



Changing Perceptions of Health Care Among Patients With Kidney Disease

Beatrice P. Concepcion, MD; Milda R. Saunders, MD, MPH

Kidney transplantation is the treatment of choice for patients with advanced kidney disease, as it not only offers improved survival and quality of life but also offers cost savings to the health care system.¹ However, the transplantation process is usually complex, involving numerous steps that patients must navigate while interfacing with the transplant team. Donor kidneys are a scarce resource, and kidney transplantation involves major surgery, so an extensive evaluation is conducted to determine a candidate's suitability for a transplant. The donor evaluation involves a comprehensive medical and psychosocial evaluation, which includes but is not limited to laboratory, radiologic, and cardiac testing; consultation with specialists; and a multidisciplinary assessment.² Pursuing a transplant can be both daunting and burdensome for patients. The decision-making process can seem opaque, leading to patient uncertainty, medical mistrust, and perceived discrimination and racism.

Vélez-Bermúdez et al³ examined the impact of a concierge-based, streamlined kidney transplant evaluation, the Kidney Transplant Fast Track, on patients' self-reported experiences and perceptions of health care. The Kidney Transplant Fast Track intervention provided patients with transplant center evaluation and testing on the same day and was complemented with coordinator and scheduling support, as opposed to having patients schedule and complete tests on their own.⁴ Among the 820 patients who completed the program and were surveyed, the study found that after undergoing the intervention, both Black and White participants experienced a significant reduction in discrimination and medical mistrust in health care, and Black participants reported lower perceived racism. Interestingly, after the evaluation, Black participants reported higher mistrust in physicians.

The authors—and the readers—are left to wonder why a streamlined transplant evaluation may increase physician mistrust among Black patients. Due to efficient scheduling, patients saw many physicians on their initial evaluation day and received a lot of information. Unclear or conflicting information could increase patient mistrust.⁵ Additionally, Black patients may have experienced poor communication or negative interactions with the physicians during the evaluation. Prior work has found that physicians provide lower quality communication with their Black patients compared with their White patients; physicians' communication with Black patients has been characterized as being less patient centered and as providing less information to Black patients compared with their White counterparts.⁶

The findings of the study are encouraging overall and suggest that shepherded interaction with the health care system may improve patients' perceptions of health care. One limitation, which is also pointed out by the authors, is that there was no comparison group to assess whether the improvements observed were associated with the intervention itself. Additionally, the authors did not analyze patient perception with time in the evaluation or with the evaluation outcome. The analysis would have been more robust if participant experiences were examined within the context of evaluation processes and outcomes.

Interventions to improve trust and reduce perceived (and actual) discrimination and racism in the transplant process are desperately needed. Vélez-Bermúdez et al³ should be commended for this health system–level intervention, but arguably, a concierge-based approach to transplant evaluation should be the standard of care for all transplant programs. Furthermore, providing patient education and logistical support during the transplant evaluation should be viewed only as the first step in addressing patient mistrust and perceptions of discrimination and racism. Greater transparency is necessary across the spectrum of the transplant process, including the criteria used to determine whether a candidate is suitable for transplantation.⁷ Criteria should not only be transparent but also

+ Related article

Author affiliations and article information are listed at the end of this article.

Open Access. This is an open access article distributed under the terms of the CC-BY License.

well-defined and applied equally. Assessments should be objective and standardized, particularly for psychosocial evaluations when clinicians assess patients' adherence and social support. Additionally, transplant center staff must provide effective and ongoing communication with patients to ensure that they understand why tests and consults are necessary, what the results mean, and how this information is used in decision-making regarding their care and transplant eligibility.

The complexity of the transplant evaluation process and the lack of transparency in decision-making not only breeds negative perceptions of physicians and the health care system, it also can lead to disparities in access to transplantation. For example, the need for dental clearance can make transplant prohibitive for patients who lack dental insurance or who cannot find a dentist who will accept their insurance. In addition, many patients experience delays in cancer screening (eg, colonoscopies, Papanicolaou tests, and mammograms) because they are disconnected from primary care. It is sobering to note that despite the intervention in this study, 27% of participants did not complete the evaluation, or the evaluation was closed, with a higher percentage among Black (38%) compared with White (23%) participants. In addition, it took a mean of 6 months for participants to complete the evaluation, and it was longer for Black (228 days) compared with White (170 days) patients. At baseline, the 2 groups were similar on health literacy, education, and social networks—all issues used to explain transplant disparities.⁵ Despite these similarities, White patients had greater transplant knowledge and preevaluation learning, which could reflect, in part, differences in nephrology care.⁵ These findings are consistent with known and well-described racial disparities in access to transplantation.⁸

Efforts to better understand underlying reasons for these outcomes, both positive and negative, should be undertaken. Additional system and clinician-level interventions should be pursued, particularly for Black and other racial and ethnic minoritized candidates.⁵ Ultimately, transplant centers should look toward their own processes to ensure that patients are supported, barriers are removed, and practices are equitable and transparent. There is certainly a lot more to be done.

ARTICLE INFORMATION

Published: November 26, 2024. doi:[10.1001/jamanetworkopen.2024.47343](https://doi.org/10.1001/jamanetworkopen.2024.47343)

Open Access: This is an open access article distributed under the terms of the [CC-BY License](https://creativecommons.org/licenses/by/4.0/). © 2024 Concepcion BP et al. *JAMA Network Open*.

Corresponding Author: Milda R. Saunders, MD, MPH, Department of Medicine, The University of Chicago, 5841 S Maryland Ave, MC2007, Chicago, IL 60653 (msaunders@uchicago.edu).

Author Affiliations: Section of Nephrology, Department of Medicine, The University of Chicago, Chicago, Illinois (Concepcion); The University of Chicago Transplant Center, Chicago, Illinois (Concepcion, Saunders); Section of General Internal Medicine, Department of Medicine, The University of Chicago, Chicago, Illinois (Saunders).

Conflict of Interest Disclosures: None reported.

REFERENCES

1. Hariharan S, Israni AK, Danovitch G. Long-term survival after kidney transplantation. *N Engl J Med*. 2021;385(8):729-743. doi:[10.1056/NEJMra2014530](https://doi.org/10.1056/NEJMra2014530)
2. Chadban SJ, Ahn C, Axelrod DA, et al. KDIGO clinical practice guideline on the evaluation and management of candidates for kidney transplantation. *Transplantation*. 2020;104(4S1)(suppl 1):S11-S103. doi:[10.1097/TP.0000000000003136](https://doi.org/10.1097/TP.0000000000003136)
3. Vélez-Bermúdez M, Leyva Y, Loor JM, et al. Health care perceptions and a concierge-based transplant evaluation for patients with kidney disease. *JAMA Netw Open*. 2024;7(11):e2447335. doi:[10.1001/jamanetworkopen.2024.47335](https://doi.org/10.1001/jamanetworkopen.2024.47335)
4. Bornemann K, Croswell E, Abaye M, et al. Protocol of the KTFT-TALK study to reduce racial disparities in kidney transplant evaluation and living donor kidney transplantation. *Contemp Clin Trials*. 2017;53:52-59. doi:[10.1016/j.cct.2016.11.011](https://doi.org/10.1016/j.cct.2016.11.011)

5. Harding JL, Perez A, Snow K, et al. Non-medical barriers in access to early steps of kidney transplantation in the United States—a scoping review. *Transplant Rev (Orlando)*. 2021;35(4):100654. doi:10.1016/j.trre.2021.100654
6. Shen MJ, Peterson EB, Costas-Muñiz R, et al. The effects of race and racial concordance on patient-physician communication: a systematic review of the literature. *J Racial Ethn Health Disparities*. 2018;5(1):117-140. doi:10.1007/s40615-017-0350-4
7. Butler CR, Wightman A, Richards CA, et al. Thematic analysis of the health records of a national sample of US veterans with advanced kidney disease evaluated for transplant. *JAMA Intern Med*. 2021;181(2):212-219. doi:10.1001/jamainternmed.2020.6388
8. Wesselman H, Ford CG, Leyva Y, et al. Social determinants of health and race disparities in kidney transplant. *Clin J Am Soc Nephrol*. 2021;16(2):262-274. doi:10.2215/CJN.04860420