

MEDICINE AND SOCIETY

Strategies for Responding to Undocumented Immigrants With Kidney Disease

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Abstract

It is a tough road for undocumented immigrants with kidney disease. There are many barriers that these patients must overcome, which prevents them from receiving proper treatments to prevent or slow the progression of their kidney disease. Those who are dialysis dependent also face an uphill battle, as some states limit access to regular dialysis. This article describes specific struggles faced by undocumented immigrants with kidney disease and how some physicians have tried to guide their treatments. It also considers how these patients might be helped through health policy changes at the national level.

Kidney Disease Among Undocumented Immigrants

There are an estimated 11 million undocumented immigrants living in the United States.¹ Since the passage of the Affordable Care Act (ACA) in 2010, the number of uninsured people younger than age 65 in the United States fell by almost 7% between 2010 and 2015.² However, the ACA does not provide coverage for undocumented immigrants, and they currently make up 27% of the uninsured population in the United States.³ Approximately 6500 undocumented immigrants in the United States have end-stage renal disease (ESRD).⁴

The overall prevalence of chronic kidney disease (CKD) in the United States is about 13% to 16%.⁵ Major causes of CKD are diabetes and hypertension. Early recognition of CKD can potentially treat or slow its progression, prevent complications related to the disease, and improve outcomes related to cardiovascular disease.⁶ Early recognition can also lead to early referral to a nephrologist, which has shown to improve mortality and increased access to transplantation among those who progress to ESRD.⁷⁻⁸ One of the major difficulties is that CKD normally does not have any signs or symptoms until the advanced stages when treatments are less effective; there is evidence that CKD awareness remains low among both patients and clinicians.⁹

This article describes barriers to accessing care faced by undocumented immigrants with kidney disease and how some physicians have tried to guide their treatments. I also consider how we might help these patients through health policy changes at the national level.

Planning Dialysis

Undocumented immigrants with CKD have very few options for management of their kidney disease, even when they are aware of their disease. Given their lack of medical insurance, many of these patients don't receive care until they develop severe symptoms of kidney disease and soon become dependent on dialysis. For this reason, the most important component of caring for these patients is screening and prevention. The National Kidney Foundation (NKF) initiated the Kidney Early Evaluation Program, which, between 2000 and 2013, offered free screening for CKD among those with high-risk features including but not limited to diabetes, hypertension, and family history of kidney disease.¹⁰ The NKF made an effort to refer patients diagnosed with kidney disease and without insurance to a clinician or public health facility,¹⁰ but it is difficult for undocumented immigrants to navigate our health care system. Currently, care for these patients is primarily through safety-net hospitals and federally qualified health centers (FQHCs). FQHCs are paid based on a prospective payment system for medically necessary primary health services and qualified preventive health services furnished by an FQHC practitioner.¹¹ However, it is not clear how many undocumented immigrants are aware of these facilities, and, based on my personal experience treating these patients, it is very difficult for them to get optimal care.

Managing undocumented patients with early CKD is generally not difficult once they are plugged into a clinic able to provide standard care for management of CKD with medications. Most medications for management of CKD are related to hypertension and diabetes and are affordable. Organizations such as Walmart and Target Pharmacy[®] offer \$4 and \$10 generic medication lists that are affordable even for low-income families.^{12,13} GoodRx also offers patients coupons so they can save even more money on prescriptions.¹⁴ However, the difficulty presents itself later when some of these patients require advanced procedures, such as kidney biopsies or vascular access placement. Many undocumented patients with advanced CKD are young, and their kidney disease might not be attributable to diabetes. This is important, as some of these other diseases, if treated, can prevent these patients from requiring dialysis. In these circumstances, a kidney biopsy would be needed to diagnose and potentially treat the disease. However, a biopsy would require a procedure room, supplies, multiple physicians—including a nephrologist, a pathologist, and potentially a radiologist—and the patient would need to be admitted to the hospital if there were any complications. It is very difficult to set up this kind of procedure in most hospitals, as it is both expensive and not covered by Emergency Medical Assistance (EMA), a public health care program for noncitizens with emergency medical conditions.¹⁵ In addition, some medications used to treat diseases that can cause CKD, such as systemic lupus erythematosus, are expensive without proper insurance coverage.

As a patient's kidney disease worsens, it is important to plan for dialysis by placing a permanent vascular access with an arteriovenous fistula (AVF) or arteriovenous graft

(AVG). Vascular access planning requires imaging, surgery, and close follow up. Although most patients in the United States initiate dialysis without an AVF or AVG, doing so is associated with increased infections and increased mortality.¹⁶ Given the expense and nonemergent nature of these procedures, it becomes difficult to provide undocumented patients with advanced CKD the [standard of care](#), as many health systems require extensive documentation prior to these procedures being scheduled. Such documentation includes a physician's statement that the intended procedure is related to an emergency medical condition and the patient's source of income, place of residence, and current immigration status. Although the hospital hopes to receive some reimbursement, in most cases, vascular access placement for undocumented patients would classify as charity care. Performing this procedure would not be an issue for the documented CKD patient with insurance. At this time, however, undocumented patients may be reluctant to provide such documentation out of fear of potential consequences, including being reported.

Managing Undocumented Immigrants' CKD With Dialysis

Care for undocumented immigrants who are dialysis dependent is difficult, and what's offered and what's covered vary from state to state. In 1972, Congress passed Public Law 92-603, Social Security Amendments of 1972, which mandated [Medicare coverage for dialysis](#) for all patients with ESRD who qualified for Social Security benefits or were the spouse or dependent of someone who did.¹⁷ Unfortunately, this coverage did not extend to undocumented immigrants even if they contributed payroll taxes. In certain states, such as Texas, many undocumented immigrants only qualify for [emergency dialysis](#), which is provided only when potentially deadly lab findings or symptoms exist.¹⁸

Several studies have highlighted the need for standard dialysis for undocumented immigrants. One study conducted in Texas found that, compared to patients receiving standard dialysis, undocumented immigrants receiving emergency dialysis on average spent more days as inpatients (162 days vs 10 days), had more emergency department visits (26.3 vs 1.4), more blood transfusions (24.9 vs 2.2), fewer dialysis treatments per year (98 vs 154), greater physical pain and lower level of physical function, and higher annual costs (\$284 655 vs \$76 906).¹⁹ A 2018 retrospective study by Cervantes et al. found that, 5 years after dialysis initiation, undocumented immigrants who received emergency-only dialysis had a 14-fold higher relative hazard of mortality compared to undocumented immigrants who received standard dialysis.²⁰ Undocumented immigrants with ESRD experience debilitating, potentially life-threatening physical symptoms and psychosocial distress resulting from emergency-only dialysis. One participant in a study evaluating the experience of immigrants with ESRD reported, "When I talk to other [undocumented] people in hemodialysis, I say, 'Live your life to the fullest because we don't know if we'll be here next week.'"²¹ Some undocumented patients with ESRD can receive scheduled dialysis through state or local funding or a charity. For example, in

California all undocumented patients who require dialysis can receive regular scheduled dialysis through Medicaid for emergency care.²²

Transplantation would be a great option for most undocumented immigrants with ESRD. Undocumented immigrants with ESRD are normally younger, have fewer comorbidities, and have a potential living donor.²³ These characteristics make them ideal transplant candidates who are likely to have good outcomes. Unfortunately, most of them are [unable to get a transplant](#) due to lack of insurance.²⁴ What is more, one study estimates that uninsured patients receive less than 1% of all organs but contribute about 17% of transplanted organs.²⁵

I have had experience caring for dialysis-dependent undocumented immigrants from the perspective of both nephrology and critical care. While I was caring for patients in Pennsylvania as a nephrologist, undocumented immigrants were able to receive regularly scheduled dialysis in the outpatient setting funded by EMA.²⁶ However, EMA does not always cover services that are not associated with dialysis. For example, if the patient were to require a colonoscopy, a gastroenterologist would need to fill out an EMA form that states that the patient has an emergency medical condition.²⁶ Such barriers to treatment require the nephrologist to take on more of a primary care role and find other ways to refer to specialists when needed. While training in Texas as an intensivist, I took care of the unfortunate group of patients that presented to the hospital for emergent dialysis. Often, these patients presented to the hospital unstable, with major lab abnormalities requiring admission to the intensive care unit. They usually improved quickly and could be discharged home, only to present to the hospital again a few weeks later. This cycle could be easily prevented through routine dialysis for these patients via permanent vascular access with an AVF or AVG. Due to presenting to the hospital in such an unstable condition, many undocumented patients with ESRD require sustained low-efficiency dialysis that requires placement of a temporary dialysis catheter. Unfortunately, due to their repeated admissions, these patients may have few places to place a temporary dialysis catheter due to severe calcification or stenosis of the blood vessels related to their kidney disease and repeated catheter placements. This is an important consideration in critical care, as vascular access is the lifeline for each dialysis patient. Lastly, these patients are unable to have normal jobs and provide for their families given their conditions.

Meeting Challenges of CKD in Undocumented Immigrants

Undocumented immigrants with CKD continue to face many challenges in the United States. The problem of access to care will not be fixed by the ACA, as undocumented immigrants do not qualify for public insurance programs even if they have the ability to pay for such services.²⁷ Few immigrants have been able to get coverage for regularly scheduled dialysis under unsubsidized commercial plans, but the sustainability of this option is unknown and still leaves many without coverage.³ Although emergency dialysis

is covered by law,²⁹ regularly scheduled dialysis is still not the standard of care for most undocumented immigrants in the United States.³⁰ Research has shown the potential benefits to both patients and the country of regularly scheduled dialysis, so continued advocacy for undocumented patients with ESRD is needed to make sure they get the proper care they deserve. However, more important may be the prevention of their kidney disease. Proper screening and primary care needs to become more easily accessible to undocumented immigrants with CKD. This includes not only treatments to treat or slow the progression of their kidney disease but also treatments focused on their diabetes and cardiovascular disease. More research needs to be directed at prevention of disease in this population, which will also require working with policymakers to find the best interventions to provide care for these disadvantaged patients.

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