

An Evolving Continuum of Care for the Kidney Disease Patient Will Help the Transplant Center Patient Navigator

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The article in this issue of the *Clinical Journal of the American Society of Nephrology* titled “Transplant center patient navigator and access to transplantation among high-risk population: A randomized, controlled trial” (1) represents a positive step in highlighting and overcoming existing barriers to kidney transplantation access facing minority patients and patients with low socioeconomic status. The article provides a comprehensive approach to support and guidance systems targeted at high-risk patients seeking transplant assessment to lead to placement on the kidney waiting list. For patients, the most desired kidney replacement therapy is a kidney transplant. The challenge for patients is navigating the continuum of kidney disease care from initial identification of kidney-related issues, such as hypertension, diabetes, or proteinuria, to dialysis to ultimately receiving a kidney transplant. As pointed out by Patzer and coworkers (1), minorities and patients with low socioeconomic status face additional challenges, such as insurance coverage issues, lack of a support network, poverty, and limited education about transplantation.

It remains unsettling the lack of progress made in decreasing disparities, especially with respect to living donor kidney transplantation (LDKT). According to the conclusions of a recent study, disparities in the receipt of LDKT increased from 1995–1999 to 2010–2014 (2). Another approach to increasing knowledge about LDKT was the use of a website intervention targeted at the Hispanic/Latino population, which is the fastest growing minority in the United States (3). This approach is an eHealth solution that addresses the lack of transplant education within a minority population explicitly. Hence, the need for targeted interventions for high-risk study populations is essential to decreasing disparities.

The concept of a patient navigator is not new. The article refers to social worker or patient navigator interventions as well as using trained transplant recipients to assist in guiding patients in completing the stages to gaining access to the kidney waiting list. The study referenced in this article used a trained social worker who worked independent of the transplant team. I applaud the efforts made to build on the work of others to develop an efficient navigator process for the

patients who statistically fare the worst in obtaining a kidney transplant. Although the findings of the study indicated that the total effect on improving waitlisting of disadvantaged patients was relatively small and only observed after 500 days of follow-up, I do see value in further fine tuning the concept. One suggestion is to further build on the navigator concept by combining the efforts of the trained social worker and a patient peer. I see the worth in the independently functioning social worker. Moreover, I envision the patient peer, with professional guidance, being able to improve on the waitlisting of the target population. I think that the patient peer will connect and motivate a fellow patient, whereas the social worker’s efforts will be better received and more productive. The synergy of the team effort will produce results that should improve outcomes. I also look at the context of the study as necessary. The context is that the transplant center in this study has the highest number of blacks in the nation and is in a southeastern state with the lowest rate of kidney transplantation in the United States. This transplant center is reflective of the challenges that must be boldly, publicly, and transparently addressed to decrease disparities between minorities and nonminorities.

The medical professional and medical research community have continued to make significant strides on issues related to access and treatment in the few years since this study was executed. This progress among professionals is quite crucial, because although most patients with kidney disease view kidney issues as occurring along a lifelong disease continuum, the reality is that our care is coordinated and delivered through a disconnected system characterized by separate and disconnected silos. For example, patient perceptions are that primary care physicians do not interact with nephrologists as much as desired. Similarly, nephrologists do not regularly interact with transplant surgeons. Dialysis providers have little interaction with Organ Procurement Organizations (OPOs) and a mixed record, at best, of being fully engaged in achieving better organ transplantation rates. The net results of this are that patients and caregivers often become, by default, the critical source of support and follow through to achieve positive outcomes—regardless of the other burdens that

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they are managing. I believe that the new Quality Improvement Programs started by the ESRD Networks will have a positive effect on improving dialysis facility engagement in transplant referral and waitlisting of their patients if strategies, such as the navigator concept, are embraced. Otherwise, an extensive learning curve may not facilitate meaningful progress in a reasonable timeframe.

The concept of patient engagement is still being refined across the medical community, but it has, at least in principle, been embraced by the medical community as an essential element to developing solutions to the long-term issues related to access and treatment disparities among populations at high-risk of CKD and ESRD. Today, minority and other high-risk patients are participating in health care deliberations and innovations in substantive and meaningful ways across nearly every sector in health care. These include the federal government, the private sector, academia, and primary nonprofit stakeholder organizations. I am very proud of the fact that, every week, the organization that I help to lead, the American Association of Kidney Patients (AAKP), is contacted by medical professionals and researchers seeking specific types of patients for more direct involvement in initiatives aimed at improving patient outcomes, especially among minorities. The demand is so significant that the AAKP initiated the National Ambassadors Program less than a year ago. The National Ambassadors Program is now in over 44 states. We have patient leaders plugging patients into emerging research and advisory opportunities to help tackle these issues.

On December 19, 2017, I attended the Kick-Off Meeting of the Living Donor Coalition. The Living Donor Coalition is being organized by the American Society of Transplantation and the American Society of Transplant Surgeons in a partnership with the Health Resources and Services Administration Division of Transplantation. The encouraging aspect of the collaboration is how strategically far sighted and inclusive the coalition and coalition agenda is—it includes the Agency for Healthcare Research and Quality, the Alliance for Paired Donation, the AAKP, the American Society of Nephrology, the Association of Organ Procurement Organizations, the John Brockington Foundation, the Centers for Medicare and Medicaid Services (CMS), Donate Life America, NATCO (the organization for transplant professionals), the National Institutes of Health, the Organ Donation and Transplantation Alliance, ORGANIZE, the Scientific Registry of Transplant Recipients, the Transplant Recipients International Organization, and the United Network for Organ Sharing.

The coalition is committed to protecting and supporting living donors, removing barriers to donation, and promoting a positive patient experience. As the only patient attending this gathering, I reflected on the patient perceptions that I referenced above and felt very positive about the possibilities of addressing disparities on the basis of the commitment and the fact that I was in the room.

In the national scene, another positive occurrence is that the CMS requires the ESRD Networks to put more emphasis on transplantation and the transplant waitlist. To accomplish this contract objective, networks, providers, OPOs, and many of the stakeholder organizations listed above must now become more engaged with each other.

As strategy evolves, the stakeholders are realizing that, to achieve success (higher quality, better outcomes, and lower costs), an integrated system that encompasses all professionals and practices that affect the patient must emerge. Of course, the foundation of the framework is shared decision making, which is often referred to as the apex of patient-centered care (4). After this framework is in place, disparities can be better addressed, and patients can look forward to more meaningful health care and a better understanding of what they own in terms of their respective responsibilities. Perhaps then, innovative programs, such as the Transplant Center Patient Navigator, will be even more efficient due to the higher emphasis and resources targeted toward transplantation all along the full kidney disease continuum.

Acknowledgments

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Disclosures

None.

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See related editorial and article, “What Else Can We Do to Ensure Transplant Equity for High-Risk Patients?,” and “Transplant Center Patient Navigator and Access to Transplantation among High-Risk Population: A Randomized, Controlled Trial,” on pages 529–530 and 620–627, respectively.