

## Dialysis in the Undocumented: Driving Policy Change with Data

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Hilda and I shared childhood stories while we enjoyed one of her favorite Mexican dishes, grilled *nopalitos* (cactus). Hilda loved *nopalitos*, but she rarely ate them because they are high in potassium. Hilda had end-stage kidney disease (ESKD), and as an undocumented Mexican immigrant in Denver, CO, she relied on emergency-only hemodialysis. Instead of receiving standard hemodialysis three times per week as required, Hilda would arrive critically ill to the hospital after her nausea, vomiting, and shortness of breath became unbearable. After three cardiac arrests from high potassium levels, she fervently avoided foods high in it. This time, however, she was not worried about potassium. This was our last meal together. She would fly to Mexico a few days later to die.

Our hospital medicine team knew Hilda well. We had continuity because we had been admitting her to the intensive care unit or medicine floor one night each week to receive two hemodialysis sessions when she was critically ill. I immediately connected with Hilda because our lives were parallel in many ways. Hilda and I were both in our early 30s, English was our second language, we both grew up in poverty, and we now had children in elementary school. I, however, was documented. My United States citizenship allowed me the privilege of pursuing a medical degree and gaining access to quality health care. In contrast, Hilda had been forced to end her education prematurely, marry her mother's friend for financial stability at the age of 14, and eventually flee to the US to escape poverty. She survived by cleaning homes until her kidneys failed. Initially, Hilda was my patient. Over time, she became a dear friend.

The first two years of emergency-only hemodialysis devastated Hilda. Too sick to work, she became homeless, staying with a nurse until we found a shelter for single mothers. Multiple cardiac arrests and resuscitations traumatized her young sons, who called 911 each time she collapsed and witnessed the resuscitations. Her boys did not understand the cycle of separation from their mother for her emergent, weekly dialysis hospital admissions and wondered if she would survive to the following week. After two years of emergency-only dialysis, Hilda's deep love for her boys and concern about the possibility that her

sudden death could leave them alone led her to preemptively decide to stop emergency-only dialysis. Had Hilda's treatment costs been covered by emergency Medicaid, as undocumented immigrants with ESKD are in some other states, she may not have been forced into this terrible decision. Moving to a state where standard dialysis is covered was not an option for Hilda because she wanted her boys to stay in Colorado where they had family and friends. With no other options, she first sought a loving adoptive family in the US so that her boys could grow up and have the opportunity to pursue an education. After carefully finding the right adoptive parents, Hilda wanted to celebrate her life with the people she loved. To show her gratitude, she organized a large Mexican Christmas party and invited all of the healthcare providers and friends that had supported her. She generously gave everyone a small gift to remember her by from the few things she owned. I received the wooden rosary her father had left her. A short while later, Hilda flew home to Mexico and passed away on Mother's Day in 2014.

Two years of caring for Hilda as an internal medicine hospitalist changed me. Grief gave way to anger, anger to determination. I found it morally distressing to continue to provide this type of care. Something had to change and there was little research in this area. One small study had demonstrated that emergency-only hemodialysis was nearly four-fold more expensive due to additional visits to the emergency department and admissions to the hospital, compared to standard outpatient hemodialysis.<sup>1</sup> After much soul-searching and advice seeking, I scaled down my clinical hospitalist shifts and gathered a team to do research. For four years, we worked on illuminating the suffering of undocumented immigrants with ESKD that rely on emergency-only hemodialysis. We conducted 20 individual face-to-face qualitative interviews with undocumented immigrants with ESKD and heard first-hand about the emotional and physical burdens and the existential anxiety associated with weekly threats to life.<sup>2</sup> We published a retrospective cohort study looking at differences in mortality and found that immigrants who relied on emergency-only hemodialysis had a 14-fold greater mortality rate than those on standard hemodialysis five years after initiating hemodialysis.<sup>3</sup> In another retrospective study, we described the circumstances among undocumented immigrants with ESKD who died in the hospital after presenting with ESKD complications, and found that the majority presented with high potassium and a recorded rhythm disturbance.<sup>4</sup> I discovered that as a hospitalist physician, I was not the only one distressed. We conducted 50 qualitative interviews to determine the perspectives of interdisciplinary clinicians on providing emergency dialysis and

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found that there are more clinicians experiencing moral distress. They described several important drivers of burnout,<sup>5</sup> including emotional exhaustion from witnessing needless suffering and high mortality, as well as physical exhaustion from overextending themselves to bridge their patient's care. Together, we discovered that the research told the larger narrative behind Hilda's struggles. These publications caught the attention of the media and enabled us to speak to a wider audience of clinicians, health policy makers, and the general public.<sup>6-10</sup> They also became a catalyst to engaging and enlisting the good will and interest of a number of key stakeholders to look for solutions.

In the US, undocumented immigrants do not qualify for insurance through traditional Medicaid, Medicare, or the provisions from the Patient Protection and Affordable Care Act. Instead, emergency Medicaid provides reimbursements for care of undocumented immigrants. According to the 1986 Emergency Medicaid Treatment and Active Labor Act, federal Medicaid payments can only be made for the care of undocumented immigrants if care is necessary for the treatment of an emergency medical condition.<sup>11</sup> However, the Centers for Medicare and Medicaid Services (CMS) has outlined certain conditions that cannot qualify for matching federal funds under emergency Medicaid (ie, organ transplant and routine prenatal or postpartum care). Beyond these requirements, federal CMS and the Office of the Inspector General defer to states to define what constitutes a medical emergency. A few states include ESKD in the definition of "emergency medical condition," thereby expanding access to standard hemodialysis to undocumented immigrants. We wanted Colorado to join that list.

On August 2018, after four years of research and months of dialog, everything changed: Colorado Medicaid announced that ESKD was now an "emergency medical condition." As simple as that, undocumented immigrants would receive standard maintenance hemodialysis. Tears streamed down my face as I read a message from a policy specialist from the Colorado Medicaid: Your team "played a big role in bringing awareness to this issue, and your advocacy for these patients is impressive ... thank you for fighting for such an important cause." I reread her message, imagining what this would have meant to Hilda and her boys.

Our work to enhance care in this community is not over. To better understand the provision of dialysis care for undocumented immigrants in the United States, our team reviewed the Medicaid language for each of the 50 US states in addition to connecting with clinicians and organizations (eg, National Kidney Foundation and ESKD Networks). We found that only 12 states provide Medicaid reimbursement for standard dialysis and that a majority of the US states do not currently define need for dialysis as an emergency medical condition.<sup>12</sup> As our Colorado team works with stakeholders in other states interested in similarly redefining their state's emergency Medicaid definition, our most important advice is that advocacy is a team-based effort. There may be resistance and some may argue that expanding access to care would be an economic burden on taxpayers; however, research demonstrates that un-

documented immigrants contribute more to the US Medicare Trust Fund than they actually withdraw toward healthcare.<sup>13</sup> Furthermore, a new study has demonstrated that a net savings of nearly \$6,000 per person per month is realized when patients are transitioned from emergency-only hemodialysis to standard hemodialysis.<sup>14</sup>

Internal medicine hospitalists on the front-line of healthcare systems are regular witnesses to its horrible injustices. We rarely share our perspectives and do not expect change to follow. With Hilda, we saw how a powerful combination of research and coalition building could lift one patient's tragic story to a level where it could produce change. Augmenting Hilda's experience of tragically poor access to care with evidence-based research gave her story validity far beyond our immediate circle of friends and colleagues, making a singular tragedy, policy relevant. Each time we shared our research to community advocacy groups, health policy stakeholders, state legislators, nurses, and staff, we began with Hilda's story, not just because it inspired us, but because its truth was undeniable. Our patients' stories matter, and it is our responsibility to tell them.

Each time I prepare *nopalitos* for my family, I think of my last meal with Hilda. No matter how painful or difficult her struggle with ESKD, Hilda persisted. She protected her boys. They were her purpose. When she knew she could no longer give them the life she wanted for them, she found a family who would. Hilda's sons now live with a loving adoptive family, are thriving in school, and her oldest is interested in becoming a physician. *Nopal*, or cactus, symbolizes such endurance—a plant with unique adaptations and strength that can flourish under extreme environmental stress. Like a cactus storing precious water, Hilda treasured her children, and her resolve to provide for them was unstoppable, right to the edge of death. When our team first took up Hilda's cause, change seemed impossible. We discovered the opposite. As I clench the wooden rosary she left me that Christmas, I thank her for giving our team the courage to adapt and persist, for in doing so we found a path, first to research and then to broader partnerships and more meaningful policy changes.

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