

Barriers and Solutions to Kidney Transplantation for the Undocumented Latinx Community with Kidney Failure

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Introduction

Latinx people experience a faster progression of chronic kidney disease (CKD) to kidney failure and a 1.3-times greater incidence rate of kidney failure compared with non-Latinx White individuals (1). Despite this, Latinx patients are less likely than non-Latinx White patients to receive predialysis nephrology care or a kidney transplant. Latinx people constitute the majority of undocumented immigrants—there are an estimated 6000–9000 undocumented immigrants in the United States with kidney failure (2). For patients with kidney failure, the gold standard treatment is kidney transplantation. Kidney transplantation reduces morbidity and mortality, improves quality of life, and is less costly compared with long-term dialysis. Per the Organ Procurement and Transplantation Network policy and the National Organ Transplantation Act of 1984, citizenship status does not preclude eligibility for transplant. However, there remain barriers at the policy, economic, cultural, and ethical levels. In this narrative, we explore the barriers faced by undocumented Latinx immigrants to receipt of kidney transplantation and propose solutions.

Barriers to Equitable Transplantation

Insurance access represents the largest barrier to transplant. Under the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (Public Law 104–193), undocumented immigrants are barred from receiving federal benefits (2). Although the Emergency Medical Treatment and Active Labor Act (EMTALA) of 1986 prohibited refusal of care in an emergency situation regardless of immigration status, it explicitly excluded solid organ transplantation: “Payment ... shall not be made for organ transplant procedures unless the State plan provides for written standards respecting the coverage of such procedures” (Social Security Act 1903; https://www.ssa.gov/OP_Home/ssact/title19/1903.htm). For undocumented immigrants with kidney failure, access to dialysis is state dependent, meaning many rely on emergency dialysis (dialysis when critically ill) without federal transplantation benefits.

Transplant allocation is framed by fiscal and organ scarcity. Transplantation is expensive, costing an estimated \$300,000 for the surgery and \$20,000–30,000 per year for clinic appointments and medications in 2016 (1). In addition to medical costs, postsurgical recovery incurs loss of a minimum 1 month’s salary, travel costs, lodging, and childcare. Many centers require a minimum financial savings for those without insurance or have strict reimbursement criteria. In a 2012 study of undocumented immigrants, most were willing to pay \$18,000 for a transplant, well under the then-current price of \$200,000 (3). Overall, transplant is less fiscally expensive for the system long term than dialysis after 1.5–2.7 years—by about \$321,000 for a patient in New York in 2012 (3). Organ scarcity also represents a significant barrier. However, in some areas, 10% of organs come from undocumented donors, even though they receive <1% of donated organs (4). Undocumented immigrants are willing to donate despite awareness that they can donate but not receive organs under federal benefits.

There are also significant barriers in achieving language- and culture-concordant kidney transplantation information. There is limited availability of language interpreters, educational materials, and culture-concordant and -responsive care at various health literacy levels. One study found that many Latinx patients with kidney failure were unaware that patients on dialysis are in need of transplantation or that living donors can select their recipient (5). Potential recipients may be reluctant to request donation, due to concern for the donor’s well-being, pressure from their family, or misinformation about their own health (5). Many Latinx patients express fear of transplant rejection, fear of the surgery, and concerns for poorer life expectancy (5). Language concordance in health care among Latinx people has been associated with less confusion/frustration and patient perceptions of better quality of care.

Many undocumented immigrants distrust the health care system due to fear of deportation or fear that their organs may be used on the black market. Distrust and lack of information deter many from seeking health care evaluation—a phenomenon also noted in the

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Latinx community during the coronavirus disease 2019 (COVID-19) pandemic (6). During the COVID-19 pandemic, many migrants were separated from their families, those in the United States faced a health protection crisis under the Public Charge rule, and undocumented immigrants undergoing emergency-only dialysis also faced an increased COVID-19 exposure risk. These issues likely widened the gap in transplantation equity. Despite these issues, undocumented immigrants have a strong interest in transplantation. In one study, 96% of undocumented patients with kidney failure expressed interest in kidney transplantation (3). Of those surveyed who were not working due to kidney failure, 82% reported they would return to work post-transplantation (3).

The Rationale for Covering Transplants for Undocumented Immigrants

According to the ethical principles in the allocation of human organs, ideal organ allocation “maximizes the aggregate amount of medical good, distributes the good justly, [and] shows respect for persons including the autonomous decisions of persons,” in line with the principles of utility, justice, and respect for persons (7). Yet, there remain many ethical arguments for and against transplantation for the undocumented community.

Opponents to transplantation for undocumented immigrants argue that the undocumented have no claim to health care benefits in the United States, assuming unequal financial contribution to society. However, the majority of undocumented immigrants in the country are working-age taxpayers who use little health care and contribute to economic growth and the Social Security tax. A study assessing Trust Fund contributions and expenditures found that US-born people generated a \$30.9 billion deficit while immigrants contributed a surplus of \$13.8 billion in 2009, with a cumulative surplus of \$115 billion from 2002 to 2009 (8). Most undocumented immigrants with kidney failure arrive without knowledge of kidney disease and have been in the United States for an average of 5 years prior to diagnosis of kidney failure (2). Only 1% of kidney transplants are noncitizens, making it unlikely that access to kidney transplantation would lead to an increase in transplant tourism.

Opponents cite the potential for an undocumented immigrant to have poor adherence to medical therapy given lack of benefits and social challenges, incurring graft loss, need for retransplantation, and jeopardy of transplant center’s certifications. However, undocumented kidney transplant recipients have favorable outcomes. Undocumented pediatric recipients have similar 1- and 5-year graft survival (4). Adult undocumented kidney transplant recipients had similar rates of graft loss compared with citizens, with 45% lower unadjusted risk for all-cause transplant loss, death-censored transplant loss, and death (9). It is thus unethical to use nonmedical factors, such as immigration status, as a proxy for likelihood of success.

Opponents note concerns over distribution of scarce organs; however, undocumented immigrants gift organs in our country. Several states offer driver’s licenses to undocumented immigrants, and this gives undocumented

immigrants the option to list themselves for organ donation if deceased. Many undocumented have a living donor available; in one study, 60% of undocumented reported at least one living donor (3). Using the organs of individuals who are not eligible for organ transplantation themselves due to immigration status is unjust.

Although respect for persons necessitates treating individuals as autonomous agents, it also demands protection for persons with diminished autonomy. Undocumented immigrants have diminished autonomy in health care as they are denied the range of all possible treatment options due to their undocumented status. It is the moral obligation of clinicians to ensure that individuals with diminished autonomy are not excluded from receiving gold-standard care; however, the current limitations of care available to undocumented immigrants do not allow clinicians to fulfill this aim.

Solutions and Next Steps

Access to benefits for solid organ transplantation for undocumented patients is possible in some states using state Medicaid funds. Illinois and California have set examples of state-led efforts, providing health care (and transplant) access to the undocumented. The largest number of transplantations is performed in California because undocumented immigrants are considered permanently residing in the United States under color of law, qualifying for Medi-Cal benefits (9). Illinois provided a novel policy solution in 2014 *via* State Bill 741 (“Comprehensive State Legislation”), which overhauled Illinois’s Medicaid program and included language providing kidney transplantation to undocumented immigrants. The bill was motivated by a separate bill allowing undocumented immigrants to acquire driver’s licenses and the option to be listed as organ donors.

Although state-led efforts are more likely to be effective as they do not require an act of Congress, this approach has resulted in patchwork transplant eligibility, which varies by state. Federal policy change is necessary to ensure just and equitable transplant access to marginalized populations. An extension of the Disproportionate Share Hospital Payment Program or the Affordable Care Act would allow for extension of care access at the federal level for otherwise ineligible groups. Elimination of the organ transplantation exclusion under EMTALA may allow more states to broaden access to transplantation—considering that transplantation is gold-standard care for kidney failure and that it is less expensive and more efficacious regarding quality of life and mortality compared with dialysis.

Transplant education to inform, educate, and empower the undocumented immigrant community is critical. Media education interventions and in-person culture-concordant education sessions have improved attitudes and knowledge about live kidney donation for both donors and recipients (10). Language-concordant community health worker (*e.g.*, navigators and health educators) programs have been shown to increase completion of the transplant evaluation process (10). A culturally responsive transplant process can increase favorability of transplant for Latinx individuals.

Undocumented Latinx individuals are disproportionately burdened with kidney disease and suffer innumerable barriers to kidney transplant. Policy change and culture-concordant education should be prioritized to improve access to transplant care for the Latinx community with kidney failure.

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