Learning From the Experiences of Undocumented Immigrant Kidney Transplant Recipients—From Exceptional Individuals to Equitable Systems

Anna Morenz, MD; Yue-Harn Ng, MD, MPH; Catherine R. Butler, MD, MA

Kidney transplant can offer improved quality of life and greater longevity compared with dialysis for many people with end-stage kidney disease (ESKD). In the US, deceased donor organ allocation policies dictate that scarce donor kidneys be allocated in a way that supports both effective utilization of organs and equitable distribution. For undocumented immigrants with ESKD, transplant is a highly valuable treatment option. However, about half of undocumented immigrants were uninsured as of 2023,¹ and concerns about the ability of uninsured individuals to maintain posttransplant follow-up and long-term immunosuppression means that this group is regularly excluded from transplant candidacy. To date, 5 US states offer insurance coverage for transplant to undocumented immigrants with ESKD;²,³ but in most states, including Colorado, transplant centers may require undocumented immigrants to personally secure sufficient funding for insurance premiums and copays before being considered as candidates for transplant. In a new study by Rizzolo et al,⁴ the authors shed light on the striking experience of undocumented immigrants with ESKD who managed—despite the odds stacked against them—to receive a kidney transplant.

Rizzolo and her colleagues interviewed 15 undocumented, Spanish-speaking transplant recipients and 10 of their family members in Colorado. Most reported less than a high school education and 60% spoke limited or no English. Until a change in coverage policies under Colorado Emergency Medicaid in 2019, the individuals in this study lacked access to routine outpatient dialysis, leaving them to rely on emergency-only dialysis. This experience has been previously described as traumatic and life-threatening.⁵ Participants described clinical care and education about kidney replacement therapies during this time to be overtly discriminatory, and the option for transplant was rarely discussed. After initiating routine outpatient dialysis, a stable treatment schedule as well as greater education about transplant offered hope for a better quality of life. However, messaging from dialysis facility staff about access to transplant for undocumented immigrants seemed to emphasize insurmountable financial barriers and could be disparaging or misleading. Given this limited support from their health care team, peers became a key source of information about avenues for obtaining needed health insurance and encouragement to pursue transplant.

After securing insurance, participants faced additional hurdles in the transplant evaluation and selection process. They reported anxiety and uncertainty about their candidacy reminiscent of their time receiving emergency dialysis. They grappled with challenges of navigating the process, received mixed communication regarding the timeline for transplant, and expressed concern for the well-being of family members who might serve as living donors. Three factors were identified as important facilitators in achieving transplant: (1) self-advocacy, (2) spiritualism and optimism, and (3) peer support. After transplant, recipients reflected on the importance of being able to return to work, noted improvements in their mental health, and underlined the vigilance needed to maintain their health with a transplanted kidney.

Rizzolo's qualitative study offers insights gleaned from the experience of exceptional individuals who have managed to survive the grueling—and often fatal—experience of emergency dialysis⁵ and who went on to navigate 2 highly complex and opaque processes: first, managing the threadbare patchwork of options for insurance coverage for undocumented immigrants, and second, completing the processes of clinical and psychosocial evaluation, waitlisting, and kidney transplant. These findings reflect the ability of an inspirational group of undocumented immigrants and their families...
to demonstrate self-advocacy, resilience, and the strengths of community. The successes of these extraordinary individuals should be celebrated. However, it is equally important to appreciate that not all undocumented immigrants who could benefit from transplant will have the personal and social resources to follow their example. Rizzolo's findings also issue a resounding call for better health system practices and policies to extend equitable transplant care to a broader population.

First, patients' self-advocacy could be complemented and reinforced by a more proactive approach, by both dialysis units and transplant centers, to provide clear communication and information surrounding options for insurance coverage and avenues to transplant. Clear messaging that lack of residency documentation does not preclude transplant candidacy as well as standardized and explicit requirements among transplant centers regarding insurance status and financial resources would support patients, their families, and local clinicians in navigating treatment options. Peer support resonated as a strong facilitator in achieving transplant among participants in this study and may be more formally incorporated into the process by training and employing peer navigators and sponsoring peer support groups. While the use of trained kidney transplant recipients as peer navigators was not validated in one randomized clinical trial, the current report suggests that more investigation along these lines, informed by community forums and tailored to individual needs of groups such as undocumented immigrants, may nonetheless be fruitful. While a valuable resource for participants in the current study, peers should not be solely responsible for supplying up-to-date information about the evolving landscape of insurance access for undocumented immigrants. With sufficient time and support, dialysis and transplant center social workers could be well positioned to help navigate insurance coverage and charitable support for copays and premiums for this population.

Ultimately, medical centers and clinicians may be limited in their ability to sustainably provide care for the population of undocumented immigrants without major changes to insurance coverage and/or reimbursement policies. As Rizzolo and colleagues comment, undocumented immigrants donate organs, pay taxes, and are often younger, productive members of the workforce—a compelling set of utilitarian and egalitarian rationales to ensure access to transplant and to health care more broadly. Furthermore, coverage of primary and preventive care (which, for example, is not included in Illinois's kidney transplant benefit) may have prevented the development of ESKD for many undocumented immigrants. In the context of this plethora of rationale for coverage, lack of access to comprehensive health care for undocumented immigrants in most states in the US suggests policy and practices that may be implicitly shaped by systemic racism, xenophobia, and individualism rather than reason.

Work to better support undocumented immigrants in access to kidney transplant is more than warranted by principles of health care ethics. However, the infrastructure needs signaled by this and other studies of the experience of the undocumented population have implications for a broader population of people with ESKD. Psychosocial barriers to this valuable treatment option may be magnified in the striking experience of undocumented immigrants, but these constitute a pervasive and troubling set of roadblocks for many populations who have been marginalized for reasons including citizenship, race, gender, and socioeconomic status. Guided by input from the communities that it serves, adaptations to the transplant evaluation and selection process, including standardization, greater transparency, and regulation, are central to supporting clinicians and improving the experience of all people with ESKD, their families, and communities.
AUTHOR AFFILIATIONS: Division of General Internal Medicine, Department of Medicine, University of Washington, Seattle (Morenz); Division of Nephrology, Department of Medicine, University of Washington, Seattle (Ng, Butler); VA Puget Sound Health Care System, US Department of Veterans Affairs, Seattle, Washington (Butler).

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REFERENCES