DISCLOSURES
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Asking Dialysis Patients About What They Were Told: A New Strategy for Improving Access to Kidney Transplantation?

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Kidney transplant remains the optimal treatment for many patients with ESRD.1 Providing timely and equitable access to kidney transplantation across age and ethnicity has been a challenge for many programs.2 Although elegant descriptions of the transplant process have demonstrated stepwise systemic barriers to equitable access to transplantation,3 few studies have examined patient–dialysis team interactions and communication, including the extent to which provision of information about kidney transplantation influences transplant listing and subsequent outcomes.

The research by Salter and colleagues4 in this issue of JASN is significant and important because it is the first to examine reports of kidney transplantation provision of information (KTPI) by both the care provider and the patient and then relate them to listing for kidney transplantation. Their work takes advantage of an ongoing study of sudden death among incident hemodialysis patients. In their ancillary cohort study, the investigators thus had access to a well characterized group of 388 patients initiating dialysis within 6 months of enrollment. They collected provider-reported KTPI from the Centers for Medicare & Medicaid Services Form 2728 and patient-reported KTPI from surveys. A notable finding was that KTPI was reported by both the provider and the patient for only 56% of patients. In nearly 28% of the sample, only the provider reported KTPI; only the patient reported it in 8.3%. Further, in multivariable analyses the provider-reported KTPI was neither strongly nor significantly associated with subsequent transplant listing status, while patient-reported KTPI was associated with an almost 3-fold increased likelihood of listing. This finding prompted the investigators to argue that patient perception of KTPI is a novel and important factor that may drive the association between KTPI and ultimate listing for transplantation.

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On the basis of these results, should we conclude that patient-reported KTPI will always be superior to any report by providers concerning whether they have given information to their patients about the options for renal care? Although we believe the findings have important clinical implications, we would nevertheless urge some caution given Salter and colleagues’ reliance on the filing of Form 2728. The Form has been recognized as providing an important but inexact snapshot of patients with incident ESRD. For example, reliability of Form 2728 data has been questioned for many items, including those referring to chronic health conditions and, recently, the underlying cause of ESRD. The item on Form 2728 used by Salter et al. (regarding whether the patient has been informed of kidney transplantation as an option) presents a unique challenge because the Form is due to the ESRD network within 45 days and existing medical records may not adequately document education about treatment modalities. Further, the nephrologist—who is the provider required to complete Form 2728—and the patient may have only very limited contact in the first 45 days depending on the timing of dialysis initiation and the local practice patterns. One can imagine that if patients and nephrologists have only one or two encounters, myriad issues, such as dialysis access and recent hospitalizations, may take precedence over a more long-term plan for undergoing kidney transplant evaluation. The lack of association between provider-reported KTPI based on Form 2728 and kidney transplantation listing is understandable given this imprecise measure of exposure to KTPI from the dialysis team.

Fortunately, the data collected by Form 2728 provide only an early snapshot of the ongoing care provided by the dialysis team. In many units, the key issue of KTPI is routinely addressed monthly by the interdisciplinary team rounds, which typically include the nephrologist, the nurse, the social worker, and the dietician. Further, the issues of treatment modality and kidney transplantation are examined more in depth at the third month and subsequent annual assessments by the dialysis team. Indeed, KTPI is part of a formal curriculum for patients in the first 120 days in dialysis practice at our centers. Overall, then, before provider-reported KTPI is discarded as a potential predictor of kidney transplantation listing or other outcomes, it would be important to more fully and directly investigate the timing and nature of education efforts by providers in the dialysis setting. This might yield a more nuanced understanding of the conditions under which provider-reported KTPI is effective.

Nevertheless, it seems intuitively obvious—although the busy practitioner may tend to forget—that even the best educational efforts will be for naught if the patient does not take in the information or understand it. The key strength of Salter and colleagues’ report lies in emphasizing this. However, it stops short of being able to tell us why patients did not report KTPI. As the authors acknowledge, just as the measure of provider-reported KTPI is relatively imprecise, the assessment of patient-reported KTPI is also limited. In particular, despite the exclusion of patients with a diagnosis of dementia, there may have been a substantial degree of cognitive or sensory impairment in the sample population. This could have led to ineffective patient-physician communication. The dialysis unit presents challenges to conveying information given the exacerbation of cognitive impairment, pain with treatment due to needle sticks and cramping, noise, distraction, and lack of privacy. Patients with better numeracy, and by association better cognitive performance, have a higher likelihood of receiving a kidney transplant or active transplant listing. Finally, the patient-reported items in Salter and colleagues’ report were solely linked to whether the dialysis team had provided information about kidney transplantation. Patients have multiple potential sources of such information, including the primary nephrologist managing their CKD, primary care providers, other patients, family, social media, and other Internet resources. It would be important in future work to evaluate the extent to which these other sources were associated with subsequent listing. Despite these issues, the authors’ findings clearly suggest that assessing KTPI may be useful during dialysis rounds and that patients not reporting KTPI should be assessed for barriers to communication and comprehension, with appropriate additional education provided as needed.

Salter and colleagues go beyond simply looking at concordance and discrepancies between provider-reported and patient-reported KTPI; they examine the association of KTPI with a meaningful clinical outcome, namely listing for kidney transplantation. Unfortunately, it is challenging to understand the 20.9% listing rate in the study sample—and to examine it relative to KTPI—because reasons other than KTPI could lead patients to be listed or to be ineligible for kidney transplantation. Ultimately, one would want to know whether KTPI, and patient-reported KTPI in particular, facilitates evaluation for transplantation, regardless of ultimate listing status. Thus, to fully understand the role of KTPI and to better evaluate potential educational or other strategies to reduce inequities in access to transplantation, it would be critical to prospectively follow a cohort such as that identified by the authors. Such follow-up would improve understanding of the facilitators and barriers along the path through referral, evaluation, listing, and ultimately transplantation for these patients.

Salter and colleagues’ report supports the need to address both patient-level and systemic barriers to evaluation (and eventual listing) for kidney transplantation. Recent work has highlighted the role that peer navigators may play in enhancing kidney transplantation rates in vulnerable populations. Peer navigators provide support to individual patients in the evaluation process. They may expedite scheduling studies and may provide culturally appropriate education and support to vulnerable populations, such as ethnic minorities. Perhaps engaging peer navigators early in the dialysis center education process would improve the patient-reported KTPI rate as well.

At the stage of the evaluation for transplant, some centers now use fast-track evaluation clinics to provide “one-stop...
shopping” for testing and evaluation to expedite listing and increase equity in kidney transplantation. While this process addresses systemic barriers to testing and evaluation for the transplant candidates, fast-track clinics would not address the provision of information about the option of kidney transplantation in the referral stage. Could we devise strategies to “fast-track” the KTPI process for our dialysis patients, and thereby increase the likelihood of evaluation and eventual listing for transplant? As suggested by Salter and colleagues, the presentation and discussion of alternate treatment modalities are an important part of the consent process for dialysis. As such, their findings suggest that we should begin the process of KTPI very early—ideally, before the initiation of long-term intermittent dialysis. But just as informed consent is a process, and not a one-time event, KTPI is likely to require repeated emphasis thereafter because of the potential barriers to effective communication that we have noted. Moreover, merely documenting that KTPI has occurred is inadequate. We need to hear directly from patients that they are fully aware of their options and understand them.

REFERENCES


See related article, “Patient- and Provider-Reported Information about Transplantation and Subsequent Waitlisting,” on pages 2871–2877.

A Nomogram for the Prediction of Kidney Stone Recurrence

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In the 1980s, Ljunghall and Danielson reported a prospective study of renal stone recurrences. Among a group of 54 patients with their first episode of renal colic, 53% of the patients developed recurrences within an 8-year period, with the highest number of recurrences taking place during the first year after the initial renal colic episode. Fast-forward 30 years to the article by Rule et al. in this issue of JASN, in which the authors have commendably created the Recurrence of Kidney Stone (ROKS) nomogram using the medical records of >2000 residents of Olmsted County, Minnesota. Rule et al. selected participants who experienced a first kidney stone episode, determined their rate of recurrence over the ensuing years, and then, using a multivariable model, developed a tool to turn participants’ characteristics at baseline into estimates of recurrence at varying times. This article highlights several important aspects of kidney stone disease that are particularly relevant in this modern era of preventive medicine, from both the metabolic and surgical standpoints.

Using the simplest interpretation of the data, the nomogram provides clinicians with reasonable prediction values for the recurrence of stone disease. A majority of patients who come to the clinic (whether staffed by an internist, nephrologist, or urologist) with their first symptomatic kidney stone episode will immediately ask if it will happen again and what they might do to prevent it. We can confidently counsel them, based on the data presented here, that symptomatic recurrence rates are about 11% at 2 years, 20% at 5 years, and 31% at 10 years. At the

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