

Knowledge Measurement Can Point to Opportunities, but Has Limits

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The authors of “The Knowledge Assessment of Renal Transplantation (KART) 2.0: Development and Validation of CKD and Transplant Knowledge Scales” (1), published in this issue of *CJASN*, have written a compelling article about the development and implementation of KART 2.0. This is a tool to identify patients who may benefit from targeted education to increase activation, improve disease self-management, and maximize pursuit of kidney transplantation.

As a family member engaged in the care of people who suffer from kidney disease, I know how important it is to have information about access to transplantation. Since first being diagnosed with CKD in 2001 at the age of 15, my daughter has spent 8 years on dialysis and has had two kidney transplants. As her advocate, I was very motivated to educate myself. Two of my sisters also have CKD; one is transplanted and the other is on dialysis, still waiting.

This study by Waterman *et al.* (1) attempts to identify patients who will be most able to learn how to manage their care and, therefore, move on to receive a kidney transplant. This assessment of knowledge could be helpful in a perfect scenario but, when dealing with humans at different levels of illness, I wonder if it goes deep enough. In what state of mind is the patient? Newly diagnosed patients may be in denial, angry, or depressed and, later on, they may become more accepting and willing to listen and learn. It is important to know the timing of the KART 2.0 survey. At what point in the patient’s care regimen was the survey administered (before, during, or after dialysis)? This can greatly affect the energy and cognitive ability of the patient.

Knowledge gained by the patient will also vary depending on circumstance. A patient who is at stage 3 CKD will likely have less motivation compared with someone who is approaching the latter stages of CKD and facing important decisions about their care.

The study mentions that CKD knowledge scales distinguish between patients who engaged in various types of CKD or transplant education for <1 or >1 hour. Is an hour of reading about or talking about CKD a benchmark that has been established? Early on in her CKD journey, my daughter was overwhelmed with a regime of new medications, fluid and food restrictions, fear, anxiety, and fatigue and had difficulty learning and retaining information about her condition. I was

not the patient. I had the energy and focus, but it was still like learning a foreign language. Knowledge about the benefits of having a family member or support person involved is critical.

Inviting the patient’s family members to participate in the decision-making process will also assist the patient in retaining information.

Did the patient attend a support group? I administer a Facebook group for people with kidney diseases, and there is often confusion or misinformation related to dialysis and transplant. Sharing experiences, asking questions, exploring topics, and involving the patient gives them knowledge while reinforcing the idea that they are not alone. Group support can engage patients in their care plan, help patients retain knowledge over time, and lead to better outcomes. A quote by a Chinese Confucian philosopher, translated as, “Tell me and I forget, teach me and I may remember, involve me and I learn,” reveals what I have seen in real time.

The following are some common educational topics I think are important to include:

- What panel reactive antibody is and how it can affect your waiting time for a transplant;
- how to go about a living donor search and options of multilisting;
- the diet and fluid changes after transplant;
- the benefits of accepting a high-risk deceased donor kidney;
- the ability of patients to self-refer to a transplant center;
- the ability of patients to get evaluated for a transplant before beginning dialysis; and
- what patients need to do to stay active and healthy while waiting for a kidney.

I was so grateful to hear legislation was passed to provide lifetime Medicare coverage for immunosuppressants in December 2020. It has limits and not everyone qualifies for it, but this ruling is a change for the better. Making sure transplant patients are knowledgeable about current health care coverage policies is critical.

But who will provide the education patients need? We often hear that patients have very short visits with health care professionals and can receive conflicting advice from different providers. Will this type of survey lead to patients being prioritized by the survey

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results? Will it leave people who may have language barriers or other issues at a disadvantage?

What incentives do patients have in answering surveys like the KART 2.0? I ran this survey by a friend who is waiting for a transplant and they said, "I would check off the answer that gives me the highest chance of getting listed," as patients perceive they must maximize their chances in the pursuit of kidney transplantation.

Finally, it would greatly benefit all if the survey could be turned into a continuing education program topic for health care professionals and provide best practices for communicating and delivering education to the patient. Only when patients living with CKD can make informed choices about their care and treatment options, regardless of their racial and ethnic background, literacy level, language of origin, and all of the factors I mentioned above, can we optimize health outcomes for all.

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Author Contributions

K.A. Franks was responsible for methodology and wrote the original draft.

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1. Waterman AD, Nair D, Purnaji I, Cavanaugh KL, Mittman BS, Peipert JD: The Knowledge Assessment of Renal Transplantation (KART) 2.0: Development and validation of CKD and transplant knowledge scales. *Clin J Am Soc Nephrol* 17: 555–564, 2022

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See related article, "The Knowledge Assessment of Renal Transplantation (KART) 2.0: Development and Validation of CKD and Transplant Knowledge Scales," on pages 555–564.