

Moving the Needle

How Hospital-Based Research Expanded Medicaid Coverage For Undocumented Immigrants in Colorado

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Health policy that serves the common good in America's unequal society should aim to mitigate health-related disadvantages. Low income, minority race/ethnicity, and lack of insurance are examples of social (non-medical) determinants of health associated with barriers to health care access and/or poorer health outcomes. Health equity starts by confronting inequality, then using tools of research and policymaking to reduce built-in – structural disadvantages a patient or population cannot fix.

Immigration status is a social determinant of health for undocumented immigrants and for low-income populations. Longstanding federal policy excludes undocumented immigrants from a range of federally funded benefits such as Medicaid; states have the authority to extend state-funded Medicaid to this population. Immigration policy prioritizing enforcement, detention and deportation has observable “chilling effects” on health care-seeking behavior by undocumented immigrants and by low-income unauthorized immigrants.¹ A chilling effect occurs when a perceived or actual policy interferes with a person or population's ability to use a right by triggering fears of authority and the consequences of disclosing identifying information. “Toxic stress,” which is the prolonged experience of anxiety and/or depression resulting from hardship, is a related observable health effect of immigration policy.^{2,3}

Immigration enforcement also may cause or worsen housing insecurity, nutritional insecurity and other social determinants of health due to loss of household income from a detained or deported wage earner and/or chilling effects on household entitlement use. Social determinants also affect citizen members of immigrant-led households, notably children born in the U.S.

The stresses and hardships on low-income immigrant households are evident to health care providers in metropolitan areas, where most immigrants live and work.⁴ They are also evident to rural providers who care for immigrant agri-

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cultural workers. Two-thirds of the estimated 10.5 million undocumented immigrants in the U.S. have lived here for more than 10 years.⁵ Clinical research on the experiences and outcomes of this settled population in metro-area health systems can guide systems and policymakers toward policymaking opportunities to mitigate disadvantages experienced by these community members.

At one health system, hospital-based research moved the needle, resulting in policy change to Colorado's Medicaid program. This policy change has resulted in more effective and humane and less costly care for immigrants with end-stage kidney disease, a life-threatening illness that can be managed as a chronic condition. By support-



ing clinical research on the consequences of sub-standard practice, health systems produce evidence that justifies policy change. By aligning health care for a disadvantaged population with standard medical practice, public policy supports the health of state residents. So many problems of health care access lack ready policy solutions. This is one problem with a solution.

END-STAGE KIDNEY DISEASE

The role of Medicare in financing appropriate treatment

The function of the kidneys is to filter blood, removing excess fluid and toxins excreted as urine. When a person's kidneys lose their ability to filter blood, levels of fluid, electrolytes and waste build up in the body: this life-threatening condition is termed end-stage kidney disease. To survive with end-stage kidney disease, a patient must receive a kidney transplant and lifelong anti-rejection medication to sustain the transplant, or undergo dialysis, a blood-filtering technology compensating for kidney function. In the U.S., the most common form of dialysis is intermittent hemodialysis, involving three sessions per week of 4-6 hours per session at a dialysis clinic; dialysis is also used as a bridge to transplant.

Since 1972, people with a diagnosis of end-stage kidney disease have qualified for Medicare, which ensures that U.S. citizens and lawful permanent residents (green card holders) have access to standard treatment. The dialysis system in the U.S. is shaped by Medicare and equivalent provisions in private health insurance. The difference between standard treatment and what is available to low-income patients ineligible for federal benefits is stark in the context of end-stage kidney disease. There are currently an estimated 5,050 to 8,857 patients locked out of the "universal" benefit and clinic system associated with this diagnosis because they are undocumented.⁶ These patients are excluded from the federally funded insurance provisions of the Affordable Care Act as well as from federally funded Medicaid insurance. Therefore, they have no ready alternative to insurance coverage for standard treatment.

In most states, undocumented immigrants' access to life-sustaining treatment for end-stage kidney disease is limited to emergency-only hemodialysis, provided after a patient presents critically ill, week after week, to an emergency department.^{7,8} The 1986 Emergency Medical and

Treatment and Active Labor Act (EMTALA), requires hospitals with public emergency departments to provide all patients with appropriate medical screening and, if a patient is found to

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need emergency medical treatment, to deliver treatment until the patient's condition stabilizes. Hospitals' EMTALA duties are mandatory as a condition of Medicare participation. Services to uninsured patients are financed by state-level "Emergency Medicaid" programs to which hospitals apply on behalf of a patient, and by municipal and/or charity-care funds.

"Emergency" care that is potentially eligible for reimbursement through Emergency Medicaid provision is associated with a medical condition (including labor and delivery) causing severe acute symptoms, including pain, such that failure to treat could jeopardize the patient's life or health or result in organ or bodily impairment. Within this framework, each state's Medicaid program determines which diagnoses and services will be reimbursed through Emergency Medicaid. This authority allows policymakers to consider a state's duties to uninsured patients excluded from public insurance coverage for reasons that include immigration status. Through Emergency Medicaid, a state helps hospitals comply with the EMTALA mandate to ensure that care is available to those unable to pay for it. How best to fulfill this duty concerning patients with a life-threatening, treatable illness that can be managed as a chronic condition arises in the treatment of end-stage kidney disease.

In Colorado, Denver Health is the safety-net hospital for Denver County. Denver is one of the

top 20 cities in the U.S. with immigrant population hubs. Most undocumented immigrants with end-stage kidney disease in Colorado rely on Denver Health for emergency-only hemodialysis. In 2013, an estimated 60 to 70 patients were admitted to the hospital for emergency-only hemodialysis after presenting to the emergency department with signs of critical illness associated with kidney failure: high potassium, fluid volume overload and symptoms from high urea. A patient in this condition is often experiencing chest pain and symptoms of breathlessness. Scheduled dialysis typically prevents these burdens of uncontrolled end-stage kidney disease. The protocol for emergency-only hemodialysis includes two inpatient dialysis sessions plus an overnight hospital stay. To prevent death, this cycle must be repeated each week.⁹

RESEARCH TO SUPPORT POLICY CHANGE

After an undocumented patient with end-stage kidney disease died, having opted to withdraw from dialysis under emergency-only conditions and repeated hospital admissions, Denver Health clinicians decided to create a research program to inform public policy supporting medically appropriate care for all patients with end-stage kidney disease. It has long been clear that the standard of care for end-stage kidney disease (if transplant is not an option) is scheduled dialysis. What the Denver Health team sought to clarify was the burden of avoidable suffering that non-standard management of end-stage kidney disease imposed on patients, families and clinicians when a population lacked coverage for standard care. The team also sought to clarify the avoidable financial costs of emergency-only hemodialysis, mindful that emergency treatment with hospitalization is typically a much more expensive route than outpatient care. The goal was to change health policy in Colorado by building an evidence-based case for recognizing end-stage kidney disease as an emergency medical condition and including scheduled dialysis in the Emergency Medicaid scope of services. This policy change would create a reimbursement pathway for outpatient dialysis after end-stage kidney disease diagnosis.

To create the research agenda, the team met with stakeholders to identify and priori-

tize research questions. Stakeholders included patients with end-stage kidney disease; clinicians such as emergency medicine physicians, hospitalists, nephrologists, nurses, physician assistants, medical social workers, dialysis technicians and interdisciplinary palliative care specialists; hospital executives; health policy experts; representatives of for-profit and nonprofit dialysis organizations, and community-based advocacy groups focused on immigrants, health and human rights. These early consultations proved crucial to the success of this effort. The stakeholders subsequently helped disseminate findings, and their involvement demonstrated wide support for policy change. Based on these consultations and other background research, the team designed a set of studies. The studies were funded by a four-year grant from the Harold Amos Medical Faculty Development Program with additional two-year support from the Doris Duke Foundation.

THE EXPERIENCE FOR PATIENTS AND THEIR FAMILIES

The first study focused on the qualitative experiences and perspectives of 20 undocumented immigrants with end-stage kidney disease who relied on emergency-only hemodialysis. Participants described the weekly stress of waiting for their accumulating symptoms to trigger an emergency department visit and meet the clinical threshold (determined via potassium levels) for emergency-only hemodialysis. As one participant told researchers, “I don’t want anyone to resuscitate me if my heart or lungs stop. It’s not that I

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don’t want to live, but sometimes the symptoms make one feel that one would be better off dead than alive.”¹⁰ Participants described their anxiety about the possibility of death should hyperkalemia (elevated blood potassium level) trigger



a fatal arrhythmia (heart rhythm disturbance), and reported near-death and resuscitation experiences. They explained how emergency-only hemodialysis caused distress among their families, who watched patients cope with symptom accumulation, fear of death and disruptive hospitalizations, week after week.¹¹

THE BURDEN OF NON-STANDARD CARE ON CLINICIANS

The team's second study focused on the qualitative experiences and perspectives of clinicians providing direct care for undocumented immigrants who rely on emergency-only hemodialysis. The team interviewed 25 clinicians in Denver and 25 clinicians in Houston, also among the top 20 U.S. metro areas for undocumented immigrants. Participants described emotional exhaustion from witnessing avoidable suffering and high mortality among patients: "People become hyperkalemic and can die in 2 seconds. They go into an arrhythmia. It just seems like we are playing Russian roulette to some extent with people's lives."¹² Some participants distanced themselves from patients to avoid empathy; it was distressing to be conscious of a patient's humanity while providing substandard care that increased suffering and risked harm. Some participants reported physical exhaustion as they attempted to bridge gaps in care through case-by-case advocacy. Clinicians also expressed confusion about the financing and sustainability of emergency-only hemodialysis, given its reliance on repeated, avoidable use of high-cost services. While participants reported feelings of burnout, they also felt strong admiration for their patients, which motivated them to advocacy.¹³

OUTCOMES ASSOCIATED WITH NON-STANDARD VERSUS STANDARD CARE

The research team also designed several quantitative and mixed-method studies to capture data on clinical outcomes on emergency-only versus scheduled dialysis for undocumented immigrants. A retrospective cohort study compared mortality and health care use among undocumented immigrants who received emergency-only hemodialysis (Denver Health and Harris Health, Houston) versus those who received standard, thrice-weekly hemodialysis

in a state (California) where scheduled dialysis is covered under Emergency Medicaid (Zuckerberg San Francisco General Hospital, San Francisco). The team found that patients who received emergency-only hemodialysis had a 14-fold greater risk of death five years after initiating dialysis compared to patients who received standard hemodialysis, and spent nearly 10 times as many days in acute care settings.¹⁴

A second retrospective cohort analysis described the circumstances of death among undocumented immigrants who relied on emergency-only hemodialysis and died between January 2006 and January 2017 at Denver Health. In this study, most of the patients who died in the

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hospital had a diagnosis of hyperkalemia and an electrocardiogram rhythm disturbance, suggesting that delaying dialysis until a patient's emergent symptoms reached the threshold needed to receive emergency-only hemodialysis created life-threatening critical events.¹⁵ To quantify the symptom burden faced by undocumented immigrants who rely on emergency-only hemodialysis, we conducted an observational descriptive study using a validated measure of physical and psychological symptom distress (Edmonton Symptom Assessment System Revised: Renal). Our team found that nausea (a symptom of end-stage renal disease caused by urea accumulation) was more often reported by patients who relied on emergency-only hemodialysis, compared to patients receiving standard dialysis.¹⁶

SHARING FINDINGS AND FRAMING THE POLICY CONVERSATION

The team disseminated the findings through peer-reviewed medical journals to garner support for policy change from clinicians reflecting

the range of specialties involved in the care of undocumented immigrants with end-stage kidney disease. The investigators published research articles in high-impact journals such as *JAMA* and *Annals of Internal Medicine*. The team also published research articles and commentaries in specialty journals in palliative care, nephrology and hospital medicine.¹⁷⁻¹⁹ For each publication, the team created a media pitch to journalists in Colorado and nationally. Describing the research to reporters expanded the audiences for the case they were making about how Colorado, and potentially others, should enable frontline clinicians to provide standard care and prevent needless suffering. The patient stakeholders volunteered to be interviewed for local and national media, giving human faces and voices to the findings.²⁰

MOVING THE POLICYMAKING NEEDLE — LESSONS FROM COLORADO

Following nearly two years of dialogue between the Denver Health research team and the Colorado Department of Health Care Policy and Financing, on Feb. 1, 2019, Colorado became the 12th state to allow Emergency Medicaid funds to be used for standard treatment of end-stage kidney disease by including the diagnosis of end-stage kidney disease as an “emergency medical condition.”²¹ Previously, undocumented immigrants with this diagnosis could access dialysis only after meeting clinical criteria (chiefly, elevated potassium level) reflecting critical illness, pushing patients to the brink of death each week. By including the diagnosis of end-stage kidney disease itself in the Emergency Medicaid scope of services, Colorado Medicaid created a policy pathway that allowed clinicians to practice to standard, prevented suffering and lowered costs. This sub-regulatory language change made scheduled dialysis accessible to 137 undocumented immigrants with end-stage kidney disease management residing in this state. Colorado Medicaid expects a cost savings of \$17 million per year, reflecting the significantly lower cost of outpatient versus emergency treatment.²² As the policy has rolled out, discussions among policymakers, researchers and stakeholders have continued, to resolve coverage issues

concerning medications and interventions (such as vascular surgery for catheter implantation) associated with standard hemodialysis.

FACTORS FOR SUCCESS

What were the ingredients of success in Colorado? We have identified three factors:

1. Support for clinical research and communications aimed at public policy change. This research was initiated by a team of clinicians who perceived an opportunity to improve care for uninsured patients via public policy. Denver Health was integrally involved in stakeholder engagement, media outreach, dissemination and research support.

2. Collaboration and trust across stakeholder groups. Colorado Medicaid officials worked with Denver Health staff, health care providers, non-profit organizations and patients to understand the consequences of emergency-only dialysis and the feasibility of policy change to support standard of care. Undocumented immigrants participated in advocacy and entrusted journalists with their stories.

3. Conducive state-level policymaking environment. Colorado Department of Health Care Policy and Financing had been interested in making this policy change but lacked clinical data, which this set of research studies provided. That Colorado’s elected leaders were all members of

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the same political party during this time frame likely reduced barriers to policy change.

The data from the Denver Health studies, including comparative data from Houston and San Francisco, is now a resource for other clinician-investigators, health systems and state policymakers who aim to improve end-stage kidney disease care and outcomes for an uninsured, low-



income population. The research team welcomes opportunities to share their experiences and to mentor similar efforts throughout the U.S. Team members also are involved in new research to understand barriers to medically appropriate hospice care for patients who meet clinical criteria but are ineligible for the Medicare hospice benefit due to immigration status.²³

CONCLUSION

The maintenance of a city and region's health care safety net involves all levels of health policy: federal, state, municipal, organizational, professional. It involves private nonprofit institutions and systems as well as public hospitals and clinics. Colorado's experience in making publicly funded health care more effective, more humane and less costly for patients with end-stage kidney disease demonstrates that, even in the current national political climate, there are opportunities to improve access to needed, medically appropriate health care. It is time to seize those opportunities on behalf of our patients, their families, our clinical work forces and the communities we serve.

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