



Impact and Implications of Solid Organ Transplant of Undocumented Immigrants versus Transplant Tourists on the Transplant Center and OPTN National Policy Development

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Abstract

Purpose of Review The Organ Procurement and Transplantation Network (OPTN) governs the transplant policy development in the United States. This review examines the impact and implications of the transplantation of undocumented immigrants and transplant tourism on the transplant center and OPTN policy.

Recent Findings Changes in OPTN policy have moved the needle towards more equitable access to transplantation for non-citizens in the US while limiting transplant tourism. However, there remains a lack of clarity for transplant centers, in addition to multiple other systemic and structural barriers, which may contribute to inequitable access to care for non-citizens.

Summary We highlight the evolution of OPTN policy for non-citizen transplantation and its effect on equitable organ allocation while addressing concerns over transplant tourism. Despite this, there is an additional need for clarity in citizenship and residency definitions at the policy level, and improved education and policy adjustments within transplant centers to enhance access for non-citizens.

Keywords Transplant · Equity · Immigrant health · Policy

Introduction

The Organ Procurement and Transplantation Network (OPTN) established under the National Organ Transplant Act (NOTA) of 1984 manages the US transplant system, including policy development. An estimated 11 million undocumented immigrants reside in the United States, and it is unknown how many of them need an organ transplant [1]. NOTA mandates that organ allocation be based solely on medical criteria [2], and OPTN policy allows transplants for non-citizens. However, this policy has changed over time due to transplant inequity and concerns for transplant tourism. This paper aims to review the implications of the

transplantation of undocumented immigrants and transplant tourism on the transplant center and OPTN policy.

History of OPTN Policy Changes

OPTN mandates transplant programs and Organ Procurement Organizations (OPOs) to collect citizenship and residency data for all transplant candidates and donors, raising concerns about potential inequity for non-US citizens. The initial 1986 OPTN policy recommended limiting noncitizens to less than 10% of kidney transplant recipients per center, later reduced to 5% for all organ transplants in 1994 [2]. This policy made many transplant centers hesitant to transplant residents with unclear immigration status, fearing potential audits [3]. The World Health Organization's call to its member states in 2004 to address concerns about transplant inequity, and international organ trafficking, and to protect vulnerable groups from transplant tourism prompted the creation of the 2008 Declaration of Istanbul [4]. According to this declaration, "Travel for transplantation becomes transplant tourism if it involves organ trafficking and/or transplant commercialism or if the resources (organs, professionals, and transplant centers) devoted to providing

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transplants to patients from outside a country undermine the country's ability to provide transplant services for its own population" [5].

In the following years, OPTN's frequent revisions of non-US citizen categories, citizenship terms definitions, and data collection guidance may have led to confusion in transplant centers and OPOs. Citizenship categories in OPTN policy before 2010 were "US citizen", "resident alien", and "non-resident alien". In 2011, in an effort to clarify transplant tourists vs non-citizen residents, non-US citizen categories were rephrased to distinguish US residency as "non-US citizen/US resident" and "non-US citizen/non-US resident." The "non-US citizen/non-US resident" category is further divided to distinguish between those who traveled to the United States specifically for transplant and those who traveled for other reasons [6]. In 2015, the country of origin was also gathered for nonresidents [7].

Lack of clarity on transplantation of non-citizens

In 2012, OPTN and the United Network for Organ Sharing (UNOS) introduced a revised policy to improve transplantation equity for noncitizen residents, replacing the "5% guideline" with an annual review of all residency and citizenship data, published in a publicly accessible report [2] (Fig. 1). The aim of this change was to address a broad misunderstanding of the 5% guideline as a cap on a program's ability to list or transplant non-citizens. To address discrepancies in citizenship and residency data collection by transplant centers and OPOs, OPTN surveyed transplant centers with greater than 5% noncitizen nonresident (NCNR) registrations of a single organ to better understand their practices surrounding non-citizens [8]. This survey showed a wide discrepancy in practice patterns used to 1) discern and document citizenship 2) understand if transplant access is limited in the country of origin and 3) ascertain whether the candidate had sought access in their home country.

In response to this survey, OPTN issued a 2021 guidance document clarifying definitions of citizenship terms and outlining procedures for recording and monitoring these patients [8]. Despite this guidance, reporting citizenship and residency status remains challenging for several reasons: OPTN's terms do not align with United States Citizenship and Immigration Services (USCIS) definitions, US

visa status is not recorded, the definition of "US resident" is vague, and there is a lack of clarity on categorizing certain statuses like green card holders, refugees and temporary protected status within OPTN's policy framework [2].

Ethical Concerns and Evidence Informing OPTN Policy

Concern for Organ Scarcity in the United States

In 2019, 5.9% of adults added to the transplant waitlist were noncitizen residents, while 1.2% were noncitizen nonresidents [6]. There is concern that undocumented immigrants and individuals traveling for transplantation purposes worsen organ scarcity in the United States, and it has influenced policy development like the "5% guideline". However, recent studies showed that noncitizen residents, regardless of immigration status, contribute to the organ donor pool and do not exacerbate organ scarcity [2]. Several states allow undocumented immigrants to obtain driver's licenses, enabling them to register as organ donors upon death. In 2019, noncitizen residents contributed 3.2% of donated organs, while 9.8% of donors had an unknown US citizenship status [9]. In some regions, noncitizens contribute up to 10% of the total organ donor pool [10]. Moreover, between 2015 and 2020, United Network for Organ Sharing (UNOS) data indicates that 91% of organs from deceased noncitizen residents and 90% of organs from deceased noncitizen nonresidents were received by US citizens [11]. This evidence should inspire transplant programs nationwide to strive for more equitable organ procurement and transplantation for non-citizens.

Furthermore, many undocumented immigrants have living donors. A 2012 cross-sectional study showed that 60% of surveyed undocumented immigrants had at least one potential living kidney donor [12]. Policy developers should therefore consider expanding coverage to fund living donor transplants to undocumented immigrants with kidney failure, given the cost-savings from transplants compared with long-term dialysis [12] and an opportunity to address organ scarcity. However, solely providing living donation provisions without the option of addressing the barriers to deceased donor transplantation, as has been suggested by some nephrologists, ignores the inequity that noncitizens



Fig. 1 Timeline of OPTN policy changes related to US citizenship and residency status. Adapted from Cervantes et al "Organ Procurement and Transplant Equity Among US Residents: The 5% Guideline" *AJKD*, July 2022 with permission

donate healthy, viable organs to this country [13]. Moreover, this underserved population, specifically the Hispanic community, faces additional barriers to living donor transplants, including limited knowledge, misinformation, language discordance, fear of surgery and transplant rejection, and cultural disparities [14]. These issues need to be accounted for and addressed in policymaking to ensure equitable transplantation.

Concern for Transplant Tourism

OPTN policy development is also shaped by concerns surrounding migration for transplantation, also known as transplant tourism, which is defined by the Declaration of Istanbul as “[involving] trafficking in persons for the purpose of organ removal or trafficking in human organs, or if the resources (organs, professionals, and transplant centers) devoted to providing transplants to non-resident patients undermine the country’s ability to provide transplant services for its own population [5].” This definition has been used by some transplant centers to curb the number of transplant evaluations from non-citizens [3]. In 2020, the OPTN Ad Hoc International Relations Committee surveyed 75 US transplant programs to better understand their policies and practices on accepting NCNR transplant patients. These 75 programs had over 5% and more than 5 NCNR transplant registrations or deceased donor transplants for a specific organ in any year from 2017 to 2019. 48% of responding programs indicated they lack a formal process for accepting NCNR candidates and there were also significant differences in the processes used to establish citizenship status. Most programs were unaware if their NCNR candidates’ home countries had transplant programs or if the candidates had sought transplant services there [8]. The survey highlights a lack of clarity among transplant centers for determining citizenship status and also demonstrates the lack of sufficient data to support the claim that transplanting undocumented immigrants poses a threat of transplant tourism.

Some argue that noncitizen nonresident patients on the UNOS liver transplant waitlist should be last in line, receiving a deceased donor liver only if it is not acceptable to a U.S. resident on the waitlist [15]. Most undocumented immigrants with kidney failure often arrive in the United States unaware of their condition and have lived here for at least five years before being diagnosed with kidney failure [16], which demonstrates the absence of migration intent for transplantation purposes. According to a 2020 study on cardiothoracic transplants [17], the majority of non-US citizen transplant recipients were not transplant tourists. Besides this, OPTN reports published between 2012 and 2013 reveal that only 1% of kidney transplant recipients in the United States were noncitizens [9, 11], suggesting that increased

access to transplantation among undocumented immigrants is unlikely to spur transplant tourism.

Concern for Inadequate Financial Contribution to Society

Critics argue that undocumented immigrants are not entitled to healthcare benefits in the United States because of a perceived burden on the US healthcare economy and immigrants’ unequal financial contributions to society. However, most undocumented immigrants are working-age taxpayers who contribute to economic growth and also use minimal healthcare. A study on Medicare Trust Fund contributions revealed that immigrants contributed 14.7% in 2009 but only 7.9% of expenditures, creating a \$13.8 billion surplus, compared to US citizens’ \$30.9 billion deficit. Immigrants also amassed a cumulative \$115.2 billion surplus from 2002 to 2009, debunking the misconception that immigrants do not make equal financial contributions to society. Notably, a significant portion of the surplus generated by immigrants was contributed by noncitizens [18].

Another study evaluated immigrants’ net financial contributions to US healthcare between 2012 and 2017 by examining the premiums and taxes they paid and the expenditures made by third-party payers on their behalf. The study found that undocumented immigrants contributed \$4,418 more per person than they used in expenditures, while US citizens collectively paid \$67.2 billion less than their expenditures. The deficit was largely balanced by immigrants’ net surplus payments, with 89% coming from undocumented immigrants [19]. These studies suggest that concerns about immigrants depleting US healthcare resources and not contributing financially to society may not be justified. Additionally, since kidney transplantation is less expensive than long-term dialysis [13], policymakers should expand coverage to fund transplants for undocumented immigrants, thereby reducing healthcare costs.

Concern for Adverse Clinical Outcomes

There are approximately 6,000 to 9,000 undocumented immigrants in the United States who are living with kidney failure [20] and in need of transplants. One concern of opponents regarding transplanting this underserved population is worse outcomes, such as graft loss and requirement for re-transplantation, due to perceived poor compliance with medical therapy from lack of insurance coverage, health illiteracy, and social challenges [14]. However, insured undocumented immigrants who undergo transplantation with Medicaid have outcomes comparable to U.S. citizens. A retrospective study of adult Medicaid patients who received their first kidney transplant between 1990 and 2011 found that undocumented immigrants had a lower unadjusted risk for transplant loss compared to U.S. citizens (HR, 0.48;

95% CI, 0.35–0.65). Results remained significant even after adjusting for demographics, comorbid conditions, dialysis, and transplant-related factors (HR, 0.67; 95% CI, 0.46–0.94) [21]. Another retrospective study in California, where transplantation is covered regardless of immigration status, found comparable kidney transplant outcomes between undocumented immigrants and US citizens [22]. Additionally, pediatric undocumented kidney transplant recipients show comparable 1- and 5-year graft survival rates and a higher one-year mean estimated glomerular filtration rate (eGFR) than US citizens [23]. These findings suggest that transplantation of undocumented immigrants does not portend to poorer outcomes, and thus denying transplants based on immigration status is unethical.

Social and Structural Barriers to Transplantation for Non-Citizens

Non-citizens face additional social and structural barriers to transplantation in the US. While non-citizens are eligible for transplantation per OPTN policy, insurance covering transplantation evaluation, surgery, and post-transplant care remains the biggest barrier for many non-citizens. Insurance is often required by transplant centers, and often uninsured people are ineligible to be evaluated. Currently, five states in the US provide state-wide insurance coverage for non-citizens who are ineligible for Medicare. In the other forty-five states, insurance coverage for non-citizens includes insurance through an employer, expensive off-marketplace exchange, expensive high-risk insurance pools, or charity care which funds private insurance premiums. In comparison to dialysis, transplant is less expensive: kidney transplantation is estimated \$136,969 for the first year (compared to \$116,160 on dialysis) and \$37,304 for each additional year, conferring a savings of \$344,000 over eight years [13].

While many non-citizens express interest in paying for transplantation out of pocket, this sum is not feasible for many. Indeed, a 2012 study showed non-citizens reported they were able to pay \$18,000 for a transplantation- well under today's going rate [12]. A more recent study corroborates this finding, evaluating the use of federal reimbursement for living donations found that minoritized individuals are much more likely to apply for financial assistance [24]; from this, it may be surmised that economic issues would affect a sub-population of non-citizens who are ineligible for public benefits. Moreover, non-citizens are often not informed that insurance is a barrier: in a 2023 study that qualitatively reviewed undocumented transplant recipients' experience receiving a transplant in Colorado (where transplantation is not covered under state policy), participants reported not being told that their ineligibility was driven by being uninsured [25]. In areas where transplantation is

covered by insurance, such as Illinois, transplantation in these communities has increased [26].

Non-citizens face additional barriers besides insurance. For those with low English proficiency, lack of culture and language-concordant transplant resources limits understanding of transplantation. Indeed many Latinx/o/a/e/Hispanic patients have reported not knowing kidney transplantation would allow them to come off dialysis, and many report fear of transplantation surgery, rejection, and health outcomes post-surgery. A study in Illinois, where transplantation insurance barriers are not a major issue, found undocumented people reported issues with communication and a lack of cultural concordance [27]. Due to these barriers, multiple transplant centers across the US have created Hispanic transplant centers aimed at improving transplant uptake through establishing language and culture-concordant services [28].

Non-citizens may face additional barriers related to socioeconomic status and inability to receive public benefits, including the inability to take time off work for appointments and post-transplant, and lack of support given the financial needs of the family. Undocumented transplant recipients in Illinois reported issues such as transportation, for example, due to the inability to receive publicly financed transportation. These issues may preclude transplantation depending on the transplant center, as the assessment of social barriers differs between providers and institutions [29].

Effect of Policy Change

Although eligible to donate, non-citizens often have limited opportunities to receive organs, posing a major equity issue. The states of Illinois and California have set precedents with state-led initiatives providing medical coverage for transplants for undocumented individuals, overcoming the biggest barrier to transplantation for this population. In 2014, Illinois passed Senate Bill 741, providing kidney transplant coverage for non-citizens with kidney failure on dialysis [30]. Though this legislation opened avenues for the transplantation of undocumented immigrants, it had little practical impact because programs arising from Illinois Senate Bill 741 relied on state funding, which ended in 2015 during a budget crisis [31]. Given the gaps in legislation, the Gift of Hope Organ and Tissue Donor Network formed the Illinois Trust Fund (ITF) in 2015, a non-government-funded agency that provides financial assistance for transplant access and post-transplant care to non-citizens, saving the healthcare system over \$10 million per year [31]. Thus, to achieve equitable care for undocumented immigrants, the State should: reimburse organ transplant costs at Medicaid rates, fully enforce Senate Bill 2294, which covers immunosuppressive drugs and post-transplant care for non-citizens,

and expand state programs to include standard-of-care CKD treatments for non-citizens [31].

The Equity in Heart Transplant Project (TEHTP) is another commendable example of institutional policy addressing financial and social barriers to transplant access for minority populations. Established in 2022, this public charity provides financial and social support to disadvantaged patients with end-stage heart failure seeking heart transplants. It has so far helped 31 patients get listed for heart transplants, 45% of whom are Black and 19% Hispanic [32]. Grants cover essential needs like food, housing, transportation, insurance deductibles, medications, and childcare [32], addressing barriers unique to these underserved populations and making transplant access truly equitable. Such initiatives should inspire national policymakers to design more equitable transplant policies that address barriers and care gaps for underserved populations.

Author's Opinion on the OPTN and Transplant Center Policy

Overall, there remains ambiguity amongst transplant centers and clinicians regarding transplant eligibility of noncitizens. Factors contributing to this issue likely include the ambiguity surrounding the “5% guideline” and a lack of understanding regarding the definitions of citizenship and residency terms. While reporting US residency status aims to identify transplant tourism candidates, who could potentially worsen organ scarcity in the US, a lack of clarification of reporting fails to take into account nuances of citizenship. For example, the non-US resident category also includes other citizenship statuses who have different access to insurance in the US, such as permanent residents or lawful permanent residents. Additionally, noncitizen residents fear reporting their status and may not be truthful due to concerns about deportation or denial of services, creating a barrier to donation and transplantation access [2].

In order to move forward in the creation of equitable policies and practices in transplantation, the role of OPTN and transplant centers in creating and implementing equitable guidelines and resources for the evaluation, listing, and transplantation of non-citizens must be considered. OPTN for example, has been working to clarify their guidelines for transplant centers through outlining best practices in terms of data collection and use. In addition to this, OPTN policy may consider working to improve uniform data collection of citizenship-related variables, as this knowledge may serve to inform the true “risks” of transplant tourism.

At the center level, transplant centers individually should work to create equitable policies for non-citizens in terms of access to evaluation, listing, and transplantation. First, education of staff regarding OPTN policies is critical to ensure that non-citizens are not deemed “ineligible” due to

citizenship status before even being evaluated. Secondly, transplant centers may improve access to evaluation through the incorporation of built-in resources to ameliorate common barriers to transplantation, such as insurance and legal immigration navigation. Lastly, working with primary end-organ clinics (such as renal, cardiology, and hepatology) regarding referral of non-citizens is critical to ensure clinicians do not restrict access to transplantation due to immigration status.

Conclusions

In conclusion, the complexities surrounding the transplantation of undocumented immigrants and concerns over transplant tourism have shaped evolving policies within the Organ Procurement and Transplantation Network (OPTN). The historical shifts in OPTN guidelines reflect ongoing efforts to balance equitable access to organs with safeguards against potential abuse of the transplant system, yet ambiguities that have the potential to limit access to transplantation remain. Moving forward, there is a critical need for continued clarity in defining and reporting citizenship and residency statuses, as well as enhancing educational initiatives within transplant centers to ensure equitable evaluation and listing practices for non-citizens. Moreover, future research should focus on evaluating the long-term impacts of these policies on transplant outcomes and addressing the unique socioeconomic and healthcare access barriers faced by undocumented immigrants in need of organ transplantation.

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