A Critical Role for Shared Decision-Making about Referral and Evaluation for Kidney Transplant

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Progression of advanced kidney disease prompts a range of complex care decisions. Primary nephrologists are optimally positioned to support patients with kidney failure in making individualized decisions about how and whether to pursue treatment options, including transplant, dialysis, and conservative care. Kidney transplant is a valuable treatment option for many of these patients, but the availability of deceased donor kidneys is far outstripped by demand, and not all patients have a willing and eligible living donor. These features necessitate a unique process of patient evaluation and selection and ultimately limit the number of patients who will receive a kidney. Early education and discussion about treatment options is critical both to promote fair access to treatment across the population and to tailor care to individual needs. However, there are likely unique and interrelated barriers to engaging patients in shared decision making about kidney transplant (1).

In a recent edition of Kidney360, Barrett and colleagues describe the experience of a group of patients with advanced kidney disease regarding discussions about dialysis and transplant with their primary nephrologists (2). The researchers leveraged data from the Talking About Living Kidney Donation (TALK) trial to describe perceived completeness of discussions about these kidney replacement therapy (KRT) options. Among 130 participants with advanced kidney disease, 82 reported discussions about KRT, including 51 (39% of the full cohort) who reported complete or mostly complete discussions about dialysis and 35 (27% of the full cohort) who reported complete or mostly complete discussions about transplant. Among the 82 participants who reported any discussion of KRT, less than half (41%) reported complete discussions about both treatment modalities. Concerningly, among participants who reported discussion of KRT options, female sex was associated with a lower frequency of complete discussions about transplant (37% for women versus 63% for men). The authors also report less frequent complete discussions about transplant compared with discussions about dialysis among participants with high school or less education (49% with discussion about transplant versus 77% with discussion about dialysis) or low-income (33% versus 81% respectively), females (28% versus 55%, respectively), and Black participants (47% versus 72%, respectively) among participants who discussed KRT. These findings identify a need to understand factors shaping early discussions about KRT options as well as a need to ensure that underserved groups have the opportunity to consider transplant as a treatment option.

In an effort to address glaring disparities in access to kidney transplant among racial minority groups and other underserved populations, empirical work and policy initiatives have focused on the most visible steps in the transplant process, including waitlisting for deceased donor transplant and receipt of a kidney. However, these disparities represent the end outcome of a complex process of referral, evaluation, and selection, which occurs before waitlisting (Figure 1). Clinical and nonclinical barriers or delays at any of these steps—including education and discussion about transplant with a local kidney care provider—may disproportionately affect underserved groups (3,4). Indeed, changes to the United Network of Organ Sharing kidney allocation system in 2014 attempted to account for delayed access to waitlisting by conferring retroactive credit for time since initiation of dialysis (5). However, this post hoc maneuver cannot fully counteract barriers to completing early steps in the transplant process, which may preclude preemptive transplant or bar waitlisting. Concerns about equity in access to transplant have fueled efforts to support education, engagement, and shared decision making about this treatment option for a broader swath of patients (1).

Although there has been appropriate emphasis on the value of early education and discussion for improving equity in access to transplant, shared decision making about this treatment option also serves a complementary role in supporting more person-centered care. Transplant can offer greater longevity and improved quality of life compared with remaining on dialysis for many people with kidney failure. However, the risks of transplant surgery and lifelong immunosuppression may not be acceptable for some patients, and many will prefer to pursue dialysis or conservative care treatment options. Further, the transplant evaluation and selection process itself tends to be more
extensive and rigorous than other types of preoperative evaluations and can be highly burdensome and emotionally taxing for patients and their family members (4,6). Even among those who complete this process, many will not be considered transplant candidates. These considerations may be especially relevant for the growing population of older adults with kidney failure who can be both more vulnerable to complications and incidental findings resulting from the extensive tests and treatments required as part of the transplant evaluation and less likely to ultimately benefit by receiving a kidney. The opportunity to receive a transplant is also a major determinant of prognosis for patients with kidney failure, and hopes to receive a kidney may shape broader expectations about longevity and decisions about other treatment modalities (7). Honest discussion about the trade-offs involved in transplant therapy, the experience of engaging in the transplant evaluation, and the likelihood of receiving a kidney is necessary to ensure that patients are informed and able to engage in shared decision making about this treatment option.

Despite the clear value of shared decision making about transplant for patients with kidney failure, there are likely unique barriers to engaging patients on this topic. The transplant evaluation and selection process is typically orchestrated by transplant centers and can be somewhat opaque for primary nephrologists and other local care providers (4), limiting their ability to counsel patients effectively about what to expect from the process. Justification for required tests and treatments may be unclear, and the diagnostic approach may seem rigid to local providers, leaving them with little agency to tailor the process to meet individual patient needs. Further, candidate selection criteria vary between transplant centers, can change over time, and are rarely explicit, which may make it difficult for primary nephrologists to offer realistic expectations about likely experience and outcomes of the process for individual patients. Nephrologists may also perceive a responsibility to act as a gatekeeper for a limited societal resource, and this role can conflict with their concurrent wish to advocate for individual patients (8). Lack of specific selection criteria means that local nephrologists may be left to make their own determinations about candidacy, which may vary between providers and can be subject to implicit biases. Subjective judgments about adequate social support or degree of adherence to medical recommendations can also be associated with race, ethnicity, and other social determinants of health, exacerbating disparities in access to transplant (9).
tend to focus squarely on the needs and preferences of individual patients, and clinical bioethics frameworks often coach providers to explicitly exclude considerations of resource limitation. However, in discussions about kidney transplant, the context of scarcity inevitably shapes patients’ experience and constrains options. Uncertainty or discomfort about how to communicate and integrate these relevant contextual features into discussion may limit providers’ ability to truly engage patients in shared decision making. Lack of honest conversations about selection criteria and unrealistic expectations (7) may leave patients with the perception that the transplant selection process is arbitrary or unfair (4).

As patients with kidney failure prepare for end-stage disease and initiate complex treatments, their life experiences, needs, and preferences will evolve and their interest and capacity for discussing and engaging in the transplant evaluation process may be dynamic. Indeed, the transplant evaluation can compete with or distract from other decision making for patients who may be simultaneously grappling with dramatic lifestyle changes and existential distress related to progressive kidney disease and initiation of dialysis (10). For these reasons, shared decision making about transplant may be better conceptualized as an ongoing process rather than a discrete event. The timing and detail of discussions about transplant and degree of engagement in the transplant evaluation must be tailored to the broader context of patients’ lives and care plans.

Coordinated efforts among national policy makers, transplant center teams, and local providers are needed to support the kind of patient engagement in decision making needed to improve person-centeredness and fairness of the transplant process. First, transparent, standardized, and specific candidate selection criteria would alleviate the need for local nephrologists to make their own determinations about candidacy and allow them to focus instead on how best to support and advocate for their patients within established and explicit parameters. A streamlined evaluation process and communication and coordination between transplant center teams and local providers would support nephrologists in helping their patients navigate and tailor the evaluation process to individual needs. Finally, an adapted model of shared decision making is needed to facilitate honest discussion about how limited kidney transplant resources shape patients’ opportunities and experiences such that they understand and are empowered to engage in the range of choices that they do have (6).

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References

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