Study finds shortcomings in doctor-patient discussions about transplantation

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In a study of dialysis patients, those who reported that they had discussed the option of transplantation with clinicians were more likely to be put on the transplant waiting list; however, clinician-reported discussions of transplantation did not increase patients' likelihood of being waitlisted. The findings, which appear in an upcoming issue of the *Journal of the American Society of Nephrology (JASN)*, indicate that better ways of informing patients about kidney transplantation may be needed.

One of the key principles of informed consent is describing alternative treatments. So when starting someone on hemodialysis, it is imperative to discuss the alternatives to hemodialysis, for example peritoneal dialysis and kidney transplantation. The Centers for Medicare & Medicaid Services (CMS) believe the discussion of kidney transplantation is so important that they mandate it. Unfortunately, though, there is no guidance as to what kind of discussion is required.

Dorry Segev, MD, PhD (Johns Hopkins University School of Public Health) and his colleagues asked 388 patients if providers (kidney specialists or dialysis staff) had discussed transplantation with them, and then they looked to see whether the providers reported to CMS that they had discussed transplantation with those patients.

The investigators discovered that in almost one-third of cases, providers reported to CMS that they had discussed transplantation with a particular patient, but the patient said that nobody had discussed it with them. Such discussions were reported by both patient and provider for 56.2% of
participants, by provider only for 27.8%, by patient only for 8.3%, and by neither for 7.7%.

The researchers also discovered that patient-reported discussions about transplantation were associated with a nearly 3-fold increased likelihood that patients would be listed for transplantation, but provider-reported discussions did not increase a patient's likelihood of being listed. In other words, it didn't matter if the provider reported discussing transplantation with the patient; it was only if the patient reported receiving this information that led to him or her to being referred for and listed for a transplant.

"This is a critical lesson for quality improvement in the care of patients with end-stage kidney disease: it's not enough to ask physicians if they provided information to the patient, but rather we need to be asking the patient, because there is major discordance between patient and provider reports, and only the patient report was associated with the expected clinical behavior," said Dr. Segev.

In an accompanying editorial, Mark Unruh, MD (University of New Mexico School of Medicine) and Mary Amanda Dew, PhD (University of Pittsburgh School of Medicine and Medical Center) noted that that "even the best educational efforts will be for naught if the patient does not take in the information or understand it." They cautioned, however, that the form submitted to CMS has been recognized as providing an important but inexact snapshot of patients with kidney failure and other conditions. They also stressed that providing kidney transplant information likely requires repeated discussions when patients are open and able to receive it.

**More information:** The article, entitled "Patient- and Provider-Reported Information about Transplantation and Subsequent Waitlisting," will appear online at jasn.asnjournals.org/ on August 28,

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