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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Is Organ Retransplantation Among Undocumented Immigrants in the United States Just?

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Abstract

Numerous undocumented children in the United States with end-stage renal disease undergo kidney transplantation funded by charitable donation or state-sponsored Medicaid. However, when these funding sources expire by adulthood, most are unable to pay for follow-up appointments and immunosuppressive medications necessary for maintenance of their organ. The organs fail and patients are then left with the options of retransplantation or a lifetime of dialysis. The dilemma of retransplantation introduces many questions regarding justice and fairness. This commentary addresses several ethical concerns about the special case of organ retransplantation for undocumented patients. Clinical guidelines and a clear public policy for best practices are needed to adequately address the challenge of retransplantation and maintenance immunosuppression in this population.

Case

Anna was 2 years old when she was diagnosed with polycystic kidney disease, a life-threatening illness. Her family was told that Anna would need a kidney transplant to live. Although Anna was an undocumented immigrant, the hospital had a pool of funding for charity kidney transplants, and the state would provide Medicaid to cover additional costs. Anna received a kidney transplant at the age of 2½.

At age 18, Anna's family was notified that Medicaid funding would no longer be available to cover her transplant-related medical care. She would now be responsible for purchasing the immunosuppressive drugs required to maintain her kidney transplant as well as costs of regular follow-up appointments. After high school, Anna found work as a waitress making below minimum wage, mostly working double shifts on an unpredictable schedule, with no health insurance. She stopped taking her

immunosuppressive medications because she could not afford them and could not follow up with her nephrologist due to her demanding schedule. Two years passed, and Anna now presents to the county hospital emergency department. Her kidney transplant has failed. She needs a new kidney or faces a lifetime of dialysis. In addition to her undocumented status, she has no health insurance. What should be done?

Commentary

Anna's case highlights an important concern in the health care of undocumented immigrants—organ retransplantation. Based on Organ Procurement and Transplantation Network (OPTN) reports published between 2012 and 2013, approximately 1% of kidney transplant recipients in the United States were noncitizens (including undocumented immigrants, permanent residents with a legal visa, and foreign nationals engaged in medical tourism).[1,2]

Although organs may be allocated to undocumented persons based on OPTN policy, federal funding for both transplantation and posttransplant care is restricted.[3] In the United States, current policy—the Omnibus Budget Reconciliation Act of 1985 and the Personal Responsibility and Work Opportunity Reconciliation Act (PWORA) of 1996—excludes undocumented immigrants from federally financed public benefits including Medicare, Medicaid, the Children's Health Insurance Program, and Affordable Care Act (ACA) insurance subsidies and exchanges.[4-9] Enacted in 1986, the Omnibus Budget Reconciliation Act prohibited the use of federal funds for undocumented immigrants except in emergency situations,[8] as dictated by the simultaneous enactment of the Emergency Medical Treatment and Active Labor Act (EMTALA). Under EMTALA, all states must provide federally funded emergency medical treatment, including emergent-only hemodialysis, which would be needed for the care of failed kidney transplants.[4,6,10] In addition, 11 states and the District of Columbia currently use state funding sources to provide undocumented immigrants with maintenance dialysis.[11] Notably, kidney transplantation is not considered an emergency treatment for end-stage renal disease (ESRD) and thus, under this legislation, is not eligible to be federally subsidized for undocumented immigrants.[5,8] Ten years after the Omnibus Budget Reconciliation Act was implemented, PRWORA (also known as the "Welfare Act") explicitly denied undocumented immigrants all state and local public benefits, forcing states desiring to extend public benefits to undocumented immigrants to pass new laws specific to their own state. Thus, under current legislation, only transplant recipients with permanent legal status have opportunities to receive *federal* funding for long-term maintenance of their transplanted organ in most states.[4-6,8]

Transplant patients, unlike other surgical patients, have a lifetime of health care costs associated with their transplant. In 2017, the total cost of a kidney transplant and a single year of necessary immunosuppressive medications was estimated to be over $400 000.[12] Posttransplant care requires numerous postoperative office visits, daily

immunosuppressive therapy, and regular tests that monitor the health of the transplant or graft. Without the ability to pay for this care, it is likely that these grafts will fail.

Among undocumented children who live in states like California, where coverage is currently guaranteed by state-sponsored Medicaid until age 18,[13] at least 1 in 5 kidney transplants fail by the age of 21 because the patients cannot afford the immunosuppressive drugs without Medicaid or alternative funding.[14] In cases where posttransplant care is not possible and the organ fails due to lack of funding, remaining options include retransplantation or return to dialysis. Many centers believe that nonadherence to immunosuppressive medications with an initial graft, even if due to lack of access, is a contraindication to receiving a second graft.[5,15-19] An inability to obtain follow-up transplant care thus can be used as a justification for avoiding retransplantation in transplant centers.

In sum, while undocumented immigrants may be allowed to receive transplants at a given hospital, there is no guaranteed funding mechanism to ensure that they can receive appropriate posttransplant care to maintain their organ in most states. The question then arises whether it is ethically sound to offer retransplantation given this knowledge.

Free Ridership vs a Right to Care

Opponents of retransplantation for undocumented immigrants argue that illegal immigrants have no claim to the limited transplantation resources in the United States due to their lack of citizenship status and unequal financial contribution to society.[10,11] More generally, they argue that persons with no legal claim to reside in a country should not be granted access to the publicly funded benefits of that country.[10,11] Accordingly, some authors believe that undocumented immigrants are *free riders* who take advantage of public services without contributing to public funding.[10,20] Some of these opponents argue that health care policies that make insurance coverage and treatment more accessible to all populations will encourage undocumented immigrants to overuse services without contributing their fair share to the tax base, ultimately placing an unjust burden on the public.[20] In cases like Anna's, in which retransplantation is considered because of graft failure stemming from lack of follow-up care, opponents argue that offering retransplantation would be an "overuse" of resources and is also more expensive than primary grafts, which could potentially place a greater burden on society.[21]

Proponents of retransplantation for undocumented immigrants argue that access to care is a basic human right regardless of citizenship status.[22] Although nonadherence to immunosuppression and follow-up care with an initial graft is still a contraindication to listing on the waitlist,[15-18] in their view, screening out undocumented immigrants conflicts with physicians' ethical responsibility to care for persons in medical need.[10]

Additionally, several studies have shown that the cumulative cost of emergent dialysis is greater than that incurred from transplantation.[23,24] Thus, transplantation should be considered the better long-term alternative for both the individual (for clinical reasons) and society (for cost reasons). Finally, concerns about inappropriate organ allocation to undocumented persons given their unequal societal contribution must be weighed against the fact that undocumented persons contribute $11 billion to our state and local tax base.[25]

Physicians' Responsibilities

Opponents contend that transplant physicians do not have an obligation to provide retransplantation due to concerns about organ supply and survival of retransplantation patients.[26] Accordingly, the only obligation transplant physicians have is to treat life-threatening conditions, particularly when there are no alternative options. Unlike in the case of heart or liver failure, patients with renal failure have dialysis as an option, albeit a time-limited one.[27] In determining eligibility for the waitlist, physicians must consider whether denial of listing could result in more harm than benefit to a patient than if a patient were listed and transplanted. It is important to recognize that some patients are harmed by transplantation and that, for these patients, there might not be benefit to retransplantation.[15] Studies have shown that repeat grafts demonstrate decreasing survival rates with each subsequent graft.[28,29] Overall, clinical outcomes of retransplanted recipients are less favorable than those of patients who have retained their primary graft.[16,17,28,29] Evidence also suggests a significantly higher risk of death for retransplanted patients during the first month posttransplant relative to patients on dialysis.[28,30,31]

Furthermore, opponents believe that physicians should be parsimonious in their provision of care when operating under circumstances of limited resources and try to minimize unnecessary costs.[32-35] Thus, physicians must judiciously weigh the considerable risks vs benefits associated with retransplantation. Without access to follow-up care, it is unclear whether the retransplanted graft will persist long enough to provide long-term survival benefit.

Alternatively, it could be argued that by failing to retransplant, the physician has essentially abandoned his or her ethical responsibilities to provide for that patient's medical well-being. Physicians cannot fully take care of their patients in need of retransplantation because the only alternative is emergency dialysis due to undocumented immigrants' lack of proper health care coverage for regular maintenance dialysis in the majority of states. Furthermore, in a qualitative study, physicians who worked in safety-net health care systems where undocumented persons receive emergency dialysis reported that determining when to provide emergency dialysis can cause moral distress.[36] Physicians felt that when required to make decisions about who was to receive emergence dialysis, they were forced to weigh social factors, sacrifice

quality of care, and even inappropriately report medical status in order for the patient to qualify for emergency dialysis.[36] Thus, in addition to the moral distress caused by the unavailability of organ retransplantation for patients with undocumented status, physicians face additional stress in providing a suitable medical alternative. Moreover, retransplantation is associated with a 50% reduction in mortality relative to remaining on dialysis if the patient survives beyond the 1-year postretransplant period.[30,31] These data suggest that retransplantation is, medically, the optimal long-term treatment for a failed kidney transplant compared to treatment with emergency dialysis alone.

Supply and Demand of Organ Transplantation

Given both the inadequate organ supply and the limited public budget for health care, opponents of retransplantation suggest that US citizens and legal residents should be prioritized or exclusively offered deceased donor organs.[22,37] They worry that retransplantation might not be worth the potential risk if a patient is subsequently deported or otherwise cut off from good follow-up care in the United States. These recipients would not have good long-term outcomes and the transplant might be seen as a waste. Risks of multiple failed retransplants thus could result in a net loss to the US organ pool.

Most transplant candidates, however, can pursue living donation as an option, which would not impact deceased donation organ availability. In a study of undocumented immigrants with ESRD, approximately 60% of participants had a family member willing to donate a kidney but lacked access to organ transplantation due to lack of insurance coverage for immunosuppressive medication, donor surgery, or both.[38] Moreover, it is unfair to deny organ transplantation to this population, as 3.3% of the deceased donor pool is contributed by noncitizens.[1] The "net loss" argument thus can be challenged given that undocumented immigrants currently contribute to the organ pool both as deceased organ donors and as living organ donors. However, their ability to contribute as living organ donors may be limited as described above. Moreover, proponents of retransplantation argue that citizenship status should not be a consideration in listing for transplantation.[21]

Recommendations

We propose the following recommendations:

1. Policy addressing access to immunosuppression and follow-up care beyond 18 years of age for undocumented immigrants needs to be created. A potential solution would be continuation of previously accessible programs like state-sponsored Medicaid and CHIP, which already exist for patients under the age of 18 in some states.
2. Funding (both federal and state) for follow-up care and immunosuppressive medications could be secured by (*a*) extension of the Disproportionate Share

Hospital (DSH) Payment Program, (*b*) state-led efforts like California's Medi-Cal program, or (*c*) extending access to the ACA marketplace to undocumented immigrants.[39,40] This recommendation is further supported by new evidence suggesting that, when insured, nonresident aliens have transplant outcomes similar to insured US citizens.[41]

In the case of Anna, the United States provided her with a kidney to save her life. The country failed to provide her with the financial means to obtain immunosuppressive therapies needed to maintain her kidney. There is an urgent need to identify potential funding sources for maintenance of transplanted organs. In addition, we call for federal and state-level examination of policies for organ retransplantation and provision of immunosuppressive drugs for undocumented persons.

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