Must Health Literacy Be a Prerequisite for Kidney Transplantation?

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Patients with ESRD want kidney transplants! A study of the impact of health literacy on access of dialysis patients to transplantation in this issue of CJASN found 90% favoring transplantation as their preferred modality of therapy (1). Regardless of original kidney disease, age, gender, ethnicity, educational status, income level, dialysis provider, or health literacy, from a patient’s perspective, transplantation is the best option. Yet fewer than 25% of patients with ESRD have functioning transplants, and only 20% of dialysis patients populate transplant waiting lists despite estimates that perhaps as many as half would live longer with a transplant than on dialysis (2-4). Why does delivery of renal replacement therapy (RRT) in the United States, offered to all Medicare-eligible patients as an entitlement accompanied by a mandate to provide optimal services, deviate so markedly from their expressed preferences (5)?

Perhaps the patients studied by Grubbs et al. (1) do not represent most dialysis patients. Ayanian et al. (6) found that fewer than 40% of patients who began dialysis were aware of transplantation as an option, but after education regarding treatment modalities, the patients they studied in Alabama, southern California, Michigan, and the mid-Atlantic area expressed sentiments remarkably similar to the Bay Area patients in the article by Grubbs et al. (1): 80% wanted transplants. It must also be pointed out that both studies, by design, excluded the 50% or so of kidney transplant recipients who had successfully navigated the “system” enabling transplantation either preemptively or within the first year of RRT (7). How intense is the preference for transplantation? An increasing number of Americans, recognizing the roadblocks in our current system, now travel abroad seeking transplants under often unsavory circumstances (8). Our response? Castigation, fines, and, potentially, criminal penalties (9). In what other circumstance do we punish desperately ill patients in search of healing?

Perhaps the patients are wrong: The perceived health benefits of transplantation are illusory. Indeed, a recent study documented that patients awaiting transplantation overestimate the relative quality-of-life benefit associated with transplantation (10). Likewise, not all dialysis patients are transplant candidates; however, the ongoing attempt to better allocate the available kidneys from deceased donors in the United States documents a longevity benefit of transplantation over dialysis for virtually every definable category of patient with ESRD and estimates quality of life among dialysis patients as 20% less than with a functioning transplant (11). Among 350,000 dialysis patients in the United States, as many as 120,000 who might benefit are not listed for transplantation (2).

It is also true that perhaps 30% of the waiting list is inactive at any given time, a statistic used as evidence that the waiting list overestimates demand (12,13). Most, however, are inactive as a result of either self-limited illness (the original stated purpose of creating an inactive category) or bureaucratic delays. Although arbitrary policies shift more posttransplantation financial responsibilities to the patient, third-party payers know transplantation is the least expensive modality of therapy (7). No, in the face of the objective data available, it is difficult to contend that patients are misguided in their expressed preferences. How many of us would choose years of dialysis for ourselves or our loved ones in equally challenging circumstances?

If the problem is not patient perceptions, then where does it lie? I fear it rests with an ESRD program that evolved at a time when dialysis was the only viable option for the vast majority of patients, with transplantation, thought to “cure” ESRD, almost an afterthought (14). Today, such a dichotomous view is no longer relevant; Centers for Medicare and Medicaid Services guidelines mandate a team-oriented approach to dialysis and transplantation to ensure optimal care (15). No longer can anyone involved in the process view a kidney transplant (with delivered estimated GFR of 50 to 60 ml/min) as a cure. Rather, transplantation provides the best outcomes of available RRT modalities. Given that most practicing nephrologists seek to offer the most effective treatment options for their patients, why must one be health literate to access optimal care in a system such as ours?

The study by Grubbs et al. (1) adds a new dimension to the debate, confirming the importance of accurate education in delivering optimal RRT. Unfortunately, some of the conclusions of this study may not be generalizable. First, as the authors acknowledge, the response rate is low; perhaps patients most inclined to favor transplantation were the ones willing to be interviewed. Second, the sample size is admittedly very small. Finally, the evaluation process at the Bay Area’s largest program is very different from most. Because of a waiting list that exceeds 3000 patients and with an allocation system based primarily on waiting time, many patients are placed on the waiting list without completing a traditional evaluation process (Vincenti F, University of California, San Francisco, CA,
personal communication, October 21, 2008) (16). Thus, conclusions of Grubbs et al. (1) that the biggest barrier to placement on the waiting list is referral may be true in the Bay Area but not elsewhere. At most centers, access to transplantation follows the more complex algorithm described by Alexander and Sehgal (17): Disadvantaged patients fail to progress at multiple steps in the process. Why is transplantation not the default position in RRT? Changing the current paradigm is one of the major challenges facing the transplant community. Our ability to deliver the promise of kidney transplantation to all those who would clearly benefit will require a multifaceted effort (18). It begins with routine identification of impending kidney failure early enough to allow early education and, when feasible, the very best of alternatives: Preemptive transplantation. Current regulations mandating education and referral of dialysis patients for transplantation remain loosely defined and erratically monitored. Transplant centers, as the repository of the most up-to-date information regarding risks, benefits, and candidacy for kidney transplantation, must be given resources to ramp up educational and evaluation efforts to meet the latent demand defined in this study. Finally, although much has been accomplished, much more must be done to increase availability of kidneys, especially from living donors (12,19). Improving health literacy among patients with ESRD, without commensurate improvements in overall access to transplantation will, I fear, prove to be a hollow achievement indeed.

Disclosures

None.

References
