Getting More People TALKing About Kidney Transplantation

Despite the attestation from providers and professional organizations that effective patient education is a priority and an essential element of care, informing patients about the fundamentals of their kidney disease and their potential care plan choices remains an area that needs improvement. Although patients often identify their physician as their desired primary source of expert information, individuals under the active care of a nephrologist consistently report limited knowledge about their treatment options: in one study, only 53% of participants expressed having any knowledge about transplantation. Similarly, among patients who initiated dialysis in the United States between 2005 and 2007, 30% were not informed about kidney transplantation prior to initiating dialysis, which was associated with a 53% lower rate of eventually either being waitlisted or receiving a kidney transplant compared to those patients who were at least in some way informed. This finding is only partially explained by whether or not nephrology care had been established prior to dialysis. Even more concerning is that, when asked, fewer than 50% of patients recalled receiving specific educational counseling about kidney transplantation as an option before beginning dialysis. Accordingly, while we may be “informing” some of our patients about their care options, the quality of that conversation remains in question.

Few nephrology providers would argue against kidney transplantation as the optimal kidney replacement therapy to improve health and quality of life for those who are medically eligible. Accordingly, expanding kidney transplantation is a goal of Healthy People 2020, which presents the target of raising the proportion of eligible patients transplanted within 3 years from 17.9% to 19.7%, including increasing the number of preemptive kidney transplantsations. The nephrology community endorses and participates in chronic kidney disease (CKD) education programs. Although clinical trials are too sparse to demonstrate their impact, such programs are supported financially in the United States if they are delivered by specified medical personnel to Medicare beneficiaries with advanced CKD. Patients with CKD have diverse and complicated medical problems, and education programs cover a broad spectrum of information within a relatively short time, which is likely an attempt to maximize available resources. Accordingly, the details about transplantation are often only a small component, with much more content focused on dialysis preparation. If we really want improve the rates of kidney transplantation, then we must commit to it as a priority by investing the time and identifying strategies that optimize our expertise and resources.

In this issue of AJKD, Boulware et al describe the results of the Talking About Live Kidney Donation (TALK) Study. The objective of this study was to determine the impact of an educational program that emphasized preemptive living donor transplantation on the combined outcome of patient discussions with family or physicians about transplantation, identification of a potential living donor, and initiation or completion of recipient evaluation. A total of 130 patients with CKD stages 3 to 5, progressive disease, and anticipated eligibility for transplantation at an unspecified future time as determined by their primary nephrologist were enrolled from their academically affiliated or community nephrology practices and randomized to 1 of 3 groups: self-guided education, education with additional multisession psychosocial support delivered by a trained social worker, or usual care. Participants were followed over a 6-month period to assess their self-reported participation in activities related to kidney transplantation preparation. Among participants, 61 (47%) achieved at least 1 additional behavior of the 5 that composed the primary outcome, and discussions with family was the most common behavior reported. All groups made improvements in this study, although analyses suggested that, compared to usual care, the TALK education group and TALK social worker group were more likely to achieve an additional behavior, with a predicted probability of 30% (95% confidence interval CI, 20%-46%) for the usual care group, 42% (95% CI, 33%-54%) for the education group, and 58% (95% CI, 41%-83%) for the social worker group.

One key element in this randomized controlled trial was the educational video and booklet used in the TALK education and TALK social worker groups. There have been no other reports to date of clinical trials examining transplantation education programs prior to end-stage renal disease, although there are some in progress. Given the paucity of available transplantation-specific written resources that have been tested in clinical trials, these materials could benefit a wide range of users. The research team
specifically developed both the video and booklet for this study to be culturally sensitive by incorporating both African American and non–African American patients and families’ experiences and perspectives. In the 20 minute TALK video, patients, family members, and clinicians describe basic information about kidney disease and offer individual testimonies, which is complemented by the detailed information available in the paired 32-page booklet (available at: http://diseasemanagementboulware.org/talk-materials/). A unique component is the inclusion of model conversations that initiate discussions and help move patients through potentially awkward exchanges related to the emotional and ethical concerns of live donor transplantation. Notably, patients who are eligible for transplantation commonly report difficulty with deciding how to ask someone to consider being a donor, and the tools developed by Boulware and colleagues address this barrier directly. Study participants engaged with the educational materials during their initial enrollment visit, which occurred in their homes and was delivered by trained personnel. Interestingly, despite the relative intensity of this distribution method, not all study participants reported using the materials, with ~80% watching the video and ~75% reviewing the booklet. Although there is increasing interest in the use of home visits for care, including for CKD education, this resource may not be widely available. Perhaps this is an opportunity to consider health information technology solutions, such as video conferencing or other mobile platforms to convene within the patient’s specified social network. Whether patients who are not enrolled in trials or are in other settings take up and use such tools, and how they do so, will be important in determining the feasibility of integrating these and similar resources into clinical care.

The goal of increasing the number of patients who receive a preemptive transplant or are active on the waitlist may also be accomplished by using specific psychosocial counseling to overcome identified challenges related to a patient’s emotions as well as financial or other administrative barriers. While many practitioners may have important roles in preparing patients for transplantation, this study emphasizes the counseling skills of social workers, in addition to physician-delivered usual care, to support patients and families in this process. In the TALK study, 67% of participants in the social worker group attended both the individual and family member social work visits, although details about the number and type of family member participants are not reported. Accordingly, we are not able to draw conclusions about the relative impact of the individual versus family counseling components, and the concerns of family participants are not reported. Even though the identified social support family members participated voluntarily and special note was made that all discussions were designed to avoid coercion, there may remain ethical concerns related to the joint provision of facilitated kidney transplantation education. Individual support for donor candidates, or at least screening them for readiness, also may be necessary to limit potential donors’ stressors. In addition, participants themselves continued to report high levels of concern about medical risk and financial matters, regardless of randomization group.

While reliance on social work expertise is a strength of this study, we must be cautious, as the feasibility of its more widespread implementation may be limited. The Medicare education benefit permits billing for educational services provided to patients with CKD 4 or 5 in either individual or group formats, but the approved providers do not include social workers. Although social workers commonly are involved in the transplantation evaluation process once a patient has been referred and are required providers for those who are receiving dialysis, social workers are not uniformly included in clinics for CKD patients who have not reached kidney failure. Furthermore, dialysis social workers have cited high caseloads and numerous competing responsibilities as barriers to providing effective clinical counseling and interventions.

A final consideration is that the optimal timing for this type of educational resource for a patient with moderate or more advanced but relatively stable CKD remains unclear. The authors and others suggest that initiating discussions early is better, presumably to allow for the time needed to navigate the evaluation process for both participants and potential donors. Patient perspectives also support beginning discussions early, with many expressing the desire for more information earlier in their course of their disease before they become “too sick” to effectively process it and make decisions. However, this may result in a longer period of anxiety and concern that persists despite educational and psychosocial support. This study included patients with CKD stage 3 even though both the clinical trial registration and previously reported protocol specified including only CKD stages 4 and 5. Most transplant centers will not consider a referral until a patient reaches at least CKD stage 4, and, more often, only when the estimated glomerular filtration rate is closer to 20 mL/min/1.73 m². The short duration of this study did not permit sufficient evaluation of referral or participation in the transplant process. Furthermore, there is recent research suggesting that, although preemptive kidney transplantation is occurring more often and at higher estimated glomerular filtration rate levels, there has been little impact on mortality and there is potential harm related to not maximizing residual kidney function prior to any
kidney replacement therapy. This introduces additional uncertainty among providers about the timing of preemptive kidney transplantation, including when to refer and therefore also when to initiate discussions about transplantation.

Although additional research is needed, this trial provides tools and direction to be considered by physicians, social workers, and other kidney providers. Flexible and dynamic programs that evolve to meet the changing needs of patients and their social networks as they progress through the stages of CKD likely will have the greatest influence on understanding, behaviors, satisfaction, and clinical outcomes. The key is not revolutionary, but simply for providers to invest the time to talk and, more importantly, listen to their patients to meet their informational, psychosocial, and decisional needs, with the added emphasis on starting conversations early and repeating them often.

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REFERENCES