t always include patients in on the decision-making,” Taylor said. “Doctors sometimes write goals for patients, instead of including [patients] in their conversation—what are their goals? You might want them to get transplanted; they might just want to be able to travel.” Taylor continued, “I always say, doctors are the experts in the science of diseases; the patients are the experts in the experience of those diseases. So, when it comes to connecting the dots, patients have an insight that doctors will never have, no matter how many times they treat a patient.”

Purnell has been researching initiatives to increase the number of living donor transplants. Oftentimes, a person needing a transplant may not know how to ask or be comfortable with asking others for help, especially beyond his or her close family members and friends. Purnell has been partnering with church and community leaders in Baltimore to develop ways to increase awareness among healthy people about the need for donations and to create support systems. Such help could include providing transportation to dialysis or pairing someone up with a medical professional in his or her community who can attend doctors’ appointments with him or her as an advocate.

“Many times there’s this notion that certain communities just aren’t stepping up, or certain communities just aren’t interested,” Purnell said. “But in reality. . . communities are willing to step up, and communities do care. It’s just that that’s not a topic often that many community members are introduced to until a loved one is faced with this decision.”

Helping patients find healthy living donors

Health care professionals can also help patients think beyond their close circle for a potential live kidney donor. Chronic conditions such as diabetes and kidney diseases are often clustered in social networks, Purnell said, making it more important to widen the search for a healthy living donor.

One successful initiative has been the Live Donor Champion program, in which people on the transplant waitlist identify someone close to them to be their champion. The champion receives education and materials through the program to help spread awareness about live donation. Ultimately, the goal is for the champion to help find a donor for his or her friend or family member on the transplant waitlist. Such programs can help people learn how to get the word out and ask for help, which can be uncomfortable and difficult.

At UAB, Kumar and her team have instituted a living donor champion and navigator program that helps those on the waitlist identify and ask potential donors. The ability for those in the program to identify a potential living donor increased two- to threefold. The navigator then helps the donor through the entire evaluation process, from identification to final decision and donation.

In one of their studies of 56 program participants, UAB researchers found that program participation was the strongest predictor of having a living donor screened—an increase

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of more than ninefold compared with standard of care. African American participants were eightfold more likely to have a donor screened than African American non-participants and threefold more likely than Caucasian non-participants, according to the study published in January 2020 in *Transplantation* (6).

Throughout a patient’s journey through CKD and transplantation, education needs to be ongoing and interactive, Kumar said. “In the name of education, we sit them down for an hour and talk at them for that entire time,” she said. “That’s information sharing, which is important but not the same as education.”

Education is providing information and then stopping to ask questions to see what they have retained, she said, ultimately ensuring that the knowledge they gained empowers them to care for themselves during vulnerable periods in their transplantation journey. It also includes space for patients or their loved ones and caregivers to ask questions and discuss the unknowns. “Education can be optimized by being early, by being bite-sized, by being progressive, and by [empowering] our patients so they can be true participants in their own care and partners with their medical care teams, as opposed to being present and led along.” ■

References

1. United States Renal Data System. 2022 *USRDS Annual Data Report: Epidemiology of kidney disease in the United States*. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2022. <https://usrds-adr.niddk.nih.gov/2022/introduction>
2. King KL, et al. Trends in disparities in preemptive kidney transplantation in the United States. *Clin J Am Soc Nephrol* 2021; 14:1500–1511. doi: 10.2215/CJN.03140319
3. Gadegebeku CA, et al. Identifying, confronting, and addressing systemic racism in US nephrology. *Kidney News*, June 2021; 13:12–13. https://www.kidneynews.org/view/journals/kidney-news/13/6/article-p12_5.xml#tbl3
4. Durand CM, et al. Direct-acting antiviral prophylaxis in kidney transplantation from hepatitis C virus-infected donors to noninfected recipients: An open-label nonrandomized trial. *Ann Intern Med* 2018; 168:533–540. doi: 10.7326/M17-2871
5. Mehrotra S, et al. Patient preferences for waiting time and kidney quality. *Clin J Am Soc Nephrol* 2022; 17:1363–1371. doi: 10.2215/CJN.01480222
6. Locke JE, et al. Enhanced advocacy and health systems training through patient navigation increases access to living-donor kidney transplantation. *Transplantation* 2020; 104:122–129. doi: 10.1097/TP.0000000000002732