

# What Else Can We Do to Ensure Transplant Equity for High-Risk Patients?

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The vision statement of the United Network of Organ Sharing is “to promote . . . equitable organ allocation and access to transplantation” (1). However, blacks, who make up 31% of all patients with ESKD (2), continue to be less likely to be referred for transplant, waitlisted, or receive transplants compared with whites (2,3). In their paper “Transplant center patient navigator and access to transplantation among high-risk population,” Basu *et al.* (4) reported on a very well designed and well executed randomized, controlled trial examining the effect of a patient navigator intervention on increasing waitlisting rates among disadvantaged patients in need of transplants. The disparities seen nationwide are even larger in the state of Georgia, which has the second lowest rate of transplant in the nation.

In the last 10 years, many patient, provider, system, and policy interventions to improve access to transplant have been recommended and tested (5–7). At a Consensus Conference on Best Practices in Live Kidney Donation, for example, 67 leaders aligned around recommendations to reduce racial disparities that included removing financial disincentives to transplant; implementing culturally tailored, community-based education at multiple stages of the transplant referral process; engaging a transplant liaison; and developing a research strategy to better understand transplant disparities (8).

Basu *et al.* (4) examined the effectiveness of a transplant center–based patient navigator approach that addressed many of these recommendations with the goal of increasing waitlisting for high-risk patients. Of all patients referred for transplant at Emory, 37% were deemed to be high risk, which was defined as <40% chance of waitlisting on the basis of a risk assessment algorithm that incorporated race, education, language, and other factors.

During the 3-year study, the patient navigator spent an average of 1.7 total hours with each patient in the intervention condition across an average of eight encounters per patient. Navigator support involved providing education about dialysis and transplantation, appointment reminders, weight loss interventions, interpretative services, and arranging Medicaid-funded transportation. Even after this comprehensive and time-intensive intervention, Basu *et al.* (4) found, after a median 2.4 years of follow-up, that waitlisting was not

significantly different among the patients in the intervention group versus control patients. However, patients in the intervention group were three times more likely to be waitlisted after 500 days (hazard ratio, 3.3; 95% CI, 1.2 to 9.1) and had more living donor inquiries (18% versus 10%;  $P=0.03$ ).

This study’s findings reveal more about both the challenges inherent in helping high-risk patients get waitlisted and the complexity of the solution. First, regardless of condition, after a median of 2.4 years from referral, only 29% of high-risk patients were waitlisted. With the time to a deceased donor transplant after waitlisting in Georgia averaging a little over 3 years, this finding shows that it is a long road, first to waitlisting and then to transplant, for many racial/ethnic minorities and patients facing greater socioeconomic challenges to transplant.

Second, even after the comprehensive intervention, there was only a 6% improvement in waitlisting rates and an 8% increase in living donor inquiries. Said simply, ten additional patients were placed on the waiting list and 14 additional living donor inquiries occurred over 2.4 years as a result of the hard work of the navigator compared with the standard communication and education occurring within the transplant center. This ratio of effort expended by the navigator to increased access to transplant is very low, although it is difficult to consider what else the navigator could have done. However, a greater number of navigator encounters per patient was associated with both starting and completing the evaluation and higher waitlisting rates. This may speak to the greater value of the navigator for patients who are more ready or motivated to pursue transplant (9).

Also of interest is the finding that, after 500 days, patients in the intervention group began to have higher rates of waitlisting versus the control patients. Further research should continue to explore why this emerged, but some combination of the lessening of communication by transplant coordinators after evaluation and the greater benefit of external support as patients grow wearier might be at play. Like people joining a gym in January to lose weight, people who hire a personal trainer have greater success continuing with their workout regime after their initial excitement lapses and as the normal challenges of life combat for time. It will be important, in future work, to gauge which

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time points and subgroups would most benefit from navigator support. The use of supplementary resources, such as video education or email or text message reminders, might also continue patient engagement with the transplant center over time with less navigator burden.

Third, this study showed the high levels of challenges faced by patients in this study presenting for transplant. For example, at least 30% of the high-risk patients had to drive over 75 miles to get to the transplant centers, had only completed high school, and received Medicaid. An ability to screen for levels of potential transplant derailers ahead of time may also allow for the implementation of targeted interventions.

This single-center study had several limitations. One limitation to this particular study and achieving a large effect may have been the use of only one patient navigator, which would limit the number of patients in the intervention and the number of encounters per patient. Another limitation may be that encounters with the patient were primarily one on one and did not often include the patient's support system. Finally, it is hard to know if this study was culturally sensitive to the intervention group, because there is limited information on how minorities and high-risk populations make kidney transplantation decisions (5).

The continuing disparities in waitlisting and transplant rates for high-risk patients are a challenge for the entire field of kidney transplantation. Although the results of the study by Basu *et al.* (4) may be discouraging, the field must continue to examine multifaceted intervention approaches to resolve the disparity, increase waitlisting, and in the end, increase kidney transplantation for high-risk patients. Interventions need to address every level of the kidney transplant system—providers, health care systems, patients, family, and the community at large (8). Interventions also need to be timed for the best efficacy, and they must be culturally sensitive to the population that they are addressing.

In closing, based on OPTN data as of February 14, 2018, in the United States in 2017, 2710 blacks died or were removed from the waiting list, because they were too sick to transplant. It is unknown how many high-risk patients of different races and ethnic backgrounds died on dialysis during that year who never completed waitlisting at transplant centers. The stakes for high-risk patients are too great to give up the search for solutions to educate and ensure them equal access to transplant.

## Disclosures

A.D.W. owns the intellectual property to the transplant education product Explore Transplant and has licensed it at no-cost to a nonprofit, Health Literacy Media, who retains all sales revenue.

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See related Patient Voice and article, “An Evolving Continuum of Care for the Kidney Disease Patient Will Help the Transplant Center Patient Navigator,” and “Transplant Center Patient Navigator and Access to Transplantation among High-Risk Population: A Randomized, Controlled Trial,” on pages 519–520 and 620–627, respectively.