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Undocumented Immigrants And Kidney Transplant: Costs And Controversy

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Abstract

A nephrologist's patient is ideally suited for kidney transplant—except that he is an undocumented immigrant.

It is a Monday afternoon like any other and time to make my weekly rounds at the San Francisco General Hospital out-patient dialysis center. I walk into the brightly lit unit just down the hall from my office. From the nurses station, I hear the usual hum of a shift change. Like a medical do-si-do, each staff member quickly, methodically, ushers a patient from his or her recliner when dialysis is complete, only to fill it right away with the next patient. I take my patients' medical charts down from the filing cabinet and load them between the vertical dividers on a waist-high cart. As I look at the names labeling each chart's spine, I am reminded that for my patients, "to live" means being tethered to a dialysis machine for hours several times each week because kidney transplantation is rarely an option for them. One patient's heart failure is deemed too severe to withstand the transplant surgery. Another has dementia, preventing him from remembering what he ate for dinner last night, let alone detailed post-transplant instructions. Then there is my patient who won't stop using heroin, when cigarette smoking alone will get you rejected from transplant consideration.

But Mr. Rojas is different.

I push my cart down the long aisle of our L-shaped dialysis unit and see Mr. Rojas, my dialysis patient for over a year now. He is in his mid-forties and slender, sitting in the burgundy-colored vinyl recliner. His blue-jeaned legs and sneakered feet are propped up on the extended leg rest. The top of his head shines through thinning salt-and-pepper hair. White earbud headphones peek through gray sideburns. He is looking intently at his Kindle, rarely glancing up at the activity around him. He stands out as the calm among a row of controlled chaos. His neighbor is yelling. "But there's nothing left to eat!" he screams at the wide-eyed dietitian with her long list of high-potassium foods to avoid. The ambulance crew is bundling up a patient on a gurney for transport back to the long-term care facility. One after another, dialysis machines beckon a technician to silence their alarms, while another technician belts out, "You are the wind beneath my wings," as he saunters around the unit, his version of whistling while he works.

I approach Mr. Rojas, knowing he will be my only quick visit of the day. I will not have to repeatedly shout or nudge him out of a drug-induced stupor. I will not have to arrange for urgent removal of a dialysis catheter that has become infected because he did not follow instructions to keep the dressing dry. I will not have to pull pill bottle after pill bottle from his bag of medications as I ask, “How many times a day are you taking this one?” Mr. Rojas is the eye in a storm of challenging visits.

I roll my cart up to his recliner, catching his eye. His right hand removes the earbuds as the left pauses his movie. He looks up at me, smiling. “*Hola, Doctora. How are you?*” he says with emphasis on the “are.”

“I am good. How are *you* doing?” I smile back at him as I grab his chart from the rack. I write down his blood pressure and pulse—both normal—and the excellent blood flow displayed on the dialysis machine. My eyes shift to his fistula, the surgically thickened vein robustly coursing halfway up his left forearm like a slithering garden snake. It is beautiful to me. Through it, Mr. Rojas is connected to the dialysis machine. Because he followed doctors’ advice to have a fistula created months before dialysis was necessary, he never had to have a dialysis catheter inserted. Although a catheter damages the large blood vessel in which it lies and is prone to infection and clotting, it’s the only option for patients who haven’t prepared but face otherwise imminent death from kidney failure.

“I am good, *Doctora*. No problems. I feel healthy. Strong.” His brown eyes glint.

I smile at him. Besides kidney failure, he has no other major illnesses. He shows up for dialysis as scheduled, every Monday, Wednesday, and Friday. He stays for his full three-hour treatment. His blood test results are almost always within goal ranges. He won’t need me to repeat again the importance of limiting high-potassium foods between treatments. He knows what his medications are—and he takes them. When I press my thumb against his outer ankle during the visit, it won’t create a dimple as it does in other patients who drink too much fluid between dialysis runs, which can weaken the heart over time. He has never used drugs, doesn’t smoke, works a steady job as a dishwasher, and has supportive friends and family in the area. He is young. Mr. Rojas is an ideal kidney transplant candidate.

But none of these details matter. Even though transplant promises a significantly longer and better quality of life, I will not refer Mr. Rojas to the transplant center for evaluation, because the only detail that matters in this case is that Mr. Rojas is a poor, undocumented immigrant. And America does not give transplants to poor, undocumented immigrants.

Exception To The Rule

Except for Jesus Navarro. Although he was a poor, undocumented immigrant like my patient, Mr. Navarro did receive a kidney transplant.

Mr. Navarro was on a local transplant center’s kidney waitlist. He had been a dialysis patient for seven years and had private insurance through his employer. Then an immigration audit exposed Mr. Navarro’s citizenship status, and he lost his welding job of fourteen years. According to media reports, he was able to keep his insurance under the COBRA provision

that allows people who lose a job to pay the full premium and maintain coverage. But even if he found a way to make those payments, that option would run out after eighteen months. When the transplant center learned of Mr. Navarro's circumstances, his status on the center's kidney transplant waiting list was changed to "inactive," making him ineligible for a transplant.

When the newspapers learned of Mr. Navarro's story, they reported that he was removed from the list because of his immigration status. That he was effectively being sentenced to die. That his three-year-old daughter would be fatherless.

The transplant center administration denied the accusation. It claimed that his status was changed to "inactive" because he didn't have stable insurance coverage, not because of his immigration status. Without the certainty of insurance coverage over the long term, the transplant center explained, he would not be able to afford expensive post-transplant care and medications.

Post-transplant immunosuppressant medications cost more than \$1,000 a month without medical insurance. These medications are required to muzzle humans' rabid dog-like immune system, which is relentlessly working to destroy anything it doesn't recognize as "self." Stop taking the pills and the rabid dog resurges to full attack. Take the pills less often, as the poor commonly do to make medications last longer, and the beast is allowed to gain strength and slowly gnaw away at the transplanted organ. The inevitable result is a kidney lost, wasted, while others die waiting for a transplant. The transplant center's goal is to transplant kidneys only into those who will likely be able to take care of them for the longest amount of time. So unfortunately, the center said, it could not take a chance on Mr. Navarro.

From around the country, an army of outraged people came together in common cause: A Community, as I will call them, emerged. This group included more than 100,000 supporters who signed online petitions in protest. A wealthy sympathizer helped Mr. Navarro resume his insurance. A local clinic promised free post-transplant care for life. Soon after, Mr. Navarro was reinstated to "active" status on the kidney transplant waitlist, and a kidney became available for him within months. Because all along, the transplant center insisted, the issue was insurance status. Not immigration status.

Standard Of Care

Mr. Navarro's story unfolded around the time Mr. Rojas became my dialysis patient. Admittedly, I took some twisted delight in the transplant center administration's squirming under the public scrutiny like a worm on a hook, trying to free itself from the appearance of wrongdoing. I saw it as a bit of retribution for the center's lack of transparency, but my delight quickly dissolved into envy. Where was A Community for Mr. Rojas and the others like him who we cared for at our dialysis center? Where were the promises for them? Where was the outrage on their behalf?

I wanted a workaround for Mr. Rojas. But there was no finagling that would allow him to obtain private insurance. The work visa through which he gained legal entry to this country

twelve years ago had long since expired. Like most undocumented immigrants, he worked in a low-income field that did not offer private health insurance, and his undocumented status alone made him ineligible for Medicaid programs available to other low-income citizens. Emergency Medicaid is the only coverage accessible to the undocumented poor, and it does not pay for transplants.

Policy Checklist

The issue

In the United States care for undocumented immigrants with end-stage renal disease is fragmented, often clinically inappropriate, and not cost-effective.

Resources

National Immigration Law Center, Immigrants and the Affordable Care Act, <http://www.nilc.org/immigrantsshr.html>

The Hasting Center's Undocumented Patients project, <http://www.undocumentedpatients.org/>

Related reading

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In a sense, my undocumented patients are lucky to be in California, where regular dialysis is an option. California is one of only a handful of states whose Emergency Medicaid programs pay for regular dialysis. Most states' programs pay only for emergency dialysis treatment, as required by the Emergency Medical Treatment and Active Labor Act (EMTALA) of 1985, which mandated provision of emergency care for uninsured people with life-threatening conditions—even the undocumented. However, it is up to the individual states to decide what constitutes "life-threatening." In most states, only those undocumented immigrants with potassium levels high enough to stop their hearts from beating are guaranteed emergency dialysis treatment.

Some immigration opponents say that providing anything but emergency care to undocumented immigrants would impose an additional financial burden on taxpayers at a time when millions of uninsured citizens already receive billions in costly, uncompensated care. They make this claim even though undocumented immigrants make up only about 1 percent of the US population with dialysis-requiring kidney disease. In reality, such restrictions may actually cost society far more over the long run. A 2007 study published in *Texas Medicine* found that for a similar number of patients, emergency dialysis cost nearly four times more than regular dialysis. What's more, a 2012 study in the *American Journal of Kidney Diseases* found that refusing individuals a transplant only to keep them on dialysis indefinitely also makes limited financial sense. After the first year of kidney transplant, its annual cost is only about a third of the annual cost of regular dialysis at a dialysis center. Yet in a shortsighted attempt to limit undocumented immigrants' burden on taxpayers, the current system actually relegates them to more expensive care.

Opponents also say that allowing undocumented immigrants to gain access to coveted health services, such as regular dialysis and kidney transplantation, would incentivize more illegal immigration. Yet according to a 2011 publication from the Pew Research Center, California—the state with the largest undocumented immigrant population *and* a regular dialysis provision—has not seen a significant rise in its undocumented immigrant population since 2005. Nor has the state seen an increase in the number of undocumented immigrants receiving dialysis.

Another argument suggests that allowing immigrants to receive transplants would take precious organs away from American citizens waiting for a kidney transplant. In 2012 only about one of every five citizens waiting for a kidney transplant received one. There are simply not enough donated kidneys to go around. However, because the undocumented community tends to be young and healthy, the few with kidney failure would likely have a healthy friend or family member willing and able to donate one of their kidneys. In these cases, a transplant would not take a kidney from the limited pool of donor kidneys. But without the money or insurance to pay for transplant surgery or the post-transplant care and medications, just having a potential kidney donor is like having a spare tire but no jack.

Undocumented immigrants come here dreaming of—and often finding—a better life than the one they could have at home. That was certainly the case for Mr. Rojas. The work visa was his way into America and his chance at a better life. He never intended to go back to his home country even if the printing job that brought him here didn't last. He hoped to earn enough money to help support his wife and three children, who were nine, six, and three when he left. He also hoped to eventually bring them all to the United States but was never able to realize that dream.

I am not an immigrant or the daughter of immigrants. As a black person whose roots trace only to Alabama and slavery, I cannot claim to understand the complexities of Mr. Rojas' history as fully as I can my own. Nor am I an expert on the complicated story of immigration in this country or the 1,000 or so pages of recently proposed immigration reform legislation. I have no horse of my own in this race to bias my position. I just want to take care of the patient in front of me in the way that I know is best for him. Considering

that the best option for Mr. Rojas also happens to be the least expensive option as well, changes in federal policy should be a given.

Yet we haven't made them.

A Broader Community

The action of A Community made a kidney transplant possible for Jesus Navarro. But his experience is rare; much more common are the many individuals who would be appropriate candidates for a kidney transplant if it weren't for the burdens of cost and access. These are persistent challenges that cannot be solved by a single wealthy advocate, clinic, transplant center, or even a single state. What we need is An Even Broader Community to come together and call on our federal government to mandate and fund a clinically appropriate and cost-effective standard of care for all people with end-stage kidney disease within our borders. This is a community I would proudly join, for Mr. Rojas and for everyone like him.

This day as I round, I don't want a quick visit with Mr. Rojas. I want to linger. I move my cart of charts aside and look for one of the medical stools scattered around the unit. I find one nearby. Its worn, black faux leather cushion has a lightning bolt-shaped crack coursing across its middle. Traces of foam padding peek through. Its metal casters swivel around and roll like a wonky grocery store cart as I guide it toward Mr. Rojas' recliner.

I sit, sweeping the back of my white coat beneath me. My knees touch his recliner. Our eyes are level now.

I tell Mr. Rojas about Mr. Navarro and how A Community advocated for his kidney transplant. A quick squint of the eyes and wrinkle of the forehead betray his surprise.

I tell him about the fragmented system of care around this country for undocumented immigrants with kidney failure. His breaths seem slightly faster, shallower—this is news to him, too.

"What do you think of this?" I ask, hoping for some insight into his world.

There is a long pause. But then he shrugs into a toothy grin. "I feel lucky," he says. "I never feel *racismo*—you know this word in English, *Doctora*?" The slight quiver in his brow tells me that he is not so sure. I nod.

As I stand to leave, I watch the glint in his eye fade. He stares ahead at nothing, focused on his own thoughts. I walk away, regretting that I've given him information he is powerless to do anything about.