

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

What Should Clinicians in Organizations Without Established MLP Programs Do When Their Patients Need Lawyers to Meet Their Health Needs?

Dinushika Mohottige, MD, MPH, Karina Albistegui Adler, JD, Allison Charney, JD, and Lilia Cervantes, MD, MSc

Abstract

Undocumented people in the United States face innumerable legal and structural barriers to health and health care services, including for kidney failure. Their experiences vary across states and regions due to wide variation in insurance coverage and unreliable access to health-promoting resources, including medical-legal partnerships. This commentary on a case canvasses key policy about structural and legal determinants of health for undocumented persons.

Case

In the emergency department (ED) of a large, urban academic health center near the US-Mexico border, Dr B encounters GG, who presents with severe fatigue, headache, dysuria (painful urination), and aching joints. After GG is stabilized, metabolic tests reveal that GG has kidney failure. Dr B refers GG immediately for emergency dialysis and then routine dialysis follow-up. However, due to GG's immigration status, the state's Medicaid program does not reimburse for routine dialysis, only for emergency dialysis.

Three weeks later, Dr B gets called back to the ED because GG is back with severe life-threatening symptoms (hyperkalemia, confusion, and hypoxia from pulmonary edema) due to lack of routine dialysis. Dr B is morally distressed and outraged that he has had to witness GG's symptoms become life-threatening due to the state Medicaid program's lack of coverage for optimal kidney care (eg, routine dialysis).

Dr B thinks, "My patient needs a lawyer," and wonders what to do.

Commentary

Clinicians' moral distress stemming from their inability to provide optimal care for individuals like GG and questions regarding how to improve care for undocumented individuals have generated critical national discourse, investigation, and equity-enhancing policy reform related to caring for undocumented people with kidney disease. Over 2 decades of studies have documented the extensive, multilevel harm and financial cost associated with emergency-only dialysis for individuals with kidney

failure.^{1,2,3,4,5,6,7} Compared to individuals receiving routine hemodialysis, those who rely on emergency dialysis experience an almost 5-fold greater hazard of 1-year mortality⁸ and a 14-fold greater hazard of 5-year mortality.⁹ Patients and their caregivers describe substantial morbidity and symptoms related to emergency dialysis treatments, including death anxiety and caregiver stress related to finances, care navigation, and emotional distress, which have multigenerational impacts.^{4,6,10} Primary care clinicians and emergency medicine and nephrology specialists also describe substantial moral distress related to providing emergency-only dialysis: witnessing suffering among individuals who have inadequate treatments, needing to balance ethics and laws, and experiencing discordance with principles of ethics that underlie medical training.^{4,9,11,12,13}

Calls for evidence-based analyses to assess the cost effectiveness of and outcomes associated with a shift from emergency-only to routine **dialysis for undocumented immigrants** have been answered with rigorous qualitative and quantitative studies spanning a decade.¹⁴ Some studies demonstrate the morbidity, mortality, social, and economic benefits of comprehensive kidney care options, including transplantation.¹⁴ Other studies report reduction in mortality, emergency department visits, hospitalizations, and length of stay with routine dialysis compared to emergency-only dialysis.^{8,9} In a study of individuals who transitioned from emergency to routine dialysis in Colorado, patients reported significant improvement in quality of life and multiple symptoms, including anxiety, depression, pain, and dyspnea.¹⁵ In Colorado, emergency dialysis expenditures for undocumented immigrants averaged over \$20 000 per person per month from 2017 until 2019, when a policy change that included kidney failure as a qualifying condition for **emergency Medicaid** (EM) went into effect, lowering routine dialysis expenditures for undocumented immigrants to an average of \$5574 per person per month in 2021 and saving the state nearly \$15 000 per person per month.⁵ A cohort study from California demonstrated that kidney transplant outcomes among undocumented immigrants were not inferior to those of US residents,¹⁶ thereby debunking myths regarding risk of kidney transplantation among undocumented individuals, who account for a substantially greater proportion of kidney donors (8% to 10%) than recipients (1%).^{17,18,19}

In light of these findings, we provide a roadmap for clinician empowerment and action, which begins with a broadened understanding of the legal and regulatory context in which undocumented individuals like GG receive kidney care. We also describe policies that have been leveraged to ensure more comprehensive care for undocumented individuals and opportunities to enhance care through policy advocacy and structurally competent practice.

Recognizing the Legal and Regulatory Context

Providing optimal care for GG and other undocumented immigrants requires **recognizing the barriers** they face in receiving high-quality care and the patchwork of legal environments and state-specific policies that shape the landscape in which health care is delivered. Each of these factors exerts a unique influence on undocumented individuals' health and sociopolitical experiences and their health care resources—from primary care to subspecialty care, including dialysis for kidney failure.^{1,2,13,20,21,22,23,24,25} The Personal Responsibility and Work Opportunity Act of 1996 (PWORA) is cited along with numerous associated restrictive federal policies as a foundational structural barrier for undocumented individuals due to explicit provisions restricting such individuals from accessing federal benefits, including health care programs and assistance programs such as Medicaid and Medicare.^{25,26,27}

Post-PWORA, several states took steps to maintain certain undocumented individuals' eligibility for health benefits through a court-created eligibility category known as Permanently Residing Under Color of Law (PRUCOL). Those states include New York, California, Connecticut, Hawaii, Illinois, Massachusetts, and Virginia.²⁸ Although benefits vary by state, many offer comprehensive health insurance coverage that mimics Medicaid. For instance, in New York, certain undocumented individuals may be designated as PRUCOL under the state's health code for the purpose of health insurance eligibility.²⁹ Not to be confused with a lawful immigration status, PRUCOL designation does, for many, confer long-term eligibility for means-tested benefits (ie, adjusted based on gross income), such as state Medicaid. In short, the patchwork of legal environments and state-specific policies provides an impetus for policy makers, advocates, and health care practitioners to consider state and federal policies that can provide overarching protections for individuals regardless of the states in which they reside.^{21,22,24,25}

Leveraging EMTALA and Emergency Medicaid

Despite challenges posed by PWORA and other restrictive policies, legal precedent exists to ensure that undocumented immigrants in the United States have access to critical emergency care.^{7,8,13,29} The 1986 Emergency Medical Treatment and Labor Act (EMTALA) is a key legal provision by which hospitals are required to screen, stabilize, and treat patients found to have an emergency, regardless of immigration status. EM, which reimburses treatment of emergency medical conditions for individuals who are uninsured and excluded from regular Medicaid due to immigration status, also offers a critical lever to expand coverage for undocumented individuals. However, the Centers for Medicare and Medicaid Services (CMS), as affirmed by the Office of the Inspector General, allows states to determine the level of reimbursement and qualification for emergency medical services.^{5,27} Therefore, CMS' deference to states' interpretations of emergency medical conditions and services under EM gives clinician advocates and policy makers a critical policy lever for expanding access to health care for undocumented immigrants.²⁷ EM supplements to state budgets have been described as critical subsidies for promoting innovation in undocumented immigrant health insurance coverage and overall population and public health.²⁷ For instance, Medicaid policy in California offers a path to kidney transplantation for undocumented immigrants via Medi-Cal, which provides immune suppression coverage for individuals who meet specific criteria.^{1,16} California's passage of Senate Bill 104 in 2019 extended eligibility for full-scope Medi-Cal benefits to undocumented youth aged 19 to 25 years regardless of PRUCOL status (with a further extension to adults aged 50 years and older in 2022 and to adults of any age in 2024),^{23,30} and other states have similarly leveraged Medicaid as a path to expand transplant access.³¹ Dr B could consider the state-specific coverage restrictions that exist for GG and work with local and national organizations to advocate for state-specific Medicaid and other policy changes that would expand coverage for routine hemodialysis, potentially further supporting Colorado's demonstration of the overall economic and health benefits of this approach.

Enhance Policy Awareness

Improving care for GG also requires organizational and individual action to recognize—and to advocate against—threats to equity-enhancing policies or programs related to immigration. One salient example is threats to the Deferred Action for Childhood Arrivals (DACA) program, created by an executive order in 2012, which protects eligible undocumented immigrants who were brought to the United States as children from deportation and grants work authorization.³² Multiple studies demonstrate positive

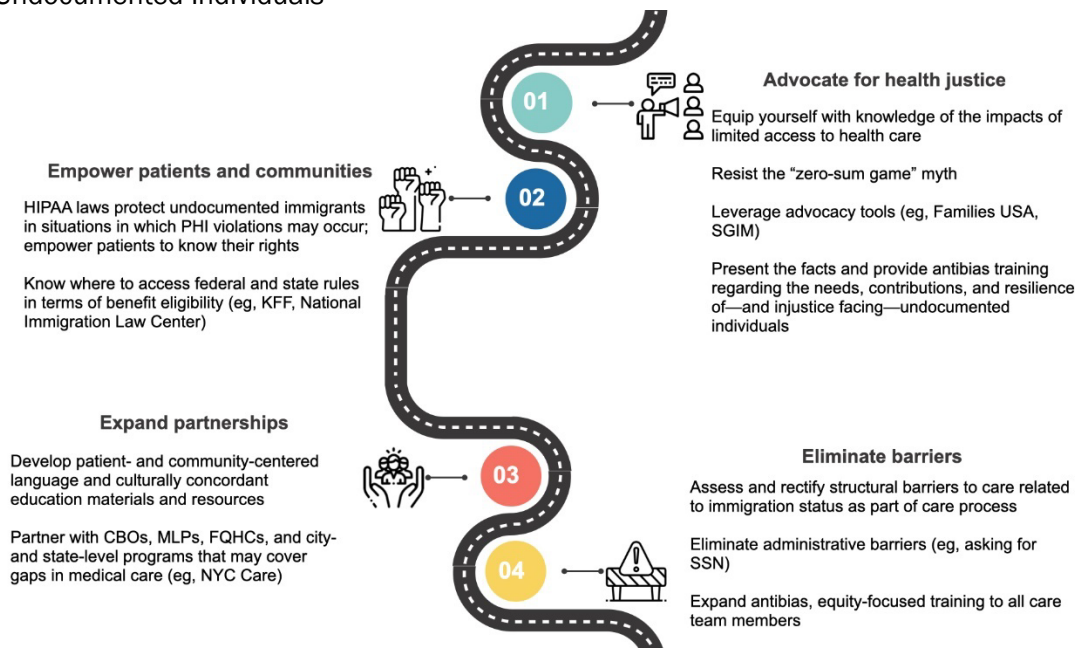
short-term outcomes for DACA recipients, including decreased delays in health care utilization and improved self-reported mental health outcomes.^{32,33} However, ongoing threats to DACA (eg, *Texas v United States*, in which the federal Fifth Circuit Court of Appeals ruled that DACA is unlawful and barred new applicants³⁴) and newer, evolving state-level restrictions (eg, SB 1718 in Florida, which requires Medicaid-accepting hospitals in Florida to inquire about immigration status³⁵) are examples of policies that cause profound social, health-related, and economic harm due to delayed presentations for care and subsequent costs to individuals and health systems.

The legal status and categories of undocumented immigrants add complexity to the structural barriers facing undocumented individuals—including their eligibility for asylum status and other immigration status designations, which impacts their care trajectories and eligibility for state-specific benefits, including transplantation.²⁷ Increasingly, restrictive border policies have ripple effects in immigrant communities, including by limiting an individual's ability to seek asylum at the border or apply for asylum once inside the United States.³⁶ Undocumented individuals also live in diverse communities with pro- or anti-immigrant climates. For instance, in some California counties, investigators found mismatches between community needs and state services and resources, as well as resistance of local law enforcement agencies and policy makers to the state's inclusive policy goals.³⁷ Clinicians like Dr B and organizations should remain vigilant about threats to these inclusive policies and ensure that patients, their caregivers, advocates, and community organizations are empowered with referrals to speak with attorneys if such policies are violated.

Protect and Expand Care Opportunities

To enhance the care of GG and other undocumented immigrants, clinicians and health care systems should be empowered with information about policy advocacy and resources that enhance equitable care (see Figure). Despite broad limitations in access to care, undocumented individuals can access limited primary care and medications through federally qualified health centers in the United States, which may have established partnership agreements with medical centers for referral and consultation (eg, nephrology subspecialty care).^{38,39} When available, medical-legal partnerships (MLPs) may enable clinicians to tackle immigration issues and address legal determinants of health, thereby improving the health and social well-being of undocumented individuals while helping them navigate resources for transportation and housing, for example.^{40,41,42,43,44,45} Finally, clinicians and organizations can demonstrate support for policies that broadly provide health care coverage to all individuals residing in the United States, including those that lift exclusions of immigrants from federal policies as well as those that offer states flexibility to tailor Medicaid for expanded coverage. One example of such legislation is the Health Equity and Access Under the Law for Immigrant Families Act of 2023,⁴⁶ which would remove barriers to health care insurance, including documented immigrants' 5-year waiting period for eligibility for Medicaid, the Children's Health Insurance Program, and access to the Affordable Care Act marketplace and Medicare.

Figure. Strategies for Leveraging Reform Roadblocks to Equitable Care for Undocumented Individuals



Abbreviations: CBOs, community-based organizations; HIPAA, Health Insurance Portability and Accountability Act; KFF, Kaiser Family Foundation; MLPs, medical-legal partnerships; SGIM, Society of General Internal Medicine.

Structurally Competent Care

One key practice that can be employed by all clinicians to improve care for GG and other undocumented immigrants is to operationalize structural competency and address structural violence, which describes social arrangements that harm individuals and populations, including their health.⁴⁷ Undocumented immigrants, due to marginalization across multiple domains (eg, race, skin color, gender, religion, sexual orientation), experience structural vulnerability and violence in the form of policy constraints (eg, immigration status), which may restrict their access to health-promoting resources, including **comprehensive kidney care**.

Antidotes to this structural violence that can be implemented at the level of a clinical encounter include utilization of structural vulnerability assessment tools to enhance clinician capacity to screen, evaluate, and mitigate the structural barriers (eg, anti-immigration policies, xenophobia) that confer substantial health risk.^{48,49,50} Clinicians and multidisciplinary care teams should also receive training regarding categories of immigration status that impact care and specific resources available for advocacy. Accordingly, traditional structural vulnerability tools, which assess environments, food access, social networks, legal concerns, education, and experience of discrimination, could be expanded to encompass the unique challenges faced by many undocumented individuals in accessing care (see Figure). These challenges include legal barriers and external constraints, such as transportation barriers, lack of linguistically and culturally tailored services, discrimination due to immigration status (eg, social security number or citizenship status required as a precursor to provision of care), complex systems that prohibit access to or produce substantial barriers to care (eg, complex care navigation, digital divide), fear of deportation and presumption of deportability by clinicians due to shifting political landscapes, financial constraints and stolen or lost wages, and stigma.^{13,21,22,24,25,38,43,47,51} Ideally, clinicians should couple these efforts with

administrative changes in their practices (see Figure), including ensuring that intake forms do not request information (eg, social security numbers) that would restrict access to care and working to establish relationships with MLPs and community-based organizations with expertise in navigating care journeys and mitigating the unique barriers facing undocumented individuals.

Beyond the clinic, **addressing structural violence** and achieving health equity in the United States necessitate a justice-focused approach to policy reform, including advocacy, community power-building, expanded partnerships, and the elimination of administrative barriers (see Figure). Evidence abounds on the profound harm of anti-immigration policies that restrict access to comprehensive health care, including kidney replacement therapy options.^{38,52} As clinicians and organizations navigate advocacy for patients like GG, they should be prepared to resist the “zero-sum game” myth, which has created innumerable barriers to health-promoting policy solutions by obscuring the collective harm of structural inequities that burden immigrant communities and by preventing coalition building across minoritized and marginalized groups who are made to perceive that “available resources” have fixed dimensions.⁵³

Critical to success are sustained multisector efforts (eg, community health worker, MLP, and navigator programs that aid immigrants in enrolling for benefits) to address the multilevel sociopolitical barriers facing undocumented individuals, along with resistance to policies that erode trust and harm health (eg, reversal of public charge rules) and the need for education on policy advances (see Table). Through our collective efforts as individuals and members of health care organizations, we can contribute to the ideal: a ripple effect of equity-enhancing policy advocacy and optimal health care provision for all.

Table. State-Level Legislative Actions^a to Extend Affordable Health Care Coverage to Income-Eligible Residents, Regardless of Immigration Status^b

Policy expansion	Population target	States involved
As of June 2024, 12 states and DC provide comprehensive state-funded coverage to income-eligible children regardless of immigration status.	Income-eligible children	CA, CT, IL, MA, ME, NJ, NY, OR, RI, UT, VT, WA
State-funded Medicaid for all adults regardless of immigration status.	All income-eligible adults 19 years and older	CA ^c
As of June 2024, 22 states and DC provide coverage from conception to end of pregnancy regardless of immigration status.	Income-eligible pregnant people	AR, CA, CT, IL, LA, ME, MD, MA, MI, MN, MO, NE, NY, OK, OR, RI, SD, TN, TX, VA, WA, WI
State-funded Medicaid coverage for individuals 65 years and older regardless of immigration status	Income-eligible individuals 65 years and older	NY ^d
Uses state funds to offer private health insurance with premium subsidies regardless of immigration status	Individuals with incomes up to 300% of the federal poverty level	CO ^d

Abbreviations: AR, Arkansas; CA, California; CHIP, Children’s Health Insurance Program; CO, Colorado; CT, Connecticut; DC, District of Columbia; IL, Illinois; LA, Louisiana; MD, Maryland; MA, Massachusetts; ME, Maine; MI, Michigan; MN, Minnesota; MO, Missouri; NE, Nebraska; NJ, New Jersey; NY, New York; OK, Oklahoma; OR, Oregon; RI, Rhode Island; SD, South Dakota; TN, Tennessee; TX, Texas; UT, Utah; VA, Virginia; VT, Vermont; WA, Washington; WI, Wisconsin.

^a Legislative actions refer to those using state-only funds or seeking waivers under the Patient Protection and Affordable Care Act.

^b Pillai et al,³⁰ Public Health Law Center.⁵⁴

^c Provided state-funded Medicaid for young adults aged 19 to 25 years from January 2020, adults 50 years and older from May 2022, and adults aged 26 to 49 years regardless of immigration status from January 2024.

^d Since 2023.

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Dinushika Mohottige, MD, MPH is an assistant professor in the Institute of Health Equity Research at the Icahn School of Medicine and the Barbara T. Murphy Division of Nephrology at Mount Sinai in New York City. She received a BA in public policy and a health policy certificate from Duke University, where she was a Robertson Scholar, and then earned an MPH in health behavior and health education from the Gillings School of Global Public Health and a medical degree from the School of Medicine at the University of North Carolina at Chapel Hill. She completed her residency in internal medicine and was chief resident at Duke University, where she also received nephrology training. She engages in patient and community-centered, inequity-focused research on the impact of socio-structural factors and racialized medicine on kidney health and kidney transplantation.

Karina Albistegui Adler, JD is a co-director of health justice at New York Lawyers for the Public Interest, where she has developed campaigns aimed at increasing access to health care and organ transplantation for undocumented and low-income individuals in New York. Her approach is rooted in community-centered perspectives and enriched by a lifetime of lived immigrant experiences. Karina obtained her BA from Sarah Lawrence College and her JD from the City University of New York School of Law.

Allison Charney, JD is the executive director of the Mount Sinai Medical Legal Partnership (MSMLP) in New York City. She is also a founding co-chair of the MSMLP board of directors. She joined MSMLP in her current role after 13 years as a partner in 2 top-tier law firms representing clients in litigation and regulatory matters. She received a BA from Brandeis University and a JD from Emory University School of Law.

Lilia Cervantes, MD, MSc is a professor in the Department of Medicine and the director of immigrant health at the University of Colorado Anschutz Medical Campus (CU-Anschutz) in Aurora. Dr Cervantes completed her bachelor's degree at the University of Colorado Boulder and her doctor of medicine degree, residency in internal medicine, and master of science degree in clinical science at CU-Anschutz. Funded by the Robert Wood Johnson Foundation, the Doris Duke Foundation, and the National Institutes of Health, Dr Cervantes has conducted studies to understand the social challenges and perspectives of Latinx individuals with kidney disease and, in partnership with a community advisory panel, translated her findings to develop and test community-based interventions.

Editor's Note

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.