

Caring for Undocumented Immigrants With Kidney Disease

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The care of dialysis-dependent undocumented immigrants exemplifies a problem at the crux of 2 US national agendas: immigration and health care reform. Undocumented immigrants represent 3% of the US population and 27% of the uninsured, and an estimated 6,500 individuals are dialysis dependent. With no uniform national policy, an estimated 30% to 50% of these individuals receive treatment only in life-threatening situations (emergent dialysis). Since 2005, about 400 undocumented immigrants have received a kidney transplant (>70% living). Although the Affordable Care Act specifically excluded noncitizens, its policies have indirectly allowed more than 200 individuals to purchase insurance from a health insurance exchange and transition from emergent to thrice-weekly hemodialysis. Under the Trump administration, uncertainties with health care plans, threats of deportation, and rescinding of policies such as sanctuary city status are bound to result in unforeseen challenges for this vulnerable population. Global variation in the care accessible to migrants, refugees, undocumented immigrants, and asylum seekers argues for the need for a framework to transform advocacy into public policy to improve the lives of patients with kidney disease worldwide. Access to nonemergent dialysis is humane and cost-effective; it deserves to be espoused and advocated by leading medical organizations.

Complete author and article information provided before references.

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Introduction

Undocumented immigrants constitute 3% of the US population and are the largest group (27%) among the uninsured, despite passage of the Affordable Care Act (ACA) and expansion of state-based insurance coverage.¹ Worldwide, globalization and mass migration of refugees have forced host countries to reexamine their health care policies for noncitizens with chronic illnesses, including those with chronic kidney disease (CKD). The fundamental question for policy makers is whether to provide equal access to health care for all individuals within their national border, regardless of legal immigration status.

There is a lack of uniform policy for provision of care for undocumented immigrants with kidney failure, with variability within and among states in the United States and also among countries worldwide.^{2,3} The result of these inconsistent approaches is increased costs for hospital systems, reduced quality of life for patients, and daily ethical dilemmas for providers forced to determine “who deserves hemodialysis today?”⁴⁻⁷

Two comprehensive reviews on the care of dialysis-dependent undocumented immigrants have been published.^{2,8} This *AJKD* Policy Forum article provides an update, considers looming US policy changes, examines how noncitizens receive kidney care globally, and proposes an approach to document and advocate solutions that can improve the care of this population. The purpose of this

Perspective is to stimulate research and public discussion of the issues to create cost-effective and humane solutions for the care of undocumented immigrants with kidney failure.

Background

In 2014, the estimated number of undocumented immigrants was 11.4 million, or 3.5% of the total US population. States with the highest shares were California (20.9%), Texas (14.7%), Florida (7.5%), New York (6.9%), New Jersey (4.4%), and Illinois (4.0%).¹ Though Mexicans account for 52% of undocumented immigrants, this percentage has declined since 2007 due to downturns in the US economy, improved economic conditions in Mexico, and a personal desire for family reunification.^{1,9} Simultaneously, immigration from Central America has increased due to regional political and socioeconomic conditions and high rates of homicide and violence. In 2016 alone, US Customs officials intercepted 46,900 unaccompanied children and more than 70,400 families from El Salvador, Guatemala, and Honduras arriving at the border between the United States and Mexico.¹⁰

Undocumented uninsured patients obtain basic care at Federally Qualified Health Centers or safety net hospital systems, which provide care regardless of citizenship or ability to pay. These facilities often provide culturally oriented care, employing local bilingual staff to overcome common barriers such as lack of

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Policy Forum highlights aspects of nephrology relating to payment and social policy, legislation, regulation, demographics, politics, and ethics, contextualizing these issues as they relate to the lives and practices of members of the kidney community, including providers, payers, and patients.

social support or English proficiency.^{11,12} Development of trust with the health care system is particularly important to undocumented immigrants, who live in constant fear of being apprehended or deported.¹³

Much of the health care for undocumented immigrants with chronic diseases is of poor quality and unreimbursed.^{7,14} Barriers to the use of health care include: (1) immigration policy (documentation and deportation), (2) characteristics of the health care system itself (bureaucracy and discrimination), and (3) individual concerns (insurance costs and shame).^{7,15} Documenting the number of such individuals with kidney failure is critical to addressing their communal problem but is impossible in the absence of registries or databases.¹⁶ One published figure is 6,500 individuals, estimated from the US Renal Data System incidence rate of end-stage renal disease (515 per million) among Hispanics.^{8,16} The cause of kidney disease in this population is also not well documented. Available descriptive analyses suggest that these patients are younger, male, and nondiabetic and present with small atrophic kidneys.^{17,18}

Dialysis for Undocumented Immigrants

In the United States, the 1972 End-Stage Renal Disease Amendment to the Social Security Act (Public Law 92-603) made access to dialysis and transplantation available to nearly all citizens.¹⁹ Undocumented immigrants do not qualify for Medicare; hence, the patchwork of dialysis options that exist among and within states. It is estimated that >30% of undocumented immigrants with chronic kidney failure receive emergent hemodialysis that is provided only when life-threatening laboratory abnormalities (usually hyperkalemia) and volume overload uremic symptoms exist.^{7,20} Emergent hemodialysis is associated with reduced quality of life and undue stress on providers, who face difficult moral dilemmas in providing their care.⁴⁻⁶ Emergent hemodialysis patients are classified as “super-utilizers,” with large estimated costs to local health care systems: \$285,000 per person annually in Houston in 2007 and more than \$400,000 per person annually in Denver in 2013.^{4,21} In a prospective study from one Indianapolis safety net system, per-patient reimbursement (\$33,329 vs \$20,309) and reimbursement to cost ratio (2.49 vs 1.49) ironically fiscally favored the emergent system over twice-weekly hemodialysis from the perspective of the medical provider.^{22,23}

Some undocumented immigrants obtain nonemergent dialysis via state funding (Medicaid) or local resources. Local municipalities support this on principle and because it is more cost-effective systemwide.⁴ In Houston, 50% of the more than 300 hemodialysis-dependent undocumented immigrants receive treatment at an outpatient clinic that is funded from city property taxes.³ In California, all undocumented patients who require dialysis are granted Permanent Residence Under Color of Law (PRUCOL) status. PRUCOL is a public benefits eligibility

category created by the US Courts of Appeals for the Second Circuit that entitles undocumented immigrants who reside in the United States to Medicaid benefits; it is not an immigration status recognized by the US government.²² Finally, some undocumented immigrants receive thrice-weekly or home dialysis as charity at outpatient centers.⁷ In Houston, more than 20 undocumented immigrant patients, who initiated dialysis therapy as children or after failed allografts under PRUCOL, continue to dialyze at the Texas Children’s Hospital as young adults.

The ACA health insurance exchanges provided a forum for nearly 13 million individuals in the United States to purchase health insurance in 2016.⁹ Eligible individuals include US citizens and lawfully present immigrants, such as permanent residents, workers with valid visas (eg, H1 and student), and asylum seekers. Although undocumented immigrants were specifically excluded from subsidized ACA plans, the elimination of preexisting conditions exclusions has enabled coverage under unsubsidized commercial plans. Since 2014, more than 200 undocumented dialysis-dependent patients in Texas and Illinois have purchased “off-exchange” plans that cover thrice-weekly dialysis in outpatient clinics.^{19,24} These plans are upheld by one insurance company, they do not require a social security number to register, and the monthly premium is funded by a third-party payer.¹⁶ Although this has decompressed overburdened hospital systems providing emergent hemodialysis, its sustainability is unknown, particularly with ongoing efforts to repeal, replace, or weaken the ACA. Opponents believe that offering dialysis or transplantation could incentivize and increase illegal immigration. However, in California, which has the largest undocumented immigrant population and a provision to cover nonemergent dialysis, there has been no evidence of a significant increase in its undocumented immigrant population since 2005.²⁵

Kidney Transplantation, Peritoneal Dialysis, and Conservative Care

Dialysis-dependent undocumented immigrants are younger, have a lower incidence of cardiovascular disease or diabetes, have a strong desire to keep working, and at least 60% of them have a potential kidney donor.²⁶ However, transplantation for this population rarely occurs due to insurance barriers, deceased donor organ shortage, United Network for Organ Sharing policies on the number of noncitizens listed per center (<5%), and the political climate regarding access to health care.²⁷ However, living kidney transplantation for young undocumented patients with no major comorbid conditions is economically beneficial to both patients and society, as evidenced from increased life expectancy, ability to return to work, potential growth of the live donor pool, and a less expensive alternative to dialysis.²⁶ Fiscally, >50% of employed undocumented immigrants pay income taxes and 100% pay sales tax (except in states in which this tax is

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