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**Compassionate and Respectful Care for Undocumented Immigrants:
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FROM THE EDITOR

Immigration, DACA, and Health Care

Isha Marina Di Bartolo, MD

Undocumented immigrant patients, constituting an estimated 11 million people,¹ are among the most vulnerable groups in the United States. They are “disproportionately poor, non-white, and non-English speaking,”² and without access to stable employment or health insurance. Anti-immigrant sentiment can shape policy, such as the Affordable Care Act of 2010, which limits participation in health care exchanges to immigrants who are “lawfully present.”³ Additionally, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 denied undocumented immigrants eligibility for federal public benefits and for state and local public benefits, with some exceptions,⁴ prompting many states and cities to create safety net programs for those immigrants adversely affected by this federal policy.⁵ Any cuts in funding at federal, state, and city levels to safety net health care facilities for underserved patients thus affect immigrant communities.⁶ Furthermore, a political climate that tolerates migration criminalization rhetoric has served to create what’s been called a *chilling effect*—reduction, due to fear rather than eligibility changes, in the number of undocumented immigrants willing to interact with staff at public agencies or enroll themselves or their children in health plans or other benefits.⁷

In this issue of the *AMA Journal of Ethics*, we explore ethical issues that arise when clinicians attempt to provide care to this extremely vulnerable population and, just as importantly, how the community of health professionals should advocate for these patients—including through self-education and the education of trainees and in the exam room and on Capitol Hill.

In this issue, several articles examine barriers to care for undocumented patients. Jonathan J. Suarez comments on difficulties accessing care that undocumented immigrants with end stage renal disease face, especially with regard to accessing regular [dialysis care](#). Ruth L. Ackah, Rohini R. Sigireddi, and Bhamidipati V. R. Murthy write about the ethical issues that arise when children who undergo [renal transplantation](#) funded by Medicaid and charitable sources enter adulthood and are no longer able to afford regular follow up and immunosuppressive care. Rie Ohta and Clara Long shed light on a formidable set of obstacles to providing medical care in [immigration detention centers](#), an issue that has received significant media attention this past year due the systematic separation of families at the border and the detention of children in substandard shelters. Rachel Fabi reviews national-level and state-level policies that affect access to

[prenatal care](#) for this population and considers the ethical challenges these policies create.

In seeking to bridge the health care gap between undocumented immigrants and the general population, health systems and individual clinicians have created safety-net clinics, including community health centers as well as free clinics, often with the backing of academic institutions. These clinics may not possess a full range of services, and a very different standard of care is delivered to these patients. Peter Ellis and Lydia S. Dugdale address the question of how to define standard of care in [resource-limited clinics](#) and the challenges that free clinics face when delivering care to vulnerable populations. Robin E. Canada further explores the [moral distress and burnout](#) that occurs when students in health professions are faced with this lack of parity when working in free clinics and community health clinics geared toward the undocumented and proposes ways to mitigate this distress.

The sheer range of obstacles that immigrants must overcome to attain health care and the subsequent disparity in quality and quantity of care they are able to receive can feel daunting to physicians who wish to care for and advocate for them. Often clinicians' day-to-day work involves finagling *workarounds*, that is, finding ways to deliver care even in systems not designed to serve patients. Nancy Berlinger comments on the ethical and logistical challenges that can arise when physicians are compelled to [improvise to deliver routine care](#). Mark G. Kuczewski, Johana Mejias-Beck, and Amy Blair discuss how training physicians to deliver care that is informed by a patient's legal status is integral to the quality of care delivered, and they suggest [materials and resources](#) to help open up this line of dialogue between physicians and their patients.

On a larger scale, several articles in this issue discuss policies on national and state levels that affect the health care that undocumented immigrants receive. Berlinger and Rachel L. Zacharias provide a practical overview of the [effects of immigration policy and enforcement](#) on health care access. In particular, documentation of a patient's immigration status in electronic health records is controversial. Grace Kim, Uriel Sanchez Molina, and Altaf Saadi explore the risks to privacy and confidentiality that undocumented patients undergo when entering health care spaces and provide alternatives for clinicians to [documenting immigration status](#) in electronic health records. And Scott J. Schweikart argues that immigration status could potentially be considered [protected health information](#) under the Health Insurance Portability and Accountability Act Privacy Rule.

The current political climate has also wrought another series of changes—recipients of Deferred Action for Childhood Arrivals (DACA) status, empowered by education and opportunity, are advocating for their communities. Medical schools have shown increased interest not only in training DACA recipients but also in teaching all students

how to advocate for patients outside the wards and exam rooms. As “DACA-mented” medical students become physicians and begin to occupy leadership roles in medicine, it is without a doubt that they will work to elevate their patients out of the shadows. I and Dominic Sisti discuss ethical issues that arise when “DACA-mented” clinicians disclose their own immigration status to their patients and also shed light on the challenges that these clinicians face in their training, including the need for added emotional and legal support from their institutions.

In addition to the detrimental effects on DACA recipients, the current administration’s immigration policy has impacted the health of children. Craig B. Mousin writes about the [Convention on the Rights of the Child](#) (CRC), a series of policies adopted by the United Nations in 1989 that recognized children’s rights. Mousin discusses the ethical and health implications of the United States’ failure to adopt the CRC, especially for immigrant and refugee children, as this past year, the United States government separated thousands of children from their families at the border with Mexico and placed many of these children in detention centers.⁸ Schweikart discusses a lawsuit filed in April 2018, under the [Flores Settlement Agreement](#), alleging that psychotropic medications were being given to detained immigrant children in order to control them and prolong their detention, raising significant ethical questions. And Nora Hiriart Litz and I highlight the ways in which [immigrant children’s artwork](#) expresses their experiences of migration, family, love, loss, and hope. Finally, Rohail Kumar’s storybook on the life of a composite fictional character portrays how [family separation](#) deprives undocumented children of food, health care, and schooling.

The health of our immigrant populations is at risk, and it is imperative that physicians are informed about the issues that affect these populations and are equipped to act as effective advocates. Advocacy should begin in medical school where social determinants of health are dissected alongside cadavers, in resident clinic exam rooms where culturally competent care is modelled, in health disparities research institutes, and in social media campaigns where physicians lead the call to action. This issue of the *AMA Journal of Ethics* hopes to begin conversations about the challenges physicians face in caring for our millions of undocumented immigrants and to empower individual clinicians to be part of the solution.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

Should Immigration Status Information Be Included in a Patient's Health Record?

Grace Kim, Uriel Sanchez Molina, and Altaf Saadi, MD, MSHPM

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Abstract

The documentation of immigration status in patient records poses a challenge to clinicians. On one hand, recording this social determinant of health can facilitate continuity of care and improved communication among clinicians. On the other, it might expose patients or their family members to immediate and unforeseen risks, such as being stigmatized and discriminated against by nonimmigrant-friendly clinicians or being exposed to immigration enforcement if staff contact immigration officials in violation of patient confidentiality. Patients may raise concerns about the purpose and risks of such documentation alongside fears about potential data sharing and violations of privacy and confidentiality. This commentary explores clinicians' options for documenting immigration status within the context of ethical, legal, and historical considerations in caring for stigmatized populations in changing political landscapes.

Case

Dr Lopez's next visit is a well-child check with Anna, an 8-year-old Korean American who is new to his county-affiliated clinic. Her intake form indicates a history of asthma with one prior hospitalization and no current medications. He makes a mental note to explore this issue and walks into the patient room to see Anna playing with her mother, Ms P.

After introducing himself, Dr Lopez asks Ms P about her concerns. "Anna used to love school, but her grades have been slipping lately. Sometimes she asks to stay home or asks me not to go to work because her stomach hurts. I don't know what's going on." After validating Ms P's concerns, Dr Lopez asks if there have been any major changes or stressors in Anna's life. She sighs, "I don't get paid much at the nail salon, and it's just the two of us at home. But that's not new."

She continues hesitantly, avoiding eye contact, “Actually, Anna once said she’s afraid I’m going to be taken away. I think she’s heard scary things in the news about what could happen to someone without papers.”

Dr Lopez realizes Anna is likely experiencing anxiety about her mother’s tenuous immigration status and possible deportation. He wonders how or even whether to document her mother’s immigration status in Anna’s health records. Documenting Ms P’s immigration status could help facilitate referrals, such as medical-legal referrals, and alert other clinicians to this significant life stressor. However, it could also impair the patient-physician relationship if he documents this detail without knowing potential risks or discussing them with Ms P. In a time of rapidly changing immigration policies, fear, and uncertainty, could he be exposing her family to discrimination or deportation risk?

Commentary

Anna and her mother, Ms P, represent millions of families struggling amid a changing immigration landscape marked by increased anti-immigrant sentiment and immigration enforcement since the 2016 presidential election.¹ Clinicians are being confronted with this reality as they care for an estimated 11.4 million undocumented immigrants living in the United States² and their family members and friends. Moreover, an estimated 5.1 million children in the United States under the age of 18 have at least one undocumented parent, and the majority of them are citizens by birth (79%)³; roughly 1 in 14 children live in families with mixed immigration status.³ Although much of the focus on undocumented immigrants has been on Latinos, Asian undocumented immigrants are growing at a faster rate than Latin American undocumented immigrants.⁴

Immigration status is increasingly recognized as a social determinant of health.^{5,6} Being undocumented is associated with multiple social and mental health conditions known to negatively impact health outcomes such as poverty, limited access to health insurance, limited employment opportunities, anxiety, and post-traumatic stress disorder.⁷ Children of undocumented parents are similarly affected, regardless of personal immigration status.⁸ Living in chronic fear of separation from family members and the aforementioned risk factors contribute to childhood toxic stress that can damage physical and mental health into adulthood.^{9,10}

Historically, increased immigration enforcement has had damaging effects on mental health, led to fatal delays in seeking treatment, and reduced already low rates of Medicaid participation for citizen children in mixed-status families, impairing continuity of care and the ability to manage chronic health conditions.^{9,11} Since the 2016 presidential election, fear of deportation as a result of accessing health care appears to be leading to decreased use of some care among undocumented immigrants.¹² Here, we explore whether it is appropriate for a clinician to document patients’ immigration status

in their health records in the context of relevant ethical, legal, and historical considerations, concluding with consideration of the question within an immigration policy context marked by fear and uncertainty.

Ethical Considerations

Clinicians' primary professional and ethical responsibility is to provide [quality care to all people](#) regardless of immigration status or background. Identifying stressors and modifiable social determinants of health might help facilitate comprehensive care for patients. In fact, the American Academy of Pediatrics' Immigrant Child Health Toolkit recommends asking families if any family members have left suddenly or are at risk for leaving suddenly and then helping to create separation contingency plans if needed.¹³ Importantly, because this screening question does not ask about immigration status directly, it serves to minimize emotional distress but still elicit information needed to offer support.

The ethical principle of beneficence compels clinicians to use known immigration status to benefit the patient. For example, legal and social work referrals could address immigration, employment, and housing concerns. Depending on county of residence, undocumented patients might be eligible for local health care coverage options and financial assistance, and clinicians can help facilitate access to these resources.¹⁴ However, explicit documentation of immigration status might not be required for referrals; verbal discussion and hand-offs between colleagues or indirect phrasing in a health record (eg, "ineligible for insurance" or "immigration stressors") could suffice.

Moreover, clinicians' commitment to *primum non nocere*—"first, do no harm"—can be challenged even if immigration status is recorded with beneficence as the goal. For example, health records can also be seen by clinicians with anti-immigrant beliefs, leaving patients vulnerable to discrimination or disrespectful treatment. There is also increased risk for detention and subsequent deportation if transfer includes traversing an immigration checkpoint.¹⁵ Furthermore, information could be difficult to remove from health records, potentially exposing patients to harm even if their immigration status changes.

Reporting undocumented immigrants to officials certainly falls outside the ethical boundary of nonmaleficence and has been denounced by the American Medical Association (AMA).¹⁶ Although much less likely to occur than discrimination, reporting of a patient's undocumented status has been reported at least once in the media: in May 2017, immigration officials detained the undocumented parents of an infant requiring emergent surgery, with clinical staff being suspected of having notified officials.¹⁷ Finally, the AMA *Code of Medical Ethics* states that "protecting information gathered in association with the care of the patient ... [and] respecting patient privacy in other forms is also fundamental, as an expression of respect for patient autonomy and a prerequisite

for trust.”¹⁸ This assurance of privacy is necessary for open communication between patients and clinicians, and patient privacy is protected by the Health Insurance Portability and Accountability Act (HIPAA) of 1996.¹⁹

Patient autonomy can be honored by approaching the topic of recording immigration status through the lens of informed consent. Can the risks and benefits of recording immigration status be fully explained by a clinician such that patients can choose whether or not to include this detail in their health record? Given uncertainty about the likelihood of risks and benefits, complicated by rapidly changing immigration policies on federal, state, and local levels, clinicians are not currently poised to engage in this conversation. As such, legal organizations such as the National Immigration Law Center and medical immigration advocates have recommended not documenting immigration status.^{20,21}

Legal Considerations

Under [HIPAA](#), personal identifiable information can be shared with others in limited circumstances, such as for treatment, payment, or public safety, or as required by law (eg, by court order). Otherwise, disclosure of this information is generally only permitted when the patient consents.¹⁹ Clinicians should respect patient confidentiality by not disclosing information to law enforcement or immigration officials unless required to do so by court order.²² For example, patient disclosures of criminal activity, such as drug use, are not to be proactively reported to law enforcement.²³ Patients should be informed of their rights under HIPAA and of limits on data sharing with outside agencies.

Documentation of immigration status could pose [potential legal risks](#) should immigration enforcement officials gain access to government or county health facility and public benefit program databases and target undocumented patients. Currently, this remains a theoretical possibility rather than a documented occurrence in the United States, but not in the United Kingdom where government sharing of National Health Service data with immigration authorities has raised alarm.²⁴ Furthermore, immigration enforcement actions and access to law enforcement data have been documented to occur covertly in self-proclaimed “sanctuary” cities in the United States.²⁵ Immigration enforcement at hospitals is unlikely, particularly given that enforcement agencies’ “sensitive locations” policies discourage such actions in clinical settings.²⁶ However, enforcement near sensitive locations has been reported,¹ warranting a proactive approach to ensure the safety and well-being of undocumented immigrant patients. The potential impacts of implicit documentation of immigration status in health records (eg, by describing patients as “ineligible for insurance” or “foreign born”) as well as explicit documentation remain unclear and merit further investigation and discussion.

It is also important to note that, in contexts beyond the clinical encounter, documentation of immigration status presents different considerations. For example,

medical or psychological evaluations conducted with an immigration attorney for an asylum application might involve explicit reference to immigration status without necessarily conferring risk of detention and deportation, as these evaluations are protected by attorney-client privilege. In fact, in most cases, medical or psychological evaluations actually support better legal outcomes, as physicians are able to document the psychological or physical sequelae of violence or torture in the applicant's country of origin.²⁷ However, these evaluations are typically included not in the patient's health record but in the patient's legal paperwork.

Historical Considerations

Controversies over documentation of social data pertaining to stigmatized populations is not new, and history can lend insight into considerations of documenting immigration status. When HIV first emerged in the 1980s, clinicians grappled with how to record HIV status in health records given the intense stigma, discrimination, and even hostility—within and outside the health care context—directed toward those diagnosed with HIV/AIDS.²⁸ Public health concerns about HIV transmission balanced against patient fears of disclosure led to highly regulated standards for consent to testing and for reporting to the Centers for Disease Control and Prevention. States often require written rather than verbal consent to conduct an HIV test and set higher thresholds for disclosing results to other clinicians.²⁹ Although undocumented immigration status poses no public safety risk like HIV, the stigma surrounding immigration status could help inform how clinicians approach documentation.

Similarly, multiple state laws restrict health insurers' use of genetic information to prevent potential employment- and insurance-based discrimination, and the Genetic Information Nondiscrimination Act of 2008 prevents insurance companies from financially exploiting asymptomatic patients based on genetic susceptibilities.^{30,31} As such, there is a higher bar for sharing pedigrees and other genetic information. Implementation of measures to reduce undocumented immigrants' discrimination fears could also be considered.

Conclusion: Minimizing Documentation

Explicit documentation of immigration status of patients and their family members in a health record should be avoided, particularly when risks outweigh benefits and risks are rapidly changing, as they are within our federal, state, and local political and cultural contexts. If immigration status is needed to facilitate the patient's receipt of services or resources, conversations with clinicians should be prioritized over written communications, or clinicians can use indirect language in the health record to describe social context (eg, "immigration stressors" or "ineligible for insurance"). Patients should be assured of confidentiality, informed of privacy laws, and invited to discuss their concerns. Regardless of immigration status, patients deserve to have their health care

needs met without fear. The priority of clinicians and the health care system should be to create policies and guidelines that reduce stigma and discrimination for all patients.

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Uriel Sanchez Molina earned his undergraduate degree in anthropology from the University of Illinois at Chicago, where he cofounded the Fearless Undocumented Alliance. Motivated by his experience as a Mexican immigrant, he later cofounded the Chicago-based Immigrant Youth Justice League and was involved in Organized Communities Against Deportation. He is completing a postbaccalaureate medical program at Dominican University and working as an emergency medical technician.

Altaf Saadi, MD, MSHPM is a neurologist and fellow at the National Clinician Scholars Program at the University of California, Los Angeles (UCLA), where she has completed a master's degree in health policy and management at the UCLA Fielding School of Public Health. A graduate of Yale College and Harvard Medical School, she completed her neurology training at the Partners Neurology Residency Program at Massachusetts General Hospital and Brigham and Women's Hospital, where she also served as chief resident. Her research and advocacy concerns health inequities and disparities among racial and ethnic minorities, immigrants, and refugees, as well as enhancing diversity within the medical workforce. Most recently, her work has focused on understanding how hospitals and health care facilities can ensure that all patients feel safe when accessing health care regardless of their immigration status.

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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

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

Ruth L. Ackah, MD, Rohini R. Sigireddi, and Bhamidipati V. R. Murthy, MD

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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 emergency 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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CASE AND COMMENTARY

How Should Clinicians Respond When Different Standards of Care Are Applied to Undocumented Patients?

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Abstract

A challenge in caring for patients in resource-poor settings is the ethical discomfort and discouragement clinicians might experience when they're unable to provide optimal care due to lack of resources. This case, in which a resident is faced with rationalizing substandard care for certain classes of patients, probably represents the top of a slippery slope. This article argues that physicians should identify and advocate for optimal care for each patient. Moreover, physicians should advocate to improve the health system that allows for substandard care. Physicians should disclose to patients all available evaluation and treatment options, even those that seem cost prohibitive or unrealistic for some other reason. Transparency and objectivity in the patient-clinician relationship require good communication skills and are central to avoiding harm.

Case

Dr K is an internal medicine resident starting his community-based rotation at Salud Completa, a clinic that provides health care primarily to undocumented immigrants. He is eager to apply his clinical skills to providing care to this underserved population. After an afternoon so busy that some patients had to be turned away, Dr K's last patient is Mr L, who presents with persistent epigastric pain and nausea. He has visited the clinic twice over the past 5 months with similar symptoms and was prescribed a proton-pump inhibitor. Since his symptoms have not resolved, Dr K wants to order an upper endoscopy. Upon discussing Mr L's case with his attending physician, he learns that the gastroenterologist, who had been performing upper endoscopies free of charge for Salud Completa patients, has moved. Since there is nowhere else to refer Mr L, who cannot afford to pay for an endoscopy himself, the attending physician told Dr K to increase Mr L's medication dose and follow up with him at the clinic in a few months.

Dr K considers this recommendation, worried that he is providing substandard care to Mr L. Although there are often no other options for undocumented patients like Mr L, Dr K still wonders about his role in providing care that's different in quality from care he provides patients in the university teaching hospital setting. He wonders whether and

how he should respond to his attending physician's recommendation. He also wonders how he should respond to Mr L, who is still waiting for him in the exam room.

Commentary

In approaching this case, we start with the ancient oath of Hippocrates, which begins its declaration on caring for patients with the line, "I will use treatment to help the sick according to my ability and judgment, but never with a view to injury and wrong-doing."¹ This deontological or duty-based ethic of helping the sick according to ability and judgment, however, does not mention resource considerations, such as ability to pay or availability of resources. In recent years, medical students have been modifying the Hippocratic oath to modernize its language and increase its relevance to the present day.^{2,3} For example, the Yale School of Medicine Class of 2018 Physician's Oath—itsself based on the Declaration of Geneva⁴—says, "We will not permit considerations of age, disease, disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing, financial status, or any other factors to stand between the care we seek to provide and our patients."³ Although at first blush this modern augmentation might appear to add little to Hippocrates' ancient oath, the explicit reference to financial status is particularly relevant to our case. The newer oath insists that Dr K help Mr L, regardless of his insurance status or ability to pay. Medical professionals should always advocate for optimal care for each individual patient and resist any temptation to settle for a lower [standard of care](#). What neither oath addresses, however, is what the clinician is to do when in his or her professional judgment a particular treatment is needed that is not readily available, due to practicing medicine in a resource-poor setting, a national shortage of a particular drug, or a patient's personal financial difficulties. The Yale School of Medicine Class of 2018 Physician's Oath does "not permit consideration of ... financial status ... to stand between the care we seek to provide and our patients,"³ but *seeking* to provide care and *actually* providing care could be two entirely different things.

Based on the case, it is not evident which disturbs Dr K more—the fact that the patient cannot access endoscopy or that the attending doctor, without compunction, recommends increasing the proton-pump inhibitor, which seemingly adopts a lower standard of care. Both lack of access and lower standard of care raise the question of beneficence. Mr L probably *needs* the endoscopy; it is an important procedure for fully evaluating his symptoms. But Dr K cannot help him access one. What should he do? Furthermore, the attending physician's seeming indifference to a substandard treatment highlights the slippery slope of acquiescing to suboptimal care for patients. How might Dr K advocate for his patient?

Strategies for Providing Care in Resource-Poor Settings

Physicians routinely face such challenges in low-resource settings and attempt a variety of strategies to address them. They prescribe generic medications instead of name

brand, order screening blood tests instead of diagnostic procedures, ask specialist colleagues to provide free care to patients, and help to enroll patients in charity care or discounted prescription drug programs. In our community of New Haven, Connecticut, we established in 2009 a volunteer specialty-physician network that donates medical care in partnership with hospitals and local community organizations for uninsured patients with urgent medical needs.^{5,6} Patients identified at our student-run free clinic with urgent specialty care needs are referred to a specialist who provides medical care at no charge to the patient in the specialist's own office.⁷ Although not a panacea for lack of insurance, voluntary physician networks and free clinics are widespread in the United States and help to shore up the safety net in local communities.⁸

In this case, in which the barrier to care is primarily financial (ie, the patient lacks health insurance due to his undocumented immigration status), the endoscopy might be difficult to obtain. Nevertheless, the ethically appropriate action is to provide the best possible care available, even if it falls below accepted standards of care. In such circumstances, the physician's task is to recognize that his or her patient is receiving suboptimal care, articulate the alternative options to the patient, and do what is possible to advocate for the patient's improved care.

An important caveat is in order. What is ethical in any scenario hinges on the intended action of the physician. If physician A intends to provide substandard care regardless of what is available, he is acting unethically and providing unethical care. If physician B strives to provide the best possible care in the face of dire circumstances, she is acting ethically—even if the treatment that the patient receives is identical to the treatment rendered by physician A. The moral philosopher Immanuel Kant argued that all people, in accordance with their means, have a duty to be beneficent toward others, although this beneficence is not unlimited.⁹ In the case at hand, Dr K and the attending physician act unethically if they purposefully seek inferior treatments for Mr L, and they act ethically if they seek to pursue the highest quality treatments available.

Dr K should be as transparent as possible and should use his best judgment to explain to his patient Mr L the options for diagnosis and treatment, including state of the art treatments that may be unaffordable or unavailable. The discussion should be sensitive and include less expensive diagnostic options that may be safer to pursue first (eg, stool testing for *H Pylori*, esophagram). Ideally, the physician, social worker, or care team could work to procure optimal care for the patient. For example, Dr K might search for other local safety net clinics or other gastroenterologists willing to provide free care. Although such individual efforts are laudable, they are not always successful, and Dr K fulfills his obligations by offering the best care possible alongside a transparent explanation of alternatives.

Transparency can be challenging but has benefits for the patient-physician relationship. It could be tempting to omit discussion of treatments that a patient cannot afford in an effort to protect the patient from feelings of disappointment, but failing to inform the patient could harm the patient-physician relationship. For example, if a patient learns elsewhere about a treatment that the physician did not discuss, it could diminish the patient's trust and confidence in the physician and in the medical profession more broadly. When clinicians explain clearly all appropriate treatments, they serve as *doctors* in the truest sense of the word. To doctor, from the Latin *docere*, is to teach. Health care professionals teach by fully informing their patients of all aspects of a specific medical condition, including treatments options, prognosis, and natural history of the disease. The informed patient is thus empowered to make decisions for himself or herself. In this way, physicians respect the autonomy of their patients.

However, beyond transparency lurks the danger of "tokenism," which Schiff defines as "doing too little and feeling satisfied and excused from addressing the social and economic injustices that underlie poor patients' suffering."¹⁰ Schiff describes the surprising professional criticism he faced after giving \$30 to one of his patients who could not afford her medication. He eloquently defends his personal investment in his patient's welfare, recognizing that it **crossed a professional boundary** and was therefore potentially risky. He also recognized that limits need to be set. He asks, "Are 'limits' protecting the patient, or are they protecting us—protecting our time or even protecting our consciences, allowing us to avoid painful questions of inequality or taking needed moral action?"¹⁰ Helping individual patients meet their medical needs through personal advocacy can inform our collective advocacy for societal change.

Agency or Activism?

Should physicians primarily be focused on advocating for individual patients or advocating for the system? Dobson and colleagues propose dividing advocacy into 2 components: *agency* (working on behalf of the interests of an individual patient) and *activism* (working to change social conditions that impact health of populations).¹¹ Both approaches are important, and they can cross-fertilize and nourish each other. Many physicians support advocacy for individual patients, but there is less wholehearted support for **advocacy for social and political change**. In support of the latter, the American Medical Association's "Declaration of Professional Responsibility: Medicine's Contract with Humanity" states that physicians should "advocate for social, economic, educational, and political changes that ameliorate suffering and contribute to human well-being."¹² Similarly, in "Advocacy by Physicians for Patients and for Social Change," Joshua Freeman argues that physicians have an ethical obligation to practice advocacy, both agency and activism.¹³ He suggests that the lack of support for activism is partly the fault of medical schools and faculty who do not provide adequate role models for students and residents. The same could be said of the attending physician in the case above.

Conclusion

Ultimately, all physicians have ethical obligations to act beneficently, to do their best for the individual patients seeking their care. But, as Kant noted, beneficence has limits. A reality of modern health care is that some patients have access to the best that money can buy and others have access to significantly less. Regardless, a physician must do her best to advocate for and inform her patient of best possible treatments even when state of the art care is not available. This is good care. Francis Peabody perhaps put it best when he said, “[T]he secret of the care of the patient is in caring for the patient.”¹⁴

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CASE AND COMMENTARY

Should Immigration Status Information Be Considered Protected Health Information?

Scott J. Schweikart, JD, MBE

Abstract

In response to a case of an undocumented patient who was reported to immigration authorities, this commentary considers whether a patient's immigration status should be deemed protected health information (PHI) under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. A legal argument, supported by clinical data, is offered that immigration status should be regarded as PHI not subject to valid exception for release without patient authorization. This argument concludes that covered entities (eg, hospitals and health care professionals) are legally precluded under the HIPAA Privacy Rule from disclosing a patient's immigration status.

Case

ABC Hospital prided itself on providing comprehensive care to the community, which included a sizeable population of undocumented immigrants. Dr A, a neurosurgeon, was first on the agenda to speak at ABC's monthly meeting. Everyone on the board had heard of the case about which Dr A was to speak, since it attracted local media attention. Dr A described a case in which MJ, an undocumented patient admitted to evaluate causes of his headaches and balance issues, was found to have a brain tumor, for which Dr A had secured charity funds to perform surgery. Immigration authorities had been searching for MJ, on whom a deportation order had been issued, and requested information from ABC. An ABC employee revealed MJ's room number, clinical condition, surgery date, and date of expected discharge. Upon discharge, just outside the hospital, MJ was apprehended by immigration officials and taken to a local detention center. As it was Dr A's view that disclosure of MJ's information compromised MJ's care and recovery, Dr A questioned whether members of the care team and the organization were obligated under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule to protect MJ's privacy and the confidentiality of MJ's information, despite requests for information about MJ from immigration officials.

Commentary

In recent years, clinicians and health care organizations have raised questions about how to regard a patient's immigration status. Are they required to report the immigration status of patients if requested by immigration officials? Will they face a penalty if they do

release a patient's immigration status? These questions have become especially relevant in the current political climate in which immigration enforcement policies and practices have been stepped up, both in the government and in society at large. For example, in 2013 the Arizona State House introduced a bill that would have mandated health care organizations to verify a patient's immigration status and report to federal immigration authorities or local law enforcement any patients for whom hospital admissions officers or representatives were unable to confirm legal presence within the United States.^{1,2} The bill never passed, but its mere introduction reflects the strength of some factions' belief that clinicians and health care organizations should play a role in curbing undocumented immigration. Instances of reporting patients, as happened in 2015 at a Houston area hospital where an undocumented woman sought medical treatment,³ also raise questions about what role clinicians and health care organizations should play in immigration enforcement. Hospital officials noticed that the patient had a fake driver's license and, suspecting that she was undocumented, called the local police and federal immigration authorities, who found a fake Social Security card in her possession after she was arrested. Instead of treatment, the patient was faced with possible deportation.⁴ The case highlighted concerns about what medical professionals are supposed to report to immigration authorities.

In light of questions and uncertainties health professionals face about how to regard and respond to a patient's immigration status, this article offers a legal and clinically supported argument for the view that, under the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, immigration status should be regarded as protected health information (PHI) with no valid exception for unauthorized release. As such, clinicians and health care organizations are not free to disclose a patient's immigration status to government authorities or anyone else without liability or penalty.

The Health Insurance Portability and Accountability Act (HIPAA)

HIPAA Privacy Rule. The [HIPAA Privacy Rule](#) is a series of regulations enacted to help enforce HIPAA. A main goal of the Privacy Rule "is to assure that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well-being."⁵ The Privacy Rule accomplishes this goal by requiring that PHI not be disclosed by a "covered entity" (ie, health plans, health care clearinghouses, providers, and clinicians) except as permitted under certain exceptions.⁵⁻⁷

Protected health information. By definition, the Privacy Rule protects individually identifiable health information, which is defined as follows:

Individually identifiable health information is information that is a subset of health information, including demographic information collected from an individual, and: (1) Is created or received by a health care provider, health plan, employer, or health care clearinghouse; and (2) Relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provisions of health care to an individual; and (i) That identifies the

individual; or (ii) With respect to which there is a reasonable basis to believe the information can be used to identify the individual.⁶

PHI is individually identifiable health information that is transmitted or maintained in “any form or media,” which includes such information that is maintained or transmitted electronically.⁶ Some exceptions to this definition include employment and educational records.⁶

Immigration Status as PHI

Determining whether a patient’s immigration status (as collected by a clinician) is PHI means asking whether such information is individually identifiable health information. The most relevant element of this definition is how the information in question “relates to the past, present, or future physical or mental health or condition of an individual.” Information’s relationship to health (in this case, the relationship of immigration status to health) is the most relevant element, as other parts of the definition of individually identifiable health information are not likely in contention; the patient’s immigration status will be received by the covered entity and this information can be used to identify the patient. Therefore, if the immigration status of a patient can be found to relate to the patient’s health condition, it will be deemed individually identifiable information and hence will be considered PHI subject to the Privacy Rule’s protections.

There is no case law directly addressing the question of whether immigration status constitutes PHI; indeed, there are few cases analyzing what constitutes PHI in any context.^{8,9} Stacey Tovino, noting this lack of substantive case law, recommends focusing on the US Department of Health and Human Services (HHS) guidance in order to understand what constitutes PHI.¹⁰ One guidance document on the Privacy Rule explains that, in assessing PHI, “the relationship with health information is fundamental” and “identifying information alone, such as personal names, residential addresses, or phone numbers, would not necessarily be designated as PHI.”¹¹ The guidance also notes that aggregate or statistical information would not constitute PHI, as it does not sufficiently identify an individual.¹¹ Relevant case law also reflects this guidance.^{8,9} Key to understanding whether information constitutes PHI is “the relationship with health information.”¹¹

At first glance, it is not immediately obvious that a patient’s immigration status would relate to a health condition or that it would have some relationship with health. Immigration status on its face is information that is not clinical in nature like a patient’s blood-pressure, pharmaceutical history, family health history, or blood diagnostics, for example. However, clinicians might ask patients about their immigration status, specifically for health reasons. For example, a recent study on the health of Mexican undocumented immigrants in the United States found that a significant percentage (23%) of participants in the study had a mental disorder.¹² The authors of the study explain:

Undocumented immigration to the United States often presents with multiple stressors and contextual challenges, which may increase risk for mental disorders. For instance, physical, verbal, psychological and sexual violence is widespread among undocumented immigrants. Also, common to the undocumented experience is discrimination, stigmatization, marginalization, isolation, fear of deportation, exploitability, victimization, living in unsafe neighborhoods, and socioeconomic disadvantage.¹²

Clinicians recognize this reality, and it is a clinically relevant reason to ask patients about their immigration status. The study just referenced suggests that undocumented status is a risk factor for mental disorders. Pursuant to the HHS guidelines on PHI, information about immigration status has a clear relationship to health. Therefore, immigration status—as information collected by the clinician—meets the definition of individually identifiable health information because it relates to the “past, present, or future physical or mental health or condition of an individual,” and thus should be legally, clinically, and ethically regarded as PHI.

Privacy Rule Exceptions

As PHI, a patient’s immigration status is protected by HIPAA and cannot be released for purposes other than treatment, payment, or hospital operations without the patient’s consent without incurring legal consequences. This means that clinicians and health care organizations may not release such status to any authority, including officials of the federal government; if they do, they face a penalty under HIPAA. Some disclosures for other purposes require patient authorization, such as disclosure of PHI for marketing purposes.¹³ Other exceptions allow release of PHI absent patient authorization; most of these exceptions are for public health activities or are applicable to specific situations, such as reporting domestic violence or complying with workers’ compensation laws.¹⁴ The “crime on premises” exception is often considered in scenarios in which a patient of undocumented status seeks treatment. This exception states that “a covered entity may disclose to a law enforcement official protected health information that the covered entity believes in good faith constitutes evidence of criminal conduct that occurred on the premises of the covered entity.”¹⁵ Applying this exception can be flawed, however, as the fact that a person with undocumented status seeks treatment does not, without additional facts, constitute a crime on the premises.¹⁶ Additionally, it should be noted that the language of the exception specifies that a covered entity *may* disclose PHI in cases of a crime on the premises, not that the entity is *required* to do so. Thus, even when a patient with undocumented status seeking treatment commits what is deemed a crime on the premises, a clinician or health care organization is not mandated to disclose PHI.

Regarding valid exceptions that allow disclosure of PHI, clinicians should continue to be vigilant, especially in the current political climate. For example, another exception to unauthorized release of PHI is for “disclosures required by law.”¹⁷ That is, if a law mandates disclosure of undocumented status, such as the Arizona Bill referenced earlier would have done,¹ clinicians might be legally required to disclose and report a patient’s immigration status to federal immigration officials. Currently, however, unless a valid

exception applies, clinicians and health care organizations may not release patients' immigration status upon request or demand, as I have argued here that such information can be validly considered PHI.

Conclusion

Clinicians and health care organizations today may have questions about whether they are allowed or required to release a patient's immigration status to federal or state governmental authorities. The simple answer is "no" because, as I've argued here, a patient's immigration status can be considered PHI under the HIPAA Privacy Rule. Immigration status is sufficiently related to health that this information meets the Privacy Rule definition of individually identifiable health information and is therefore PHI. It is important for clinicians and health care organizations to understand that releasing a patient's immigration status to authorities, without valid exception, is a HIPAA violation.

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CASE AND COMMENTARY

Are Clinicians Obligated to Disclose Their Immigration Status to Patients?

Isha Marina Di Bartolo, MD and Dominic Sisti, PhD

Abstract

Undocumented immigrants are part of the health care workforce, whether they are eligible to work in the United States through the Deferred Action for Childhood Arrivals (DACA) program or other visa programs or permits. This case commentary considers whether—and if so, when—a clinician should reveal her immigration status to patients. After reviewing the literature on clinician self-disclosure, this commentary discusses how sharing immigration status could benefit the patient—particularly if the clinician has an immigration status that could interrupt care—but could also draw the focus away from the patient, possibly eroding trust between patient and physician. Finally, this commentary addresses mental health burdens experienced by undocumented and “DACA-mented” trainees and considers the roles that hospitals, residency programs, and health professions schools should play to support them.

Case

Dr T has a busy morning ahead of her in the cardiology clinic. Her first patient is Mr B, a 67-year-old man, for whom she has been caring since he suffered a heart attack 3 years ago. Dr T always enjoys seeing Mr B, and they have developed a good relationship over the years. Dr T walks into the exam room, greets Mr B, and notices that he isn't his usual jovial self. “What's wrong, John?”

Mr B responds, “I saw you in the newspaper the other day, Doc. The article mentioned that you were an illegal immigrant and were one of those ‘Dreamers.’ I've told you some pretty personal things about my life, and I feel like that was something you should have told me.” Dr T has recently become active in advocating for immigrants' rights and, as a Deferred Action for Childhood Arrivals (DACA) recipient herself, she has been vocal about her own status as undocumented. Until now, she had not considered how her immigration status might affect her relationships with her patients. She wonders if she should have disclosed her immigration status to Mr B earlier and how to address his concerns now.

Commentary

This interaction between a patient and his physician raises important questions that this paper seeks to answer. What information can physicians disclose about themselves to their patients within the clinical encounter? What are the advantages and disadvantages of self-disclosure? Is immigration status a part of Dr T's identity that she should disclose to her patients? This last question leads to a broader question regarding the extent to which a physician can or should disclose her own political views within the patient encounter. Finally, we discuss the challenges of a career in medicine for undocumented and "DACA-mented" trainees and physicians and suggest how programs can support trainees.

Physician Self-Disclosure of Personal Information in a Clinical Context

Physicians have grappled with the question of how to approach [types of self-disclosure](#) and whether there is an optimal amount of self-disclosure that is appropriate within the patient encounter, partly because many physicians initially entered the medical profession motivated by their own personal experiences with illness and their desire to be advocates. Disclosing details about one's own life, family, relationships, and interests is a natural part of human relationships and can be a healthy part of relationships with patients as well. Self-disclosure can contribute to a greater sense of closeness with patients and can create a therapeutic relationship built upon mutual respect and trust. Some types of self-disclosure can have clear benefits in the clinical encounter. For example, one study showed that physicians' disclosure of healthy personal behaviors can improve their credibility and their ability to motivate patients.¹ Physicians can also use personal disclosures to reveal how they handled an event in their family life or to lend authority to their clinical recommendations.²

Although self-disclosure is beneficial in some contexts and can be used as an effective tool to improve quality of care, it should be exercised with caution. One study of 113 patient visits to primary care physicians showed that physicians shared personal information in 34% of visits and that patients described 85% of those disclosures as not useful and 11% as actually disruptive of the visit.³ Another study found that patients were less satisfied with primary care appointments in which self-disclosure occurred and reported feeling less warmth, comfort, and reassurance during those visits.⁴ It is unknown why physician self-disclosure led to less positive feelings for patients in these studies, but one could postulate that the physician's shifting the focus of the visit to her own experiences could make the patient feel less heard. Additionally, if the disclosures are too personal, patients could feel a break in their therapeutic relationship with their physician. In fact, Kelly Curran suggests in "Too Much Information—The Ethics of Self-Disclosure" that self-disclosure be used as a tool to enhance the patient encounter only after the physician has carefully considered her rationale for and potential risks of disclosure and weighed self-disclosure against other ways of addressing patient's

needs.⁵ In addition, the physician should consider whether disclosing this information truly serves the patient instead of serving her own therapeutic purpose.⁵

Weighing Whether to Reveal Immigration Status to Patients

The notion of self-disclosure of a physician's immigration status presents additional potential advantages and disadvantages. One potential advantage of Dr T sharing her immigration status with Mr B would have been transparency in the amount of continuity of care that she could provide for her patient. The DACA program, which was initiated by President Obama in 2012,⁶ has been in a state of flux, with President Trump ending the program in September of 2017 only for it to be upheld the following year by federal courts.^{7,8} Dr T knows that, depending on politics at the state and federal levels, she might or might not have work authorization renewal options available to her, and Mr B's care could be interrupted. In this context, disclosure of her status is beneficial for her patient. There are potential disadvantages related to this disclosure as well. Because being undocumented carries a negative stigma, it would not be unreasonable to assume that this disclosure could negatively impact the patient-physician relationship.⁹

Dr T made the reasonable choice not to disclose her immigration status, perhaps because she chose to keep the focus on the patient within the clinical encounter. Even if the patient had been accepting of Dr T's immigration status, revealing this information in any context could trigger further lines of questioning that could have derailed the patient encounter and shifted focus away from the patient and his medical issues. Now that Mr B is aware of her status, it would not be unreasonable for Dr T to address his concerns and discuss how her immigration status may or may not affect Mr. B's continued care, all the while paying attention to how this information could change the nature of the patient-physician relationship.

Weighing Whether to Reveal Political Views to Patients and to Advocate for Patients

In entering into a conversation about her own immigration status with her patient, should Dr T address her own political beliefs? This question stems naturally from considerations about self-disclosure—how much should a patient know about his physician and what is at stake, especially given the possibility of discordance in political views between patient and physician? The root of the ethical arguments for and against [physicians openly expressing their political views](#) are, on the one hand, freedom of speech and, on the other hand, physicians' position of power and the negative effect on the physician-patient relationship of expressing discordant political views. The AMA (American Medical Association) *Code of Medical Ethics* suggests that physicians consider context, including patients' preferences and emotional pressures due to "significant medical circumstances," as cues to determine whether to engage in political discussion.¹⁰ The context depends in part on the particular relationship that the physician has with the patient, the stakes of the political issue being discussed, and the severity of the clinical context. Because physicians can direct the script of the clinical encounter, they should

exercise judgment about whether to discuss their political views with their patients. In an increasingly connected world, it will become easier for patients to find out the political leanings of their physicians, even though the physicians' political activities transpire outside the exam room.

Whether physicians have an [obligation to be politically engaged](#) is another question. For example, it has been suggested that physicians have an obligation to advocate for increased access to care and improvement in socioeconomic conditions that affect their patients' health.¹¹ The toll that fragile documentation plays in the mental health of immigrants has been widely documented.¹² Dr T is thus within her right as a citizen to advocate for the rights of undocumented immigrants. She has appropriately not raised the issue or advocated for her political views in the context of the clinical encounter, but she should be aware that Mr B and her other patients have access to information about her political advocacy. She should therefore be prepared to address questions or concerns that patients might have about her views, provided that these questions continue to allow her to maintain a therapeutic relationship with her patients. Should Mr B decide subsequently to transfer his care to another physician or not to return to care, it would be difficult, given the information presented in the case, to discern whether his choice had to do with a perceived breach of trust, a discordance in political opinion or, worst of all, his beliefs about Dr T's right to be a physician given her immigration status and nation of origin.

In summary, physicians should not feel obligated to disclose their immigration status to their patients and, in fact, physician self-disclosure has been linked in some studies to decreased patient satisfaction. If Dr T felt that sharing this information would have been of benefit to her patient or would have spared him harm or inconvenience, she could have considered revealing this information, weighing how it could affect her own comfort and safety as well as the dynamic of the patient-physician relationship. Dr T is within her right as a citizen to advocate publicly for the rights of undocumented immigrants. She has, until now, kept her political views from her patients, thus avoiding potential patient alienation and discomfort, but she should feel empowered to share these views if she deems unprompted disclosure is appropriate or if she is asked by her patient to explain her views.

Changing the System

Dr T should not be alone in handling situations like the one above, and she should count on the support of her peers and mentors when confronting difficult patient encounters, when facing discrimination or hate speech because of her immigration status, and when advocating for herself, her patients, or other vulnerable populations. As the number of undocumented or "DACA-mented" immigrants in residency programs increases beyond the more than 50 medical schools accepting applications from DACA recipients,¹³ academic institutions and hospitals should become equipped to address legal, logistical,

and mental health issues that can be associated with the stressors of being a practicing physician with fragile documentation.¹⁴

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MEDICAL EDUCATION

Best Practices for Teaching Care Management of Undocumented Patients

Robin E. Canada, MD

Abstract

Different standards of care for undocumented Latino patients raises ethical questions for teachers and learners. This lack of parity can cause moral distress for both and prompts consideration of whether decisions made on a patient's behalf are ethical. Teaching advocacy and creating projects and partnerships to improve access and quality of care for this vulnerable population can help fight burnout and improve health outcomes.

Care for Undocumented Immigrants in Philadelphia

Over 11 million undocumented persons are living in the United States.¹ Approximately 50 000 of them are living and working in Philadelphia.² Given the surge of Latinos in this country, many in academic medicine have opportunities to supervise and teach students and residents working with this vulnerable population.

Puentes de Salud clinic in Philadelphia is a low-cost clinic designed for the care of undocumented patients and has been in existence for 11 years. The clinic serves primarily Latinos, mostly from Mexico and Central America, who are employed in physically demanding and sometimes dangerous jobs such as construction, landscaping, factory work, and restaurant work.³ To date, 6500 patients have been served by Puentes. Although the clinic is a nonprofit, it shares close ties with several Philadelphia academic institutions. The clinic teaches internal medicine and family medicine students and residents, nurse practitioner students and residents, and nurses. In this brief paper, I will describe ethical, clinical, and pedagogical challenges encountered by trainees when providing medical care to undocumented Latinos.

Ethical Challenges in the Care of Undocumented Latinos

Our students and residents are working in some of the most well-resourced hospitals, where patients receive incredibly complex and novel treatments. A quick bus ride across town places learners in an entirely different clinical environment, where health care professionals cannot order off a menu of services and offer comprehensive medical care for little additional cost to the patient. These inequities manifest in various ways and affect both patients and clinicians.

Different standards of care. First, our residents and students are exposed to inequity through different standards of care for this population. Puentes is mostly staffed by volunteers, residents, and a few core clinicians, so patients often do not receive follow-up phone calls about lab results or continuity with a clinician. In addition, patients cannot get urgent specialty care or low-cost or advanced diagnostics.

Clinically, we practice and teach differently at Puentes than at our home institution due to financial and access issues for patients. For example, due to cost, we may start a certain blood pressure medication preferentially rather than first checking a urine protein, which is the standard of care. We may use a less potent cholesterol drug due to price or treat empirically for a stomach infection with extensive antibiotics costing \$60 without ordering the \$125 definitive test first. Our patients trust us to make the best decision on their behalf, and cost weighs heavily in the risk-benefit tradeoff as all of our patients lack insurance. Shared decision making is challenging, as patients usually ask us to make decisions on their behalf. The clinician is thus in an impossible situation—can we justify asking patients to pay \$20 per month for the “gold standard” cholesterol medication rather than \$4 per month for the less powerful alternative? Will that small increment of lipid treatment really prevent a true cardiac event? Is it worth the \$190 per year that the patient could save to feed his or her children or send home to family in Mexico or Central America? As we make these decisions in the patient’s best interest, the nagging question remains: Are we propagating a hidden curriculum that teaches that substandard care is good enough?

Lack of access to medical care and moral distress. It is often shocking for learners to discover that undocumented patients cannot get the surgeries, diagnostics, and specialty care that are routine in academic medical practices. Sadly, patients also come to Puentes with the expectation of a full offering of medical services. We meet countless patients seeking treatment for chronic conditions such as severe hernias, advanced arthritis, disfiguring lipomas, chronic ear infections, sinus infections, severe uterine fibroids, and joint deformities, to name a few. It is morally distressing for practitioners and learners alike to tell patients that quality of life surgeries cannot be paid for.

Perhaps even more ethically challenging than the inability to refer patients for surgery is the absolute denial of [organ transplantation](#) to patients in Pennsylvania and throughout the United States. We are treating several cases of alcoholism, especially in men. We care for at least 5 patients with end stage liver disease from alcohol, ranging from age 26 to 52. They are out of options for treatment. I can remember the night when I met the first of these patients. I was accompanied by one of my favorite medical students, and I told the patient that he would die if he kept drinking and that he cannot get a new liver here in the United States, and certainly not in Mexico. The student suddenly left the room. After the visit, I found the student weeping in an empty exam room. He could not believe that this patient and all undocumented persons in this country are not eligible for

organ transplantation. We now have a patient who is on [dialysis](#) with no hope for a kidney transplant and another young woman days away from dialysis. Given the high prevalence of diabetes and end-stage renal disease in Latinos,^{4,5} millions of undocumented Latino immigrants are marching toward dialysis with no hope for a transplant that would allow them to continue to lead productive work lives and support their families. Medicare spends on average \$88 000 per year on dialysis per patient, when a transplant would cost considerably less (about \$33 000).⁶

Seeing these disparities in care can create deep [moral distress](#) for clinicians and learners. We need to balance the acceptance of what is not feasible with providing the best care possible to these vulnerable patients. Structured teaching and advocacy would help fight burnout and contribute to advancing the care of the undocumented population by avoiding complacency and moral defeat.

Teaching Points for Learners Working With Undocumented Latinos

Understanding social determinants of health and unique health issues. Learners must first understand the unique social determinants of health for undocumented patients. Our patients are often working 60-hour weeks and living with overwhelming toxic stress due to their undocumented status. Patients can experience severe trauma crossing the border but then experience further trauma living in the United States, such as fear of deportation, financial stress, discrimination, language barriers, and stigma.⁷ Patients divulge to us additional stressors, including deep depression and anxiety from family separation and sexual violence. As mentioned previously, there is a concerning rate of alcoholism in our population, leading to devastating health outcomes. Learners should be taught to ask specifically about a patient's occupation, hours spent working, living situation, family structure in the United States and abroad, journey to the United States, depression, and substance use. Often this history can illuminate the true threats to health.

Navigating the medical system for patients with complex health care needs. Clinicians can address their moral distress by leveraging the resources that they do have to provide the best care possible for undocumented patients. We teach residents how to apply for Emergency Medical Assistance (EMA), which provides 5 months of health insurance for patients in crisis with an organ-threatening or life-threatening condition.⁸ Learners are taught to identify eligible patients, write a medical letter of necessity, and complete the application. EMA also covers hospital admissions for serious medical conditions. As such, we teach learners to use the emergency room as a point of admission for undocumented patients with a concerning medical condition. Our clinicians call the emergency room directly to ensure that the patient is admitted for a full workup rather than a "treat and street" encounter. This sort of care and communication is made possible by our academic partnerships. We have had some wonderful wins. We diagnosed a young man with autoimmune hepatitis through an admission and liver biopsy. He now has completely

recovered, has normal liver function, and is off his immunosuppression. Another very young man with a family history of Lynch syndrome was admitted with severe iron deficiency anemia and abdominal pain. He was found to have a large colon cancer on a Friday and had a hemicolectomy with successful removal of the cancer on the following Monday. These sorts of emergency situations do not cause additional financial distress for our patients, as the admission or emergency visit is almost always covered through EMA. For those patients not needing emergency care but for whom specialty care, diagnostics, and monitoring are needed, we teach learners to guide these patients to city clinics, which provide low-cost care and referrals for any resident of Philadelphia.⁹

Connecting to community resources. In addition to understanding how to navigate the medical system, learners should be taught advocacy. For example, when patients are denied EMA, learners should be taught how to advocate for these patients through writing a letter of appeal and contacting a lawyer. As physicians, we are ill equipped to address workplace discrimination or injury, deportation fears, or asylum evaluations. Lawyers are vital for our patients. In every major city, there are immigration lawyers and immigration advocacy groups. Medical professionals caring for undocumented patients should become familiar with these groups and contact these partners for help. At Puentes, we are lucky enough to have a [medical-legal partnership](#) with Justice at Work in Philadelphia, which provides our patients with onsite legal services.

Learner-driven quality improvement projects. After gaining understanding of the myriad challenges facing undocumented populations, learners can create projects to address inequity and quality improvement. Such efforts both improve patient care and, in my experience, combat burnout, as learners feel that they are engendering positive change. For example, the author and collaborators currently have a grant funded by Penn Presbyterian Medical Center to provide free fecal immunochemical testing (FIT) for colorectal cancer screening and have negotiated a low-cost fixed price for colonoscopy. This community-academic collaboration to provide care is truly novel and exciting and will hopefully be just the beginning of more partnerships to provide further access to care for undocumented patients in Philadelphia.

Cultural humility. Puentes de Salud offers learners the opportunity to practice in a multidisciplinary team and to subvert the paradigm of physician as leader. Nurse practitioners provide vital continuity of care, and community health workers, or *promotoras de salud*, are key partners in the health of our population. The *promotoras* have all received training through the DPP Group Lifestyle Balance™ (GLB) Program¹⁰ and can counsel patients with diabetes and obesity in a much more effective way than most clinicians due to their specialized and culturally appropriate training. In my experience, over half of patients referred to *promotoras* control their severe diabetes with just diet and oral medication, and data show that *promotoras* help patients reduce the risk of developing diabetes.¹¹ I advise learners to fight the urge to always treat uncontrolled

diabetes with insulin: this population is different. Our patients have risked so much to get to this country and have incredible resilience and investment in their own health. Patients' self-efficacy combined with culturally appropriate teaching yields incredible results.

Philadelphia is reflective of many other cities in the United States. The 11 million undocumented people aging and developing chronic disease will be sick and will need us. It is our moral imperative as physicians to understand the unique challenges facing this population and to teach our students and trainees to expertly care and advocate for this highly vulnerable population.

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MEDICAL EDUCATION

Resources for Teaching and Learning About Immigrant Health Care in Health Professions Education

Nancy Berlinger, PhD and Rachel L. Zacharias

Abstract

How to provide good care to uninsured undocumented immigrants who are broadly excluded from federally funded health benefits in the United States can raise ethical challenges for clinicians. The chilling effect of current immigration enforcement policies on health care access affects other immigrant populations and US citizens in mixed-status families. In the current political environment, students in health professions, house staff and other early career professionals, and teachers and mentors in health care settings that serve low-income immigrant populations need a shared understanding of how to provide good care under changing and challenging conditions. This article suggests key resources for clinical teaching and learning and for self-directed learning and reflection, with special attention to the “public charge” rule and its effects on immigrant health.

Immigrants as Patients in Safety-Net Health Care Systems

Most immigrants throughout the world live in or near cities, which are sources of jobs and other resources. In the United States, most immigrants live in just 20 metropolitan areas.¹ Health care professionals who work in safety-net settings in metropolitan areas are likely to see patients whose lives are shaped by immigration enforcement policies in ways that affect health care access. Safety-net settings include public hospitals and outpatient clinics, nonprofit community health centers, private nonprofit hospitals (also known as *community* or *voluntary* hospitals), and academic medical centers with emergency departments. Professionals who work in hospitals near immigrant detention facilities or shelters for child migrants in the custody of the Office of Refugee Resettlement (ORR) of the US Department of Health and Human Services (HHS) are responsible for the medical care of immigrants in detention or custody when a patient is transported to a hospital for medical treatment. Health care professionals who work in rural agricultural areas will also see low-income immigrant patients because nearly three-quarters of [farmworkers](#) are immigrants.²

Undocumented Immigrants and Barriers to Health Care Access

An undocumented immigrant is a person who crossed a border into the United States without authorization or who is living outside the terms of an entry visa or other authorization. (Other terms referring to this population's immigration status include *unauthorized*, *irregular*, or *out of status*; *illegal* tends to be perceived pejoratively and connotes disrespect for persons.) Undocumented immigrants in the United States are broadly excluded from federally funded health-related benefits such as Medicaid, Medicare, the Children's Health Insurance Program (CHIP), and the Supplemental Nutrition Assistance Program (SNAP, commonly known as food stamps) because they are not legally present in this country.³ Exclusions also apply to recently arrived immigrants who are legally present but not yet eligible for these benefits.³ This means that their access to health insurance is limited to state-funded provisions or to insurance provided by their employers. Under the federal [Emergency Medical Treatment and Active Labor Act](#) (EMTALA) of 1986, all patients who present in an emergency department must receive an appropriate medical screening and, if in need of emergency medical treatment, must be treated until stable.⁴ This mandate covers emergency medical treatment regardless of insurance status or immigration status. EMTALA is not a funding mechanism, however. Hospitals that admit patients under EMTALA who are later determined to lack health insurance and to be ineligible for Medicaid or other public insurance can apply to state Medicaid programs for Emergency Medicaid reimbursement. Because Emergency Medicaid, whose provisions vary by state, covers specific services, hospitals often must contribute to the cost of emergency services that are uncompensated. The EMTALA provision, which provides health care access, and Emergency Medicaid provisions, which provide reimbursement, do not apply to many forms of nonemergent care. In some cases, these emergency provisions are the only means of access to life-sustaining treatment for conditions such as chronic kidney disease.⁵

Meeting the health care needs of uninsured patients who are undocumented and therefore ineligible for Medicaid and other federally funded programs calls for close collaboration between the clinician (physician, nurse-practitioner, physician assistant) with direct responsibility for patient care and medical social workers who are responsible for determining patients' insurance eligibility and for identifying potential sources of aid for patients who are uninsurable due to immigration status or other reasons. These sources include a health system's charity care provisions, which may, on a case-by-case basis, finance health care that is needed but not reimbursable under a state's Emergency Medicaid provisions. Medical social workers are also often the link between inpatient services covered by Emergency Medicaid or charity care and referrals to affordable posthospital services. For example, federally qualified health centers and migrant health centers throughout the United States are federally funded to provide low-cost primary health care to medically underserved populations, including immigrants regardless of immigration status. In some cities, public health systems or community-based nonprofit

organizations offer services to immigrants that include patient navigation and care coordination. These services vary greatly by locality and availability of financing.

Medical-legal partnerships (MLPs), in which attorneys aim to resolve legal barriers to health care access through a team approach by contributing expert knowledge of relevant law, are also a key educational resource for health professionals. All professionals who work in settings where they are responsible for the care of immigrant patients, including undocumented patients, should know whether their institution includes an MLP. The website of the National Center for Medical-Legal Partnership provides an interactive map of participating institutions nationwide⁶ and includes information on legal services in farmworker health programs.⁷ Attorneys with expert knowledge of health-related provisions in immigration law can be crucial sources of health care access for some undocumented patients. When a patient is undocumented, MLP attorneys can advise on the prospects for securing a change in a patient's immigration status and assist with immigration filings that may provide access to public insurance. Even if an MLP does not offer immigration-related legal services to patients, it can be a helpful source of up-to-date, state-specific health law information that can support good practice and strengthen clinical teaching and learning.⁸

Immigration Enforcement and Its Chilling Effect on Health Care Access

Providing good care to patients whose legal status is uncertain or threatened is often experienced as an ethically fraught aspect of clinical practice. In clinical teaching and learning, it is important both to acknowledge the distress and other emotions that clinicians feel when they perceive that a patient or patient population is being treated in an unfair or inhumane way and to frame these situations in terms of justice and injustice.

A *chilling effect* refers to the behavioral effect of policy that interferes with a person's ability to use a legal right that this person technically holds, often by inducing fear. For example, laws that require citizens to show identification to vote may have a demonstrable chilling effect on voting behavior by depressing turnout among populations who fear the consequences of being required to show identification. The immigration enforcement priorities of the Trump Administration and the US Department of Justice, which has broad responsibility for immigration courts, have created multiple chilling effects on health care access for undocumented immigrants, immigrants with legal status, and US citizens—often children—in mixed-status families. When immigrant patients are afraid to approach health care settings or disclose personal information to medical staff because they fear that interaction with perceived authorities (such as security guards) or a record of use of health services will result in detention, deportation, or other action against them or their families, their fears should be recognized as chilling effects of immigration enforcement priorities on health care access.

The announcement in late 2018 of a proposed rule that would change federal public charge policies is of greatest concern to health care professionals and organizations nationwide for the dramatic chilling effects it has induced.⁹ The effect of this rule, which would allow use of health-related programs for which immigrants or their family members are eligible to be counted against them in applications for permanent residency (green card) status, would be to discourage immigrants from enrolling in or using these programs out of fear of the consequences. As the public charge era unfolds, the long-standing health care access problems of undocumented immigrants, who are ineligible for federally funded programs, are likely to be mirrored among authorized immigrants who are eligible for but afraid to use these same programs, which include nonemergency Medicaid, the Medicare Part D Low-Income Subsidy Program, SNAP, and subsidized housing and rental assistance programs, among others.¹⁰⁻¹²

Three Resources for Clinicians

Three resources are valuable for helping clinicians understand and provide appropriate care under the public charge rule.

1. The National Immigration Law Center (NILC) is an educational resource on the public charge rule and the legal rights of immigrant patients. The public charge rule is complex and requires expert guidance to understand its actual provisions and to communicate clearly and compassionately concerning the fears it triggers among immigrants. The website of the National Immigration Law Center (NILC) offers reliable, regularly updated information on the public charge rule that can support clinician education and professional practice.¹³ The NILC also offers guidance for health care professionals on discussing enrollment in public programs with immigrant families.¹⁴ A specific NILC resource, "Health Care Providers and Immigration Enforcement: Know Your Rights, Know Your Patients' Rights," offers detailed information and recommendations for health care professionals and organizations on how to safeguard rights in clinical practice and in interactions with immigration enforcement.¹⁵
2. MLPs (discussed in the previous section) are another helpful educational resource on the public charge rule; professionals are encouraged to reach out to an MLP in their institution or community⁶ for guidance on this evolving issue.
3. The American Academy of Pediatrics (AAP) is also a helpful practice resource. The AAP website offers an Immigrant Health Toolkit with practical information and resources for pediatricians and other health care professionals on topics such as medical screening and treatment recommendations for newly arrived immigrant children; access to health care and public benefits; immigration status and related health concerns; and mental, emotional, and behavioral care.¹⁶

Immigration Enforcement and the Health of People Crossing Borders

Policies of family separation, open-ended detention, and refusal of asylum to people fleeing violence are also associated with a range of threats and harms to health.¹⁷⁻¹⁹

These policies are technically distinct from the public charge rule but have unfolded during the same period and contribute to pervasive fears across immigrant populations that affect health-seeking behavior.

Whether or not a health professional is likely to care for immigrants in custody, understanding something of the experiences of these immigrants and their families is important for professional practice in the current political environment. Below are 2 resources for clinicians.

1. The investigative journalism organization ProPublica and other partners have applied game technology to the challenges of learning about the conditions that drive asylum seekers and understanding the stress of the asylum-seeking process. The Waiting Game, an app for self-directed learning and clinical teaching about immigrants in detention,²⁰ offers an engaging way for nonspecialists to learn about this aspect of migration through 5 cases. It can be used as an individual resource for learning and reflection and to support group teaching and learning on the political context of providing good care within the safety net.²⁰
2. The Undocumented Patients website, a project of the Hastings Center, offers a frequently updated searchable database of articles, reports, and other publications relevant to health care for undocumented immigrants in the United States that serves as a resource for clinical teaching on health care needs of immigrants.²¹ This database also includes a selection of recent literature on the emerging health consequences of immigration enforcement as it affects lawfully present immigrants, asylum seekers, and citizens in mixed-status households.

In a time of great uncertainty and fear for immigrant populations across this immigrant nation, professionalism in health care work calls for close attention to the political, social, and economic context of health care delivery. To treat immigrant patients as persons and members of families and communities, professionals should aim to understand the challenges their patients face, respond with compassion, and keep abreast of necessary knowledge. Clinical teachers and mentors should support these aspects of contemporary professional practice and offer opportunities for professionals to discuss ethical uncertainties even when ready solutions are not at hand.

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HEALTH LAW

Rights Disappear When US Policy Engages Children as Weapons of Deterrence

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Abstract

In 1989, the United Nations adopted the Convention on the Rights of the Child (CRC), which the United States provided significant guidance in drafting. The CRC focused on those under 18 years of age, recognizing the rights most other international conventions and declarations accorded to adults. This article explores the ethical and health implications of the United States' failure to ratify the CRC with an emphasis on refugees. Federal policies have led to separation of families, mass detention of children and families, and accelerated removal, revealing the United States' disregard for global concern about children and families. By failing to ratify the CRC, the United States not only abdicates moral leadership, but also invites other nations to emulate its lack of care for children.

Origins of the Convention on the Rights of the Child

At its core, international human rights law upholds human dignity as a universal right inalienable through the laws or policies of specific nation states. After the tragedies of the Holocaust, nation states formalized this protection through the 1948 Universal Declaration of Human Rights¹ and other international treaties, including the 1951 Convention Relating to the Status of Refugees,^{2,3} which mostly define adult rights. Almost 40 years later, the global community recognized that it had failed to fully protect one significant segment of the world's population: children. In 1989, most nations adopted the Convention on the Rights of the Child (CRC), which focused on enabling those under 18 years of age to flourish as human beings.⁴ One commentator praised the CRC as "the first significant steps toward creating a world in which any child—even the most vulnerable separated immigrant child—can be aided to reach his or her full potential."⁵ The United States provided significant guidance in the drafting of the CRC, so much so that some called it the "US child rights treaty."⁶ Although the CRC has reached almost universal accord, only one United Nations member nation has failed to ratify it: the United States.^{7,8}

The United States' refusal to ratify the CRC has ethical consequences for children, families, and all who participate in detention and deportation mechanisms. Ratification would have demonstrated the United States' intent to adhere to the language of the CRC

and hold itself accountable. It would also have enabled the United States to exercise international leadership in protecting the best interests of the child under the CRC in a world with more than 10 million refugee children.⁹ By failing to ratify the CRC, the United States not only abdicates moral leadership, but also invites other nations to emulate its lack of care for children. Most pernicious, US policies employ children as weapons of deterrence on the theory that if we treat children poorly, parents fleeing persecution will not seek safe haven at our borders. Based on a purported border crisis, federal policies have led to separation of families, mass detention of children and families, and accelerated removal, broadcasting worldwide the United States' disregard of the child and family rights under the CRC. Although failure to ratify the CRC precludes the United States from CRC liability, the nation also falls short of protecting children under US refugee law. This article explores the ethical and health implications of the United States' failure to ratify the CRC with an emphasis on refugee issues.

International Law and the US Refugee Act of 1980

After acknowledging domestic immigration laws' shortcomings in protecting those fleeing the Nazis, the international community in 1951 adopted the Convention Relating to the Status of Refugees (also known as the Refugee Convention), which holds that persecuted persons or those fearing persecution should be permitted to request asylum at another nation's borders without fear of immediate return to danger.² Although US law establishes a civil violation or a potential misdemeanor for failing to enter at designated ports of entry,¹⁰ those fleeing persecution rarely can make plans or simply arrive at a port of entry with the necessary papers. Thus, while a nation's border defense constitutes one element of national sovereignty by designating proper documentation for entry and a proper place for inspection and admission, nations established additional procedures to determine bona fide asylum applicants. The US Refugee Act of 1980, which accepted most of the principles of the Refugee Convention, provides that anyone who arrives "whether or not at a designated port of entry ... irrespective of" their status may apply for asylum.¹¹ Prior to 2018, federal practice prescribed that when persons requested asylum, authorities permitted examination of their asylum claims and did not refer cases for criminal prosecution.

In April 2018, then Attorney General Jeff Sessions reversed that policy by referring asylum seekers to criminal prosecution before initiating asylum procedures, which resulted in the separation of children from family members.¹² Sessions' "zero-tolerance" policy also led many parents to waive important procedural protections in both criminal and asylum proceedings with the hope of facilitating family reunions.¹³ Although the administration halted family separations in June, over 100 children remained separated from their parents in October 2018—several months after the court deadline passed for the government to reunite families separated at the border.¹⁴

In addition, Sessions issued an administrative decision overruling earlier cases that had enabled those fleeing certain types of domestic violence or gang recruitment to obtain asylum.¹⁵ As a result, many approaching a designated point of entry are turned away, as the holding allegedly invalidates their asylum claim.¹⁶ Although litigation will challenge these developments,¹⁷ the length of litigation could make conditions so intolerable that many might withdraw their asylum request prior to adjudication of their fundamental rights. Those turned away at the border face increased vulnerabilities to criminal exploitation and violence.¹⁸

US Refugee Policies in Light of the CRC

The new policies stand in stark contrast to the purpose of the CRC: to ensure the “special care and assistance” owed to children, necessitate “appropriate legal protection,” and recognize the fundamental role of the family.⁴ With regard to refugees, the CRC emphasizes the best interests of the child; ensures that any care conform to standards and competent supervision; prohibits involuntary separation from parents without judicial review and in accordance with law, and only if “such separation is necessary for the best interests of the child.”⁴ When seeking refugee status, children should receive “appropriate protection and human assistance,” enjoy their rights under the CRC and other human rights instruments, and have access to legal representation and [appropriate health care](#).⁴ The CRC prohibits deprivation of liberty unlawfully or arbitrarily, emphasizing detention shall only be a last resort and for the shortest time possible.⁴

US policies wither in light of the CRC. Separation, detention, and deportation are a first resort instead of a last resort. Children have become a weapon of enforcement and deterrence. Further US policies take aim at the CRC’s very core, raising significant ethical issues on a number of fronts.

Criminalization of bona fide refugees. The US government grounds its policies on protecting the border against individuals entering “illegally,” a term the media seems to repeat and the body politic seems to adopt without question. By implication, children who cross the border do so illegally prior to any formal adjudication, notwithstanding the CRC’s call for appropriate legal protection for children. No rationale warrants the appellation *illegal* prior to a hearing and conviction. US refugee law supports the right of bona fide refugees to seek entry anywhere, regardless of status,¹⁹ and applicants are permitted to seek asylum prior to any criminal prosecution. If charged with a criminal violation, they have a constitutional right to a hearing and legal representation before conviction. To base a policy on “illegal entry” prior to such adjudication cannot be reconciled with a child’s right under the CRC to appropriate legal protection.

The US government exacerbates the issue by claiming an immigration crisis when the statistics reveal diminished numbers of families and unaccompanied children attempting to cross from October 2017 through April 2018 over the same 7-month period in 2016-

2017.²⁰ By casting immigrants and refugees as *illegals* and repeating the term in the context of a purported tsunami of illegal crossings, the government, media, and public remove from the policy debate the ethical foundation of US law, the CRC, and the rule of law.²¹ The ethical challenges mount when the new policies result in criminal proceedings in which parents often have mass (more than 50 persons) criminal hearings and often plead guilty without knowing their legal rights or remedies.²² If parents then choose to continue with the asylum procedures, they face lengthy separation from their children or will be forced to endure detention as a family, further restricting their rights. For children especially, the absence of legal representation exacerbates their losses. An increasing number of children, some as young as 3 years old, are appearing in court without family or an attorney.²³ The Office of the United Nations (UN) High Commissioner for Refugees criticized such procedures more than 10 years ago and declared that “government authorities will need to investigate and make a determination on refugee status before seeking to prosecute or penalize asylum-seekers for their unlawful entry or presence.”²⁴

Failure to follow the CRC exacerbates childhood trauma. Refugees fleeing persecution and violence often arrive with posttraumatic stress disorder (PTSD) and physical and mental wounds from the stress of life in exile, which US policies exacerbate. The UN states that detention of child refugees “always constitutes a child rights violation.”²⁵ The CRC recognizes the special needs of children that are denied under US policies of separation, criminalization, detention, and deportation. The cumulative effect of these policies, especially on children, raises ethical questions of how medical staff respond to and avoid aggravating children’s stress, especially in private detention centers. These centers, often private for-profit corporations, have long records of inferior medical care, [abuse](#), and neglect, all in contravention of the CRC’s call for special care for children.²⁶

Children in detention have significant health concerns, and some even die.²⁷⁻²⁹ In a 2018 federal case, one “psychiatrist testified that the government’s forcible separation of children from their parents had caused them to suffer PTSD and put them at risk of grave short- and long-term physical and mental health consequences.”³⁰ The judge ordered the children reunited with their family but acknowledged that the harm was “likely to continue even after family reunification.”³⁰ One federal court found that the policy of family separation and the manner in which it was implemented was likely to be—citing an earlier case³¹—“so egregious, so outrageous, that it may fairly be said to shock the contemporary conscience.”³² Another federal judge held the separation “arbitrary and conscience shocking” and “causing irreparable harm.”³³ Underscoring the harm, some children did not recognize their parents when reunited.³⁴

Weaponizing children in defending the border. US officials unabashedly name family separation “a tough deterrent” by using children as weapons to defend the nation’s border in contravention to the goals of the CRC.³⁵ Furthermore, the Department of Justice instructs immigration judges and asylum officers to avoid considering the best

interests of the child in immigration decisions.³⁶ Former Congresswoman Elizabeth Holtzman, a coauthor of the 1980 Refugee Act, poses the ethical challenge to each of us: "DHS [Department of Homeland Security] has been transformed into an agency that is making war on immigrants and refugees."^{37,38} Holtzman concluded:

The final straw has been the separation of children from their parents at the Southwest border. This is child kidnapping, plain and simple. Seizing children from their parents in violation of the constitutional rights of both is bad enough ... but doing so without creating proper records to enable family reunification shows utter depravity on the part of the government officials involved.³⁷

Abdication of legal and moral leadership in protecting children. The CRC calls for universal recognition of children's human dignity. The United States' failure to ratify the CRC and its current detention policies will encourage nations with less dedication to the rule of law or less robust medical establishments to ignore the CRC's promise to protect children and their families. In the Cold War hysteria over national security fears, detention of an alleged Cold War spy led Justice Robert Jackson, a former prosecutor in the Nuremberg trials, to challenge the claim that the alleged spy posed a security threat: "Since we proclaimed him a Samson who might pull down the pillars of our temple, we should not be surprised if peoples less prosperous, less strongly established, and less stable feared to take him off our timorous hands."³⁹ We hold out our Republic and our Constitution as exemplars of the rule of law, yet we succumb to fear based on a purported border crisis and pejorative appellations for refugees while seeking to hide the problem in detention centers. Balancing the requirement not to return refugees to persecution with the duty to protect the border will always raise significant constitutional, legal, and ethical challenges. Even when upholding the Executive Travel Ban case, Justice Anthony Kennedy warned that we must recognize our leadership role in protecting rights, stating, "An anxious world must know that our Government remains committed always to the liberties the Constitution seeks to preserve and protect, so that freedom extends outward, and lasts."⁴⁰

Duties of Professionals

Finally, the CRC suggests that medical and legal professionals have a duty to hold our government accountable to appropriate care of children. The CRC, as part of international law, establishes an affirmative duty to protect rights. When governments fail to protect such rights, its citizens should call them to account. The American Medical Association⁴¹ and the American Bar Association⁴² have spoken out against separating children from their families. Still, the vast chasm between the CRC's international standards and current federal policies raises ethical issues for all members of the body politic. Should immigration judges and government attorneys participate in asylum adjudications if a child appears without family or a legal representative? What role should medical professionals play when contracted private detention centers become places of sexual abuse, inferior medical care, and poor nutrition?⁴³ What more can professional associations do to hold those accountable who provide such minimal care?

Conclusion

"We, the people, in order to establish a more perfect Union,"⁴⁴ have enabled government to implement these policies. We have succumbed to the false rhetoric of an invasion of illegal immigrants and refused safe haven to those fleeing violence, causing irreparable harm. The ethical foundation of the CRC calls on each of us to understand how far our government has strayed from what was once called the "US child rights treaty."⁷ The world community sought, through the CRC, to enable children to live and flourish with dignity. Given the medical and psychological harm children face through family separation, detention, and deportation, our refusal to abide by the CRC's principles denigrates our values of equality and freedom while teaching the world the wrong lesson.

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HEALTH LAW

April 2018 Flores Settlement Suit Challenges Unlawful Administration of Psychotropic Medication to Immigrant Children

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Abstract

A lawsuit filed in April 2018 alleges unlawful administration of psychotropic medications to detained immigrant children in US custody. The suit, under jurisdiction of the Flores Settlement Agreement of 1997, alleges misuse of psychotropic medication to chemically restrain and control immigrant children and prolong their detention. This article describes the legal scope of the suit and considers significant ethically and clinically relevant questions it poses.

What Is the Flores Settlement Agreement?

The border immigration crisis that began in May 2018, when then Attorney General Jeff Sessions announced that undocumented adult immigrants would be prosecuted and separated from their children,¹ has raised numerous legal, clinical, and ethical concerns about the housing of immigrant children who cross the southern border—both those children who cross unaccompanied and those who cross accompanied and have become separated from their parents by the US government. The number of immigrant children in US custody is at a record high.² As of September 2018, 12 800 immigrant children remained in federally contracted shelters.² Of the 2600 children separated from their parents in the spring of 2018, 497 remained separated as of August 30, 2018.³ Abuses and unlawful practices regarding the housing of children have been alleged, one of which is the administration of psychotropic medication to detained immigrant children. A suit, under jurisdiction of the Flores Settlement Agreement [hereafter, Flores Settlement], has been filed in federal court seeking to enjoin the US government from these practices.^{4,5}

The Flores Settlement is a 1997 federal court-ordered agreement that “sets standards for the detention and release” of minor immigrant children⁴; in the absence of further government regulations and laws on the matter, it has acted as the binding authority on issues concerning detention of immigrant children.^{5,6} The Flores Settlement broadly requires the US government to move children in US custody—both those who arrive accompanied and those who arrive unaccompanied⁷—to a close relative or friend “without unnecessary delay” and to keep children in custody in the “least restrictive setting appropriate to the minor’s age and special needs.”⁴

The Flores Settlement has become increasingly relevant during the 2018 border crisis, as the settlement has been interpreted by a US district court to hold that the US government cannot keep children in custody longer than 20 days.⁸ Although President Trump's June 20, 2018, executive order was written with intent to reunite families,⁹ the Trump administration mounted a legal challenge to exempt the federal government from the 20-day requirement of the Flores Settlement that was subsequently rejected by the Central District of California.¹⁰ Therefore, despite reunifying but detaining families indefinitely, Trump's executive order arguably violates the Flores Settlement mandate that children be moved out of detention "without unnecessary delay."⁴

What Is the April 2018 Flores Settlement Suit?

On April 16, 2018, the Center of Human Rights and Constitutional Law (CHRCL) filed a lawsuit in the Central District of California federal court alleging that the US federal government is violating the Flores Settlement, principally through the Department of Health and Human Services' Office of Refugee Resettlement (ORR)—the governmental body tasked with housing unaccompanied immigrant minors.^{4,5}

Differing from the federal government's legal challenge to the 20-day detention limit referenced above, the CHRCL's lawsuit alleges that the ORR is unlawfully administering medication to immigrant children housed in a residential treatment center (RTC) located in Texas and that this action violates the Flores Settlement's requirements that ORR facilities be "safe," "comply with all applicable state child welfare laws and regulations," and only provide children with "appropriate mental health interventions when necessary."^{4,5} The CHRCL also alleges violation of the Flores Settlement by the ORR's prolonged detention of children in RTCs on the specious grounds that a child's "psychiatric or psychological issue" cannot "be addressed in an outpatient setting,"¹¹ which essentially justifies the detention of children on the assumption that mental health care is not available elsewhere. The CHRCL's allegation implies that [psychotropic medication](#) is being administered as a method to control and further detain children rather than to properly provide health care.⁵ Indeed, the suit argues that without proper oversight, "the potential for abuse—including using drugs as 'chemical straight-jackets' to control children, rather than to treat actual mental health needs—is unacceptably high."⁵

The CHRCL documents in its suit that children in ORR custody are being given psychotropic drugs, including clonazepam, duloxetine, guanfacine, ziprasidone, olanzapine, lurasidone, and divalproex.^{5,12} The suit alleges that detained children are given these medications without parental consent, children's assent, or purposeful assessments of clinical indications that warrant these drugs' administration and that ORR staff improperly sign forms "consenting" for the children.^{5,13} The suit details forcible, sometimes violent, administration of medication, such as throwing a child to the ground and prying his mouth open.⁵ The suit also details iatrogenic consequences of these

medications in children, including dizziness, depression, weight gain, and other serious side effects, which the CHRCL believes threaten children with long-term injury.⁴ The CHRCL explains that forced medication administration violates the Flores Settlement, as the settlement mandates compliance with child welfare laws, which require parental consent to administer medication.⁴ The Flores Settlement also mandates a “safe” environment, and harmful effects of medication eliminate a “safe” environment for children. The April 2018 suit further alleges that children’s detentions are being prolonged in violation of the Flores Settlement, as the ORR justifies not releasing children from RTCs if ORR staff physicians determine that children cannot get adequate mental health care outside of their facilities. Only ORR staff physicians can approve release and, without their approval, children are often subject to prolonged and even indefinite detention.^{5,13}

On July 30, 2018, the Central District Court of California ruled on the CHRCL’s April 2018 Flores Settlement Suit. The Court noted that, under the Flores Settlement, the US government must follow Texas law, as the Flores Settlement mandates that facilities housing children “comply with all applicable state child welfare laws and regulations” and the children in question were detained at an RTC in Texas.^{4,10} The Court held that

evidence establishes that Defendants [the US government] have violated Texas state child welfare laws and regulations by administering psychotropic medications to Class Members at Shiloh [detained children] without first: (1) providing the disclosure required by 26 Texas Administrative Code section 748.2253 to a “person legally authorized to give medical consent[.]” and (2) securing the informed written consent of [a] “person legally authorized to give consent by the Texas Family Code or a person authorized by [a] court[.]”¹⁰

The Court ordered the US government to “comply with *all* Texas child welfare laws and regulations governing the administration of psychotropic drugs” to detained immigrant children, ordering the US government not to administer any psychotropic medication to a detained child unless staff clinicians have sought written consent from a “person legally authorized to give medical consent.”¹⁰ With regard to prolongation of children’s detentions if staff physicians determine that they cannot get adequate mental health care outside of their facilities, the Court ultimately held that such practice is “not necessarily a violation of the *Flores* Agreement,” as a detained child may seek judicial review if an ORR staff physician refuses to authorize release.¹⁰ However, the CHRCL remains concerned that “administering psychiatric medications is part of a broader program to avoid releasing the children and teens” and that these medications are not clinically indicated or administered with the intention of motivating a child’s wellness.¹³ The CHRCL has compiled voluminous affidavits and narratives to support its allegations.¹⁴

Clinical Ethical Dimensions of Crises at the Border

Aside from whether psychotropics are clinically indicated for use in the children to whom they are administered, perhaps the most immediate ethical concern arising from

practices alleged to be occurring in the detention centers is disregard for the standard ethical requirement for parents or guardians to authorize medical treatment for their children.¹⁵ The suit alleges that parental wishes, if solicited at all, are being ignored, while ORR staff are “consenting to children’s medication,”⁵ which clinicians—assuming ORR staff are indeed licensed clinicians with appropriate expertise and professional training to diagnose, assess, and manage care for a child whose symptoms indicate psychotropic medication—typically have no legal or ethical authority to do.

Another concern, alluded to earlier, is that the drugs are given to “control” the children and that the treatments are not in the [children’s best interests](#). To be clear, legally, clinically, and ethically, treatment decisions should be in the “best interest” of the child¹⁵ and not for purposes of chemical restraint or other restriction of liberty. Amy Cohen, a physician who treated detained immigrant children in 2018 noted, “These children tend to be overmedicated with combinations of meds that are really not indicated for children with PTSD [posttraumatic stress disorder], particularly small children. The purpose of that medication is not really to treat an illness, but to tranquilize them. It’s not a tool of therapy, it’s a tool of control.”¹⁶ Medication as a “tool of control” is a real problem. As Jonathan Moreno and Arthur Caplan have suggested, “Too often mental health care drugs have been used to make the job of caregivers easier rather than in the service of the patient’s best interest.”¹² Indeed, if drugs, including psychotropic drugs, are administered improperly or for purposes other than the best health interests of the child, their capacity to injure is significant, and they may create serious lifelong health risks, such as possible long-term alterations in brain function and behavior, metabolic syndrome, or infertility.¹⁷

Allegations of the April 2018 Flores settlement suit are substantiated by evidence, and the Central District Court of California found that such evidence supported a holding that the US government breached its obligations under the Flores Settlement.¹⁰ The US government’s administration of psychotropic drugs to children—without parental consent or proper oversight and against the best interests of the child—constitute unethical, unlawful, and clinically inappropriate practices. The nature and scope of the roles of health professions and health professionals should be considered as one possible response to the April 2018 suit and the practices that prompted its filing.

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AMA CODE SAYS

AMA Policies and *Code of Medical Ethics*' Opinions Related to Health Care for Patients Who Are Immigrants, Refugees, or Asylees

Rachel F. Harbut

Abstract

Accessing health care resources in the United States often proves to be a difficult task for vulnerable populations. Immigrants, in particular, face barriers and difficulties in obtaining continuous medical care, which negatively impacts both patients and clinicians. The *AMA Code of Medical Ethics* offers guidance on how physicians and health care systems can best support undocumented and lawfully present immigrants alike to promote the best possible care for all who need it.

Health-Related Challenges Facing Vulnerable Immigrant Populations

Undocumented and lawfully present immigrants alike regularly find themselves in difficult financial and social situations that complicate access to the US health care system. These groups consist of an estimated 23 million persons, representing a large (7%) and largely underserved portion of the total US population.¹ The considerable social, institutional, and personal barriers to obtaining health care might exacerbate pre-existing health conditions and rule out typical treatment plans, forcing immigrants without access to safety net clinics to seek care in already-strained emergency facilities.² Providing sanctuary doctoring, which focuses on meeting the medical and social needs of undocumented immigrants,³ is supported by a number of American Medical Association (AMA) opinions and policies. These guidelines speak to the general concept of health care as well as the care of specific populations including refugees, asylees, victims of human trafficking, and other categories of both undocumented and documented immigrants.

Physicians' Duties to Vulnerable Populations

The *AMA Code of Medical Ethics* outlines the role of health in the lives of all people and calls upon physicians to care for those who need it, regardless of medically irrelevant details. Opinion 11.1.1, "Defining Basic Health Care," defines health care as a "fundamental human good" and health as a necessary component of a full life.⁴ It also discusses the obligation of society to ensure that all members have access to an adequate level of health care, regardless of their ability to pay for services. Opinion 11.1.4, "Financial Barriers to Health Care Access," builds on this idea, detailing specific ways physicians can fulfill their responsibility of ensuring access to health care for all who need it by politically advocating for vulnerable patient populations and seeking to

safeguard the interests of all patients in the distribution of health care resources.⁵ Opinion 11.1.3, "Allocating Limited Health Care Resources," reaffirms that the primary ethical obligation of physicians is to promote the health and well-being of their patients.⁶ This opinion provides guidance on how [limited resources](#) should be allocated and states that it is "not appropriate" to base allocation policies on attributes including "social worth, perceived obstacles to treatment, patient contribution to illness, past use of resources, or other non-medical characteristics."⁶ This guidance is corroborated by Opinion 11.1.4, which states that "the medical profession must work to ensure that societal decisions about the distribution of health resources safeguard the interests of all patients and promote access to health services."⁵

Undocumented Immigrants

The AMA sets forth certain policy statements on how health care systems might best provide medical care for undocumented immigrants who do not qualify for the [Deferred Action for Childhood Arrivals](#) (DACA) program and are therefore not eligible for state-funded government or workplace insurance and, like DACA grantees, are also ineligible for federally funded health insurance programs and Affordable Care Act benefits.⁷ AMA Policy H-440.876, "Opposition to Criminalization of Medical Care Provided to Undocumented Immigrant Patients," opposes "any policies, regulation or legislation that would criminalize or punish physicians and other health care providers" for providing health care to undocumented immigrants and opposes proof of citizenship status as a factor in receiving health care.⁸ Some states, such as Alabama, Arizona, and Utah, have laws against knowingly transporting and harboring undocumented immigrants that may cause health care systems to feel legal pressure to verify immigration status before providing care.⁹ Recognizing that immigration status also affects health, AMA Policy D-65.992, "Medical Needs of Unaccompanied, Undocumented Immigrant Children," acknowledges the special health care challenges posed by unaccompanied and undocumented minors and encourages special consideration of their physical, mental, and psychological health in the determination of their legal status.¹⁰

The AMA also advocates policy change to improve accessibility and quality of care for undocumented immigrants. AMA Policy H-160.917, "Federation Payment for Emergency Services for Undocumented Immigrants," supports the expansion of legislation providing federal funding to states for emergency services for undocumented immigrants.¹¹ The AMA also encourages the revision and improvement of health care standards in immigrant detention centers in AMA Policy D-350.983, "Improving Medical Care in Immigrant Detention Centers."¹²

Immigrants, Refugees, and Asylees

Unlike other noncitizens, refugees and asylees qualify for Medicaid and the Children's Health Insurance Program without having to wait 5 years to enroll.⁷ Despite their security relative to that of undocumented immigrants, lawfully present immigrants also

face barriers to accessing health care. AMA Policy H-350.956, "Increasing Access to Healthcare Insurance for Refugee Populations," supports programs that aim to minimize gaps in health care for refugees through expanded language offerings and education about low-cost health care plans.¹³ AMA Policy D-60.968, "Ensuring Access to Health Care, Mental Health Care, Legal and Social Services for Unaccompanied Minors and Other Recently Immigrated Children and Youth," affirms this stance with the intention of securing better services for young immigrants through the AMA's promotion of collaborations between medical societies, clinicians, and "other child-serving sectors" with funding from governmental and private sources.¹⁴

The AMA recognizes the "unique health needs of refugees and encourages the exploration of issues related to refugee health" in AMA Policy H-350.957, "Addressing Immigrant Health Disparities."¹⁵ This policy also calls for policies to increase and effectively allocate resources "needed to eliminate health disparities affecting immigrants, refugees or asylees."¹⁵ AMA Policy D-345.994, "Increasing Detection of Mental Illness and Encouraging Education," encourages the examination of "variations in psychiatric illnesses" among immigrant, minority, and refugee populations for the purpose of increasing access to care and appropriate treatment.¹⁶ Mental health care is particularly important for US immigrant populations, who can be at increased lifetime risk for certain psychiatric illnesses.¹⁷

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POLICY FORUM

Good Sanctuary Doctoring for Undocumented Patients

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Abstract

Clinicians whose practice includes a significant immigrant population report a climate of fear adversely affecting their current patients. Increased immigration enforcement targeting undocumented immigrants increases these patients' stress and negatively affects their willingness to seek medical care. To address these concerns, this article draws upon the literature and the authors' experience to develop guidance on sanctuary doctoring. These materials provide opportunities for patients to open a dialogue about their immigration concerns and can assist clinicians in connecting patients to networks and resources that can address their needs. The materials are designed to be used in single, brief clinical encounters.

Health Challenges Facing Undocumented Immigrants

An estimated 11 million undocumented immigrants make the United States their home.¹ Approximately two-thirds of adults in this population have been in the US for more than 10 years, including many young adults who have spent most of their lives in this country.¹ While most undocumented immigrants are long-standing contributing members of our communities, they face barriers to good health. For instance, undocumented people are uninsured at high rates, as they often work in low-wage jobs that do not provide insurance and are ineligible to participate in the insurance exchanges of the Affordable Care Act.²

Of more immediate concern, in the United States, undocumented immigrants and immigrants in "mixed-status" families (ie, in which at least one member is undocumented) are now in increasingly vulnerable situations because the deportation efforts of the federal government have increased. It is relatively unpredictable whether a particular undocumented immigrant will be the target of Immigration and Customs Enforcement (ICE). The previous administration had deprioritized the apprehension and deportation of immigrants who have lived in the interior of the United States for an extended period and had no major criminal offense. Unfortunately, all undocumented immigrants now seem to be priorities for deportation.³

This situation has two consequences that health care professionals should consider addressing. First, immigration-related stress can impact health negatively much like any long-term uncertainty and uncontrollable stressor.⁴ Second, immigration-related fears can cause patients to avoid medical care because they might not be sure if a hospital or clinic cooperates with immigration authorities and might place them in jeopardy.^{5,6}

It is well established that there are general values and ethics that govern the health care environment. Whatever the prevailing ethos of society, we wish health care professionals and institutions to guard health. This requires that health care professionals and the organizations for which they work be seen as welcoming lest patients' avoidance of them leads to the spread of contagion and illness. We expect health care institutions to accept and treat those *in extremis*, to place primacy on the health of the community, and to seek to do so in an efficient manner. Upon reflection, caring, public health, and efficiency are among the elements of the mission of nonprofit hospitals.^{7,8}

We developed the *sanctuary doctoring* approach to enable clinics and health care professionals to fulfill their mission by promoting these values so that patients will not hesitate to present for their medical needs. We created an online toolkit including a 10-minute lecture that provides an overview of key objectives to be accomplished in a short clinical encounter with a patient who is an undocumented immigrant.⁹ The toolkit also provides training materials such as a demonstration video that clinicians can use to prepare themselves for these interactions and templates of a brochure for patients and [lapel buttons](#) that clinicians can wear to prompt discussion of immigration-related concerns.

What Is Sanctuary Doctoring?

The sanctuary doctoring approach combines the emotional support of an empathetic physician-patient relationship with patient empowerment by supporting patient networking and identifying helpful actions the patient can take.⁹ Sanctuary doctoring works on the precept that health care should be a safe environment that provides support and resources to help patients deal with chronic stress and its sources. The materials in this toolkit—ie, a brief lecture outlining the objectives of the intervention, a demonstration video, and templates of a patient-centered resource brochure and clinician lapel buttons—were designed by drawing on suggestions for addressing needs of undocumented immigrant patients as articulated by experts in public health,¹⁰ law,¹¹ and advocacy¹² and modestly adapt the principles common to public health awareness campaigns.^{13,14} The patient needs to feel safe enough to present for care and able to trust that what he or she says to a physician will not be used by the physician to harm him or her. As stress can take a significant toll on a patient's health and well-being, physicians can and often do become skilled at addressing common sources of stress

among their patients. However, creating such a dialogue can be difficult and facilitating its establishment is the first goal of a sanctuary doctoring approach.

Establish a dialogue. Some immigrant patients may have fairly limited experience with health care systems, with the result that their expectations are not well developed. They might not be sure whether they can trust a physician with information. This lack of a shared framework can make it somewhat perilous for the physician to be forthright in probing immigration-related concerns. In a worst-case scenario, the physician's well-intentioned effort to open a dialogue could lead to patients avoiding the clinic because they fear being asked about their immigration status. As a result, we suggest creating an environment that enables patients to initiate a conversation about their concerns.

We suggest utilizing written materials, signage, and wearable buttons that transmit a clear message to patients that they are welcome to raise immigration-related concerns.⁹ We have focused on developing a brochure that can be left in clinic waiting areas and on buttons to be worn on the white coat. The brochure displays this statement on its cover: "If you would like to talk to your doctor about problems having to do with immigration, just take this sheet into the exam room and hand it to the doctor." To hand a physician a brochure is a simple exercise and spares the patient the difficulty of trying to find the right words with which to open the dialogue. Similarly, we have utilized buttons that say, "Immigration worries? Talk to me." This language is at once inviting and enables the patient to signal a desire for a dialogue with minimal verbal effort. Simply gesturing toward the button can invite a physician to open a discussion of the subject.

Provide reassurance. Once the patient signals interest in the topic, the physician has an opportunity to address the patient's particular experience, which could include a sense of shame, isolation, and trepidation. We suggest that contextualizing the patient's situation helps the patient to see his or her situation as commonplace. Physicians can simply address a sense of isolation by saying, for example, "Many people are going through similar struggles right now. You are not alone." Explaining that there are medical reasons why physicians wish to discuss these matters can contextualize and normalize this conversation. Physicians should make clear to a patient that they are motivated by health concerns, by saying, for instance, "This kind of anxiety can influence your health."

Of course, patients might be concerned that physicians, while well intentioned, could inadvertently place them in jeopardy by letting others know of their undocumented status. As a result, physicians should reassure a patient that they will **not record the patient's immigration status** within the health record.^{15,16} This assurance of confidentiality is important. The physician could say, for example, "I will not write your immigration status in the medical record. Only health-related issues will be recorded."

Provide resources. While human connection and the supportive understanding of a physician is important to establishing dialogue, it is also important to refer the patient to appropriate resources. A physician cannot be expected to be an expert on matters such as immigration law but can provide leads as to how such resources might be accessed in the community. We designed the sanctuary doctor brochure template⁹ that contains 2 kinds of information: (a) networking resources for undocumented youth, including Deferred Action for Childhood Arrivals (DACA) recipients (sometimes called “Dreamers”) and (b) resources related to law.

Young people who have grown up in the United States as undocumented immigrants may benefit from being encouraged to network with advocacy and informational organizations relevant to their situation. As is true of adult patients, undocumented young people benefit from knowing that there are many others experiencing similar challenges and that their common experience represents an opportunity to gain information. As an example, undocumented youth can utilize networks to access information regarding scholarship opportunities and [welcoming colleges and universities](#).¹⁷⁻¹⁹ They can also utilize networks to monitor legal and political changes in the DACA program.²⁰⁻²¹ For instance, many DACA recipients are unaware of their current eligibility to renew their 2-year grant of deferred action that was created by district court decisions.²² Being in touch with advocacy organizations and Dreamer networks provides a flow of information as events take shape, which enables these young people to take advantage of developing opportunities.

The legal resources section of the brochure encourages patients to take advantage of what is called *know-your-rights* (KYR) training. Such training sessions typically empower immigrants by providing them with knowledge of important facts, including their right not to open the door to their home to federal agents unless presented with a valid judicial warrant. The brochure can be altered to add information regarding local organizations that may offer in-person training as well as local immigration attorney services. We suggest that physicians avoid endorsing specific private-practice attorneys. However, there might be reputable and established nonprofit organizations that serve as a clearinghouse for pro bono or sliding-scale legal services locally. By identifying these local resources and listing them in the brochure, clinicians would be offering a great service.

Develop an accepted emergency plan. People who fear sudden detention and deportation might live with a myriad of related fears concerning, for example, what will happen to their children in such an event. It would be beyond the scope of most physicians to help the patient develop a comprehensive emergency plan. However, via the brochure, the physician can provide contact information for local legal advocacy that may be very important in any emergency. The physician should also address updating emergency contacts at a patient’s children’s schools or day care centers in the event the patient is

unexpectedly detained. Doing so could prevent such potential unfortunate occurrences as the children being taken into the custody of the local child welfare agency.²³

Information regarding how to develop a more complete emergency plan is often available as part of a KYR training session, and the physician might note this in closing as something the patient might wish to consider.

Beginning to Use the Sanctuary Doctoring Approach in Clinical Practice

The sanctuary doctoring approach provides some simple steps and resources to enable a physician to support his or her patients who have immigration-related concerns. The physician is addressing a true medical problem because anxiety, fear, and stress can have a significant effect on the health and well-being of a patient.⁴ As these particular stressors are socially determined, the primary means to address them is by encouraging patients to access networks and resources. This approach has 2 implications.

First, while willing clinicians can be helpful by using this approach and a brochure appropriately tailored to their locales, a physician is likely to be more comfortable and effective if he or she is reasonably [networked and knowledgeable](#) about current developments. Thus, physicians who begin using the brochure and wearing the button may wish to continue their own professional development by, for example, going through KYR trainings, developing a reading list, and becoming more engaged in advocacy.²⁴

Second, increased engagement with immigrant patients and supporting networks inspires new advocacy efforts outside of the exam room. For instance, physicians may wish to offer occasional KYR training sessions at the clinic. Using the clinic setting for dissemination of information may enable patients to keep their concerns private in a way that being seen entering the office of an advocacy organization might not. As a result, physicians might find that the clinic increasingly becomes a "sanctuary" for addressing immigration-related concerns.

In sum, at a time when many patients feel the stresses of their immigration status and fear sudden loss of control of their lives or removal from their community, physicians have an opportunity to play an important role by utilizing the simple techniques and materials of sanctuary doctoring to provide emotional support and resources to their immigrant patients.

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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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MEDICINE AND SOCIETY

Why Physicians Should Advocate for Undocumented Immigrants' Unimpeded Access to Prenatal Care

Rachel Fabi, PhD

Abstract

Nearly 7% of US citizens born each year have at least one undocumented parent, but many pregnant undocumented immigrants are ineligible for public insurance covering prenatal care due to their immigration status. This article reviews national-level and state-level policies affecting access to prenatal care for members of this population. This article also considers ethical challenges posed by some policies that create obstacles to patients' accessing health care that is universally recommended by professional guidelines.

A Call for Prenatal Care

Under the Fourteenth Amendment to the US Constitution, babies born in the United States receive American citizenship at birth, regardless of their parents' immigration status. As of 2014, about 7% of citizens born each year, around 275 000 babies, are born to undocumented parents.¹ Despite the size of this segment of the population, however, there exist significant barriers to care for pregnant undocumented immigrants, including several that are directly related to federal policy restricting immigrant access to publicly funded health care.

Prenatal care is a vital and necessary health care service that the American College of Obstetricians and Gynecologists (ACOG) recommends for all pregnant people.² Despite this recommendation, however, undocumented immigrants are less likely than the US general population to receive adequate levels of prenatal care.³⁻⁵ Undocumented immigrants are also more likely than the US general population to experience complications of labor,⁶ and undocumented foreign-born Latinas are more likely than documented foreign-born Latinas to experience low birthweight.⁷

There are many potential explanations for these disparities, including financial and psychosocial barriers to care, but structural policy barriers erected by the federal government are chief among them. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (also known as welfare reform) maintained and further codified an existing prohibition on the use of federally funded programs, including Medicaid and Medicare, by undocumented immigrants, with an exception for emergency

medical conditions and active labor as required by the Emergency Medical Treatment and Active Labor Act of 1986.^{8,9} The bar on undocumented immigrant access to these programs was continued under the [Affordable Care Act](#) of 2010, which also prohibited undocumented immigrants from purchasing insurance in the state and federal marketplaces.¹⁰ Undocumented immigrants are thus left with few affordable choices for health care; although they are able to seek care at federally qualified health centers on a sliding-fee scale, access to these centers is dependent on geographic proximity, which, along with language barriers, can restrict health care access.¹¹

In recognition of the critical importance of prenatal care for infant and maternal health, several state and federal policy mechanisms have emerged that provide access to public insurance coverage for pregnant undocumented immigrants in some states. This commentary lays out the various ethical considerations related to the policies providing or restricting undocumented immigrant access to prenatal care and concludes that the American Medical Association should support a policy of increased access to health care for this population.

Policy Mechanisms for Providing Insurance

Although federal policies restrict access to publicly funded insurance for undocumented immigrants, 18 states and the District of Columbia do provide some amount of public insurance to pregnant undocumented immigrants.¹² These states do so through 1 of 2 policy mechanisms. The first of these, known as the “unborn child” option, allows states to define a “targeted low-income child” as any financially eligible person “under the age of 19” including the period from conception to birth under the federal [Children’s Health Insurance Program](#) (CHIP).¹³ By including the period from conception to birth, states are able to receive CHIP funding for prenatal care provided to pregnant undocumented immigrants carrying a CHIP-eligible fetus, the fetus being the beneficiary. This option restricts the services covered to only pregnancy-related services and services for conditions that could complicate pregnancy, although some states are able to offer more comprehensive services through a bundled payment for the entire pregnancy.¹⁴ As of January 2018, there are 16 states that use this option.¹²

An alternative policy mechanism used by 2 states (New York and New Jersey) and the District of Columbia creates a Medicaid look-alike option to provide coverage to undocumented women during pregnancy and for 3 months after birth.¹² This option avoids the restriction on the use of federal funding for this population by using state-only (or, in the case of the District of Columbia, city-only) funds for the program, which allows these states to provide coverage directly to the pregnant mother. This option also allows these states to cover the full scope of Medicaid benefits during pregnancy rather than covering only pregnancy-related services, although New Jersey opts not to do so, making it functionally equivalent to the CHIP option. Also, unlike New York and the District of Columbia, New Jersey offers this program as a block grant program rather

than as an entitlement program, meaning that once the funding appropriated by the legislature has been exhausted, no new pregnant immigrants can be enrolled in the program.¹⁵

Ethics of Restricted Prenatal Access

Although the Universal Declaration of Human Rights notes that everyone has a [right to health care](#), it emphasizes that “motherhood and childhood are entitled to special care and assistance.”¹⁶ The 32 states that opt not to provide coverage for this population fail to uphold their moral obligation to respect the human rights of pregnant people. While states enacting the policy options described above do make some progress towards realizing this human right, they are not without their own ethical challenges. Additionally, clinicians who treat undocumented patients could find themselves caught between the demands of ethical medical practice and the demands of other policies.

The unborn child option involves a variety of ethical issues. Although the federal CHIP program has been in existence since 1997, the option to modify CHIP state plans was a 2002 product of the George W. Bush administration.¹³ The framing of the policy, which allows states to name a fetus as the beneficiary of public insurance and makes the rights of the fetus the determining factor in a pregnant person’s ability access to health services,⁵ was almost certainly intentional. Indeed, one Nebraska state senator, in supporting the policy, argued that the unborn child option was “the most significant piece of pro-life legislation” the state had considered in recent years.¹⁷ Moreover, this framing of the policy could set a precedent that undermines reproductive rights by essentially conferring official recognition of moral personhood on a fetus, which could have negative implications for abortion rights. Policymakers who support reproductive rights might therefore prefer to find an alternative policy mechanism, such as the Medicaid look-alike option, to provide coverage to this population.

In addition to this abstract moral personhood concern, there are also immediate consequences of the unborn child option’s benefit structure that can affect the health of patients. Since the policy directs that CHIP cover only services that directly affect the fetus, services that are exclusive to the mother might not be covered. Although it is very difficult to parse out which services a pregnant person might receive that would not affect the fetus in some way, several states do exclude these sorts of services; for instance, Louisiana does not cover postpartum care except in cases of emergency, in which case Emergency Medicaid is billed.¹⁴ Excluding these services could have negative consequences for the health of undocumented mothers, and the injustice of doing so can be compounded by the downstream effect that poor maternal health has on child health over time.¹⁸ Recent research indicates that though the unborn child option improves prenatal care utilization in this population, there are mixed findings as to whether it improves birth outcomes relative to states in which there is no prenatal policy.¹⁹⁻²¹

Policy restrictions on coverage for pregnant undocumented immigrants create ethical challenges for clinicians as well. When clinicians are caught between a professional obligation to provide comprehensive prenatal care to this population and policy restrictions on which services are and are not covered, it can cause significant moral distress, defined by Nancy Berlinger as “an acute feeling of risk to one’s own personal and professional integrity that is associated with the perception of powerlessness to prevent some wrong.”²² The sense that these policy restrictions are inherently unjust, because immigration status is the only factor distinguishing patients excluded from receiving medical and social services from other pregnant patients who are able to receive them, could sharpen a clinician’s feeling of moral distress. Although arguments could be made that immigration status is morally relevant in the distribution of public resources, that discussion is beyond the scope of this commentary. What matters here is that clinicians who believe that it is not relevant might experience moral distress when required to limit the services provided to patients in need because of their immigration status.

Although states that employ a Medicaid look-alike option avoid the fetal personhood questions associated with the unborn child option and the justice issues inherent in its exclusion of certain medical services from coverage, there is still potential for clinicians in those states to experience moral distress. Their moral distress, however, can derive from policy restrictions on nonmedical services rather than from the Medicaid look-alike policy itself. Even New York State, which provides the full scope of Medicaid services to financially eligible pregnant undocumented immigrants, does not provide other necessary social services like nutrition assistance for the undocumented families of these women (eg, the Supplemental Nutrition Assistance Program), which is only available to citizens or legal residents.²³ Consequently, clinicians who feel a moral or professional obligation to address the social determinants of health with their undocumented patients are frequently unable to do so, which can lead them to [bend the rules](#) or to implement other “workarounds” that enable them to provide services not explicitly covered.²² States seeking to promote the best outcomes for undocumented patients should expand their eligibility for other social programs.

The Need for Advocacy From Organizations

Despite federal restrictions on the provision of public insurance to undocumented immigrants, several states have taken steps to cover the most vulnerable members of this population. This article has discussed 2 such initiatives to provide coverage for vital health services during pregnancy, which, though fraught with a variety of ethical complications for policymakers, patients, and clinicians, serve as important steps towards the realization of the human right to health care regardless of immigration status.

In 2017, the American Medical Association (AMA) voted to adopt policies to improve the health of immigrants and refugees but did not include a policy advocating for increased access to basic health care services like prenatal care for undocumented immigrants.²⁴ The AMA should join other professional organizations like the ACOG⁵ and the American Academy of Pediatrics²⁵ in supporting the adoption of state or federal policies that improve access to health care for vulnerable undocumented immigrants. Promotion of the immigrant-friendly prenatal policy mechanisms described here, particularly the Medicaid look-alike option, would provide an excellent opportunity for the AMA to use its powerful platform to advocate for ethical public policy change.

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MEDICINE AND SOCIETY

Is It Ethical to Bend the Rules for Undocumented and Other Immigrant Patients?

Nancy Berlinger, PhD

Abstract

Physicians and other health care professionals who work in hospitals and clinics serving low-income populations will encounter undocumented immigrants as patients, family members, community members, and persons whose health-related rights can be overlooked, imperiled, or difficult to use. The routine uncertainty arising in how to provide good care to patients who are excluded from key public insurance provisions, together with the desire to be a good advocate for this patient population, can give rise to so-called workarounds as problem-solving strategies. This article explores the ethics of workarounds in the care of undocumented patients and considers how advocacy by health care professionals and organizations can assist immigrants in communities they serve.

Responding to Ethical Challenges in Care of Undocumented Patients

Physicians and other health care professionals who work in hospitals and clinics serving low-income populations, especially in the 20 metropolitan areas that are home to most immigrants who live in the United States,¹ are likely to encounter undocumented immigrants in at least 4 ways: as patients with structural barriers to health care access and insurance coverage; as family members of patients with the same or a different immigration or citizenship status; as community members; and as persons whose health-related legal rights can be overlooked, imperiled, or difficult to use. A new federal rule (commonly known as the “public charge” rule) proposed in September 2018 would consider the use of federally funded programs by legally present (authorized) immigrants as a factor in an application for permanent resident (“green card”) status. The proposed rule is a new factor in the care of immigrant patients who are eligible for these programs but apprehensive about using them.^{2,3} This article focuses on undocumented (unauthorized) immigrants, who are excluded from federally funded programs,⁴ mindful that health care access for authorized immigrants is also being affected by the so-called chilling effects of proposed policy (in particular, the proposed public charge rule) and anti-immigrant rhetoric.⁵

In caring for this patient population, professionals routinely face uncertainty in how to provide good care and [meet standards of care](#) when patients’ undocumented status and

inability to change this status exclude them from public provisions that cover medically appropriate treatment for low-income populations. Broad exclusion of undocumented immigrants from federally funded benefits because they are “not qualified” aliens means they cannot make use of benefits for which they would otherwise qualify due to low income,⁴ eg, Medicaid, the Children’s Health Insurance Program, the Supplemental Nutrition Assistance Program, or insurance subsidies under the Affordable Care Act (ACA). There is significant variation in how state Medicaid programs, local public health systems, and nonprofit (also known as private or voluntary) health systems invest in and sustain access to services to undocumented patients in light of federal restrictions. It is often the responsibility of medical social workers to identify potential sources of coverage or care (such as prenatal care) for uninsured patients in a system, municipality, county, or state and then to determine whether these sources include or exclude patients based on immigration status.⁶

As a result of the immigration enforcement priorities reflected in executive actions since the beginning of the Trump administration, a set of separate but related problems has arisen for professionals in health care systems serving populations targeted by immigration authorities or serving communities that include immigration detention facilities; other facilities in which immigrants and asylum seekers might be held; or shelters housing children who crossed the border alone (unaccompanied minors) or who were separated from a parent after crossing the border.⁷ This article focuses on undocumented immigrants outside the detention context; professionals should keep in mind that this related context may shape the concerns and fears of patients who are immigrants.

Examples of ethical questions arising in this complex practice environment include the following: (1) How should I provide good care to a patient who is or is presumed to be undocumented? (2) How could my actions have harmful consequences for this patient? (3) Which actions of mine could introduce bias or be unfair to this patient or to others? (4) What should I do when my practice is constrained by a policy that is clearly harmful to patients?

Workarounds

Complex systems, such as health care systems, characteristically produce situations in which rules intended to guide normal work do not match the conditions of work as they are experienced by workers. Devising, using, and sharing strategies known as workarounds⁸⁻¹⁰ relieves pressure resulting from a perceived mismatch between work rules and work reality. Because health care work is work that happens under pressure, using workarounds to manage workflow problems is a normal, if unofficial and semisecret, part of how work gets done. Ethically relevant motives for different types of workarounds include efficiency, problem solving, fairness, and—more negatively—avoidance.

For example, a worker who aims to “get the job done” and satisfy a system’s continuous pressure to be efficient may look for ways to complete tasks more quickly through strategies that she may call “shortcuts,” or simply describe as “my way.” These workarounds tend to involve judgments about how tasks can be abbreviated and whether rules can be ignored or steps skipped without harm. Research on the implementation of checklist memory aids suggests that these patient safety tools are vulnerable to shortcut-type workarounds when they are perceived as too time-consuming and therefore out of synch with the drive to work efficiency and when they are perceived as “imposed” on workers.¹¹

Workarounds that aim to solve problems, not merely save time, are often called “fixes,” “patches,” “hacks,” or even “inventions.” These can involve the unofficial creation, adaptation, or nonstandard use of a clinical tool, and they can be associated with the idea of clinical judgment and the application of clinical wisdom to practical problems (“getting creative”).

Workarounds that aim to solve a problem of fairness in patient care tend to be called “bending the rules,” “working the system,” or “advocacy.” Tailoring the chart to emphasize a patient’s [eligibility for a resource](#) or to de-emphasize factors detracting from eligibility is one example of this type of workaround. Workarounds that aim to secure resources for undocumented patients are also likely to be of this type. The idea of “getting creative” concerning resource allocation often applies to unofficial efforts to assist this population or other uninsured or underinsured populations.

Workarounds that aim to avoid or relocate a problem, often for reasons of cost, can take the form of “turfig,” for example, as when undocumented uninsured patients are referred to public health systems by systems that have community benefit obligations as a condition of nonprofit status. Efforts to medically repatriate patients to their countries of origin could also reflect this motive, or they could be consistent with a patient’s preferences. Medical repatriation requires informed consent.¹²

Moral Murkiness of Rule Bending

Workaround behaviors are hard to avoid. They can be perceived by some as good advocacy, a way of “going the extra mile” for a patient or population in need. But, even when their aim is justice, they are ethically problematic for several reasons. First, a professional’s or group’s decision to help a patient or population secure resources through an unofficial route—for example, by stashing supplies for ad hoc distribution—may involve biased judgments against another patient or population with equivalent needs. Without scrutiny of why one patient or population is being helped while another is not, an effort to promote justice risks introducing a new source of injustice, without challenging the resource allocation policy that is perceived as unsatisfactory. The association of workarounds with secrecy is another problematic factor, contributing to

“siloed” solutions rather than a comprehensive approach to understanding what a population needs, the barriers to meeting these needs, and how an organization’s resources should be allocated in recognition of these needs.

Health care organizations that serve undocumented patients and other uninsured populations should provide opportunities for clinicians and administrators to discuss how patients’ lack of insurance coverage—or other barriers to accessing medically appropriate services—creates an ethically challenging practice environment on top of the built-in pressures of health care work.

Greater transparency about how organizations address or could address these challenges using internal resources may help to alleviate pressures that drive workaround behaviors. Public policy advocacy aimed at state or local policymakers may, in some situations, be possible even given the highly charged politics of immigration. However, as a rule, “shadow systems,” such as municipally funded direct access services or hospital food pantries, cannot fully compensate for broad federal exclusions or for the [consequences of federal policy](#) that trigger chilling effects on health program enrollment even when a population is technically eligible for these programs.

A hospital’s ethics service or an academic medical center’s social medicine program may play a convening role, facilitating efforts to describe common and less common resource allocation challenges and providing a nonpunitive forum for professionals to talk about their unofficial solutions and explore those solutions’ ethical dimensions. Just as some “fixes” can be the first drafts of innovations, so incidents of “bending the rules” can point to justice problems with potential solutions that can be discerned through open discussion.

Avoiding Complicity in Unjust Policy

Acceleration of immigration enforcement in the United States has threatened or harmed immigrant health in multiple ways.¹³ These threats and harms to undocumented immigrants themselves may also threaten or harm the ethical integrity of health care professionals and others responsible for the health, safety, and well-being of immigrant adults and children. These issues of professionalism in the practice of medicine in the contemporary United States should be squarely addressed in undergraduate medical education and clinician education for house staff; through venues such as journal clubs and ethics committee discussions; and through professional societies. Important topics for reflection and discussion and for professional or organizational guidance for patient care situations tend to involve complex human rights issues, including situations in which health care professionals may observe evidence of harm, such as psychological trauma, among immigrants in federal custody or in the custody of local subcontractors, such as shelters or jails.¹⁴ Guidance for situations in which health care personnel interact with

immigration officials or their subcontractors could also help motivate justice for patients and mitigate conflict and distress for caregivers.¹⁵

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ART OF MEDICINE

Journeys of Immigrant Families Across the Border

Nora Hiriart Litz and Isha Marina Di Bartolo, MD

Abstract

In an exhibition called *El Viaje de los Niños (The Children's Journey)*, members of the undocumented Mexican community in South Philadelphia created stories of their journey to the United States. With help from lead artist Nora Hiriart Litz, their experiences and thoughts on migration, family, love, loss, and hope are conveyed creatively via artwork.

Figure 1. *El viaje fue la oscuridad mas profunda y sin un destino seguro, solo la infinita luz de la luna que me permitio continuar a mi destino, by Ali*



Translation

The journey was the deepest darkness without a certain destiny, just the infinite light of the moon, which allowed me to march towards my future.

Media

Acrylic-based paint on wood.

Figure 2. *La desesperación, pobreza [sic] y un futuro incierto fue mi boleto. El telefono es mi pañuelo de lagrimas de tristeza y alegria que dia a dia vivo,* by Mirna

**Translation**

Desperation and poverty and an uncertain future, those things were my ticket. The telephone is my handkerchief of tears, of sadness and joy, which I live through every day.

Media

Acrylic-based paint on wood.

Figure 3. *Camine asia el norte y tome el toro por los cuernos para trabajar pero me siento aun solo*, by Rico



Translation

I walked to the north and I took the bull by the horns so I could work, but I still feel alone.

Media

Acrylic-based paint on wood.

Figure 4. *La tristeza de mi mamá cuando me despedí*, by Rosi



Translation

My mother's sadness when I said goodbye.

Media

Acrylic-based paint on wood.

Nora Hiriart Litz is a Philadelphia-based artist who has long worked with the city's Mexican immigrant community. She is involved in legal and educational initiatives through Puentes de Salud and other local organizations and has taken leadership in creating artistic and cultural projects that provide emotional support to the community.

Isha Marina Di Bartolo, MD is a graduate of the Yale School of Medicine and is currently a primary care resident at the University of Pennsylvania Medical Center in Philadelphia. A "DACA-mented" physician, her primary research interests include health disparities,

investigating how implicit biases affect services delivered to patient populations, immigrant health care, and access to care.

Editor's Note

The artwork was provided by Nora Hiriart Litz and the captions were translated by Dr Di Bartolo.

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ART OF MEDICINE

Sofia's Story: The Sad Reality Behind a Humanitarian Crisis

Rohail Kumar, MD

Abstract

This graphic narrative is a storybook drawn on sketch paper with graphite and charcoal pencils and scanned into Microsoft Word. Sofia represents children of undocumented families currently living in the United States who are being denied fundamental human rights including health care, education, shelter, and food.

Figure. Detail from *Sofia's Story: The Sad Reality Behind a Humanitarian Crisis*

Sofia's Story
The Sad Reality Behind a Humanitarian
Crisis



Rohail Kumar, MD

[\(Click here to view the entire graphic narrative\)](#)

Media

Graphite and charcoal pencils on paper, scanned into Microsoft Word.

Caption

Sofia's story is told in this storybook based on numerous clinical encounters over the last 4 years of the artist's residency training in New Orleans, Louisiana. The artist has worked closely with undocumented children, providing medical and psychiatric primary care. Sofia is a composite fictional character representing these children and their families. Illustrations elicit the viewer's consideration of human rights violations and injustices experienced by these immigrants.

Rohail Kumar, MD is a resident in triple board (pediatrics/adult psychiatry/child and adolescent psychiatry) at Tulane University in New Orleans, Louisiana. He completed his medical school training at Aga Khan University in Karachi, Pakistan.

Editor's Note

This is the co-winning artwork of the 2018 John Conley Art of Medicine Contest.

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VIEWPOINT

How Should Health Professionals and Policy Makers Respond to Substandard Care of Detained Immigrants?

Rie Ohta and Clara Long, JD, MSc, MA

Abstract

More people, including children and pregnant women, are being detained for longer periods in a patchwork of over 200 detention centers around the country, most of which are private facilities or county jails. Human Rights Watch has documented systemic medical care failures at these facilities, including incompetent treatment, which is linked to patient deaths. Clinicians working in these facilities face formidable obstacles to providing adequate care, two of which are the Department of Homeland Security's lack of reasonable alternatives to detention and insufficient staffing. Harm caused by these conditions and detention itself should be enough to prompt clinicians to insist that the government enable provision of care consistent with generally accepted standards, including through reducing the detained population.

Deaths in Immigrant Detention

For a 2018 report, Human Rights Watch worked with independent medical experts to review government records pertaining to deaths in immigration detention from late 2015 to mid-2017.¹ The report, entitled "Code Red: The Fatal Consequences of Dangerously Substandard Medical Care in Immigration Detention," found that in 8 of the 15 cases experts reviewed, poor medical care contributed or led to deaths. Of the 52 deaths since March 2010 in immigration detention that have been evaluated by government or outside experts, 23 were linked to substandard care.¹ We examine here the reasons for substandard health care in detention centers and propose actions and policies necessary to address these sometimes-deadly failures.

Neglect, Scope of Practice Violations, and Barriers to Care

In one case detailed in the documents, a 54-year-old male patient began to have symptoms of a heart attack in the Adelanto Detention Facility in California. At about 9 am on December 19, 2015, another detained person told a correctional officer that he was sick and needed medical care. An officer heard him vomiting but did not check on him. At 9:30 am, a licensed vocational nurse entered the patient's unit and the officer told her that the patient was sick and vomiting. The nurse did not check on the patient, however, because purportedly "she did not want to get sick."¹ This was the beginning of a 2-hour

delay in the patient's transfer to a hospital. By then, it was too late—his heart was damaged, and he died 4 days later.

The extreme indifference exhibited in this patient's case is the outlier in these deaths. What is more common is systemic problems with the quality of care, including frequent use of licensed vocational nurses to assess and diagnose symptoms that require the attention of more highly trained practitioners. In one case we reviewed, a nurse resigned in protest over the facility's medical practices, which included having licensed vocational nurses regularly conduct clinic visits and clinically assess patients for danger that might follow placing them in isolation—which was far outside the nurses' scope of practice.² In another case, a 65-year-old male patient

suffered from the symptoms of congestive heart failure for most of the 15 months he was detained at the LaSalle Detention Facility in Louisiana, including fainting, swelling, anemia, coughing, and shortness of breath. Instead of properly diagnosing and treating these classic symptoms [or referring him to a clinician who could], a nurse recommended he increase his fluid intake, which likely increased his risk of heart failure.¹

Barriers to accessing care and detention center staffing models also cause concern. We reviewed court filings in a wrongful death suit brought by the family of Gerardo Cruz-Sanchez, who died in the Otay Mesa Detention Center in San Diego, California, in 2016. Cruz-Sanchez was a migrant who had recently crossed the border and was being held in the US Immigration and Customs Enforcement (ICE) detention facility as a material witness for the US Marshal Service. According to a wrongful death suit filed by Cruz-Sanchez's family, his cellmate said Cruz-Sanchez reported shortness of breath, respiratory distress, and wheezing a few days after being detained and complained to correctional officers.³ Another detainee reported that the officers did nothing, "saying that they only take detainees to the hospital when they are dying."¹ The family's complaint said that "an officer screamed at Cruz-Sanchez, angry that he stained a table when he spat up blood in the cafeteria. It was not until later, when an officer happened upon him after he had coughed up so much blood that his bedsheets were soaked, that he was taken to a hospital."¹ In a deposition for the case, the former training manager for the company that runs the Otay Mesa facility said that "understaffing issues" meant that correctional officers often did not have sufficient backup to go to the bathroom much less escort someone to the medical unit.³ In a detention facility in Eloy, Arizona, run by the same company, a nurse who resigned in 2007 released her resignation letter, which described severe nursing shortages on nights and weekends, an understaffed and understocked pharmacy, and directives from medical directors instructing staff to stop the medications of stable psychiatric patients to save money, which had resulted in suicide attempts.⁴

The 2018 Human Rights Watch report also documents the continued misuse of isolation, detailing 3 cases of people with psychosocial disabilities who committed suicide after being held alone and denied adequate mental health treatment.¹ In all 3 cases the

detention staff knew of the detainees' mental health problems, as all of them had been on various forms of treatment, but the staff nonetheless isolated them as punishment for prior self-harm or for psychiatric observation.¹

Increased Detention and Detention of Families

The problem of poor medical care in immigration detention is growing in scale and potential severity. As of September 2018, the US immigration detention system held an average of 40 770 people on any given day, but the current administration has requested funding to increase that number to 47 000.^{5,6} These developments place more people at risk in a poorly run and dangerous system. Detention facilities hold recent migrants and asylum seekers, some separated from their children and others detained together, as well as long-term US residents, including people with lawful permanent resident status.

The vulnerabilities of the detained population are also increasing. An ICE directive made public in late March eliminates the presumption that ICE should not detain **pregnant women** except in extraordinary circumstances, allowing ICE to detain many more pregnant women.⁷ ICE officials have told the media that detention centers are equipped to care for pregnant detainees,⁸ but in 2017 advocacy organizations filed a formal complaint to the Department of Homeland Security on behalf of 10 pregnant women who had been detained.⁹ Some said they received poor prenatal care. Others miscarried and blamed their miscarriage on the stress of being detained.

More **children** also risk being detained. After sustained and vociferous public outcry about the mass separation of families at the border in the summer of 2018, an executive order was signed that halted family separation by ordering federal agencies to work together to detain tens of thousands of families with children together.¹⁰ Proposed federal regulations would remove court-mandated limitations on the length of time children may be detained in ICE facilities, exposing more children to potentially substandard care for prolonged periods.¹¹ The mother of a toddler who died this year after being detained in one of these family detention centers filed a wrongful suit in August, claiming her daughter received substandard care while detained.¹²

Policy Recommendations

The report concludes that ICE has proven unable or unwilling to provide adequately for the health and safety of those it detains. Oversight and accountability mechanisms have too often failed, and the current administration's proposal to expand detention and weaken existing standards will further endanger lives. In light of these findings, action is needed on many fronts.

As an immediate priority, Human Rights Watch has called on Congress to decrease rather than expand detention; demand robust health, safety, and human rights standards for all types of immigration detention facilities; and monitor and engage in

strong oversight of detention facilities through frequent information requests, hearings, and investigations.¹

In the medium-to-long term, the United States government should use proven alternatives to detention to restructure this system and dramatically reduce unnecessary detention. One alternative ICE piloted was the Family Case Management Program, which had 630 asylum-seeker enrollees as of April 2017. As the second author has noted elsewhere,

In the program, social workers helped participants in five US cities navigate the immigration court system, get housing and health care, and enroll their kids in school. Of those participating, 99 percent attended their immigration hearing and check in requirements and it cost only \$36 dollars a day per family. That's in contrast to an average cost of \$319 a day per person in family immigration detention and \$124 a day in adult facilities.¹³

Unfortunately, ICE canceled this program last year despite its promising outlook as a viable national model.¹³

We should not overlook the important role that medical institutions and practitioners can play in addressing substandard care in detention. State licensing boards can be an effective avenue for ensuring quality of care, particularly with respect to disciplinary proceedings against clinicians who practice outside the scope of their license. Clinicians can also seek to join [medical-legal partnerships](#) to find opportunities to help individual detained people. One such program is being developed by New York Lawyers for the Public Interest (NYLPI).^{14,15} As part of this program, NYLPI is recruiting qualified doctors nationally "to perform outside evaluations of detainees health conditions and current treatment regimens" in support of efforts to get individuals treated and released appropriately.¹⁴ Clinicians contributing to such efforts could well be ensuring that their patients do not join the list of people whose deaths are linked to substandard care in detention.

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