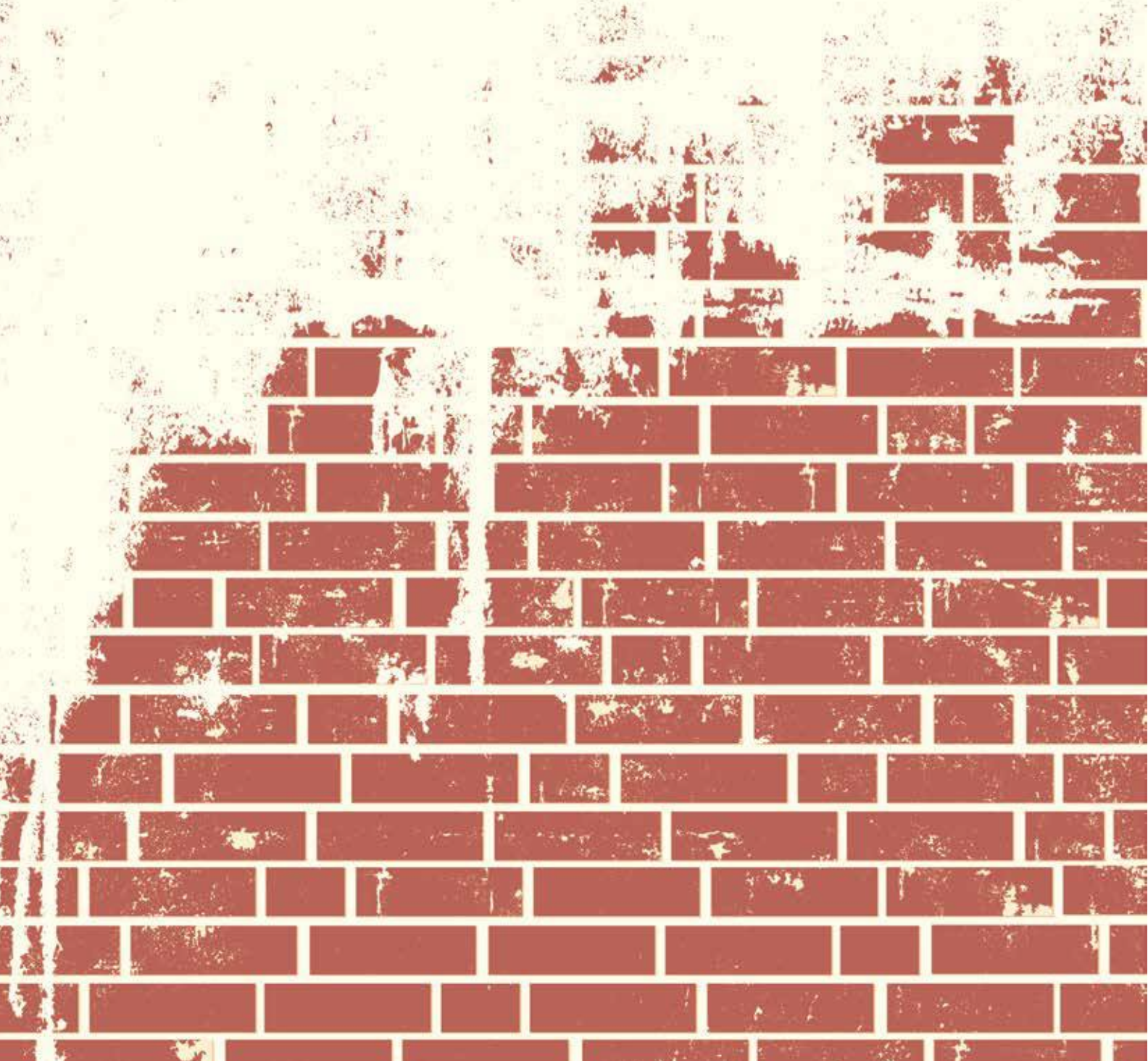
Brick by brick: The advocacy journey of Dr. Lilia Cervantes



Juan N. Lessing, MD, FACP

Dr. Lessing (AΩA, University of Colorado School of Medicine 2019, Faculty) is Associate Professor of Medicine, Division of Hospital Medicine, Department of Medicine, University of Colorado School of Medicine, Aurora, CO. Dr. Lessing's essay is the recipient of the 2023 AΩA Robert H. Moser Essay Award.

It was Mother's day 2014 when Dr. Lilia Cervantes' life changed forever. That was the day her patient, Hilda, died. Hilda and Cervantes shared parallel lives. They were both around the same age. They were both mothers to two small children. Their families were both from Mexico, they both grew up in poverty, and both learned English as a second language. But Hilda was undocumented and Cervantes was not. And, Hilda had end-stage kidney disease (ESKD).

In her fourth year after completing medical training in internal medicine, Cervantes met Hilda. Like countless patients with ESKD, Hilda presented herself to the emergency department unwell. She would sometimes get turned away, while other times she was admitted for emergency dialysis through inconsistent, patchwork policies. Once stabilized, she would be discharged back into the horrific cycle of again awaiting crisis for re-admission for life-saving dialysis.

Hilda's experience differed vastly from that of many others in this country with kidney failure who need dialysis. Regardless of insurance status, U.S. citizens, through a special provision of the 1972 End-Stage Renal Disease Amendments to the Social Security Act, could receive thrice weekly scheduled dialysis meant to more approximately simulate native kidney function and stave off the worst issues that could cause symptoms or death.[1] But, as an undocumented person in Colorado, Hilda only received emergency dialysis. Through a patchwork of rules and policies, each state and institution, decided when to dialyze undocumented immigrants.

Of an estimated 11 million undocumented immigrants in the United States, around 5,500 to 8,857 have kidney failure.[1,2] Like others, Hilda cycled through near-death hospitalizations for brief emergency dialysis followed by discharge. Near death. Hospitalization. Bandaid. Discharge. Complication. Near Death. Hospitalization. Bandaid. Discharge.

Cervantes tried every route to get Hilda scheduled dialysis, but to no avail. Pleas for *pro bono* care failed. Emergency dialysis was the only available option.

It all became too much. After years of countless hospitalizations, countless complications, and two cardiac arrests, Hilda decided she could not continue to go through this again and again, nor to have her young boys be re-traumatized seeing her ribs again cracked by the force of repeat chest compressions when her heart stopped. It was time. With unimaginable bravery, she arranged for her own children's adoption. Discussing with her boys, community, and with Cervantes, Hilda decided to stop emergency dialysis and to die. On Mother's day, Sunday May 11, 2014, Hilda passed away, surrounded by family and loved ones. Before she died, Hilda asked Dr. Cervantes to continue the fight so others could avoid her suffering. Spurred by Hilda's death, Cervantes redoubled her efforts to change these injustices.

A nurturing community

Growing up in Denver's predominantly working-class, Mexican-American Valverde neighborhood, Cervantes' Mexican roots were nurtured by her family. Just before her birth, her parents obtained legal U.S. entry to pursue a better life.

Cervantes was born at Denver Health, the same safety-net hospital where she would later train, work as an internal medicine hospitalist, and care for and befriend Hilda. At Denver Health, Cervantes was part of a team that sought to provide exceptional care models for underserved patients. But she also witnessed first-hand how state policies leave some behind.

Patients presented to a U.S. health care system that provided emergency only care that predictably resulted in returning to their prior dire situation, and, inevitably, eventual return to the emergency department, hospital, or the ICU, often worse off than before. Cervantes experienced policies and procedures and a model that made sense for no one: rampant yet unbeneficial costs; and rules that not only frustrated but frayed the very moral fiber of what it means to be a physician.

Angry, hurt, and spurred by Hilda's death, Cervantes knew she had to act. She continued talking with anyone who would listen (along with some who would not), and poring through everything she could read on the topic. An editorial by the Chief Medical Officer of the Center for Medicare and Medicaid Services (CMS), Dr. Barry M. Straube, sparked an idea.[3] The editorial highlighted The Emergency Medical Treatment and Active Labor Act (EMTALA) vague language about emergency conditions which resulted in inconsistent state dialysis

Hilda and her sons. Illustration by Ezra Gilmore

policies. Colorado, like many states, did not consider ESKD an emergency condition, therefore provided financial reimbursement for dialysis only when hospital admission was required for an immediately life-threatening condition, such as severe electrolyte imbalance or hypoxia with fluid overload. This meant often having to wait six or seven days[4] until reaching the brink of death to receive life-saving dialysis at the hospital, rather than receiving standard-of-care, scheduled dialysis that worked to prevent said emergencies. Because CMS had limited data for undocumented people, Straube called for more research.

Despite feeling like there was an immense wall preventing progress, and with no research experience, Cervantes applied for the competitive Harold Amos Faculty Development Program through the Robert Wood Johnson Foundation. To her surprise, she won. Through the award she sought to gain and develop the skillsets and know how to begin to build the coalition to reshape immigrant dialysis access in Colorado.

Cervantes would dismantle this obstructive wall brick by brick with each phase teaching and imparting powerful lessons in advocacy.

The first brick—the patient's perspective

Elevate patient voices and stories. Narratives from those directly affected catalyze change.

The first critical brick was amplifying the patient voice. Cervantes recognized lasting change was rooted in the human stories and perspectives of those living this reality. Though many clinicians expressed outrage, she understood narratives from the patients' viewpoint must take center stage.

Cervantes interviewed patients and caregivers, exploring their daily lives and illness experiences as undocumented dialysis patients.[5,6] Their accounts highlighted immense suffering and steep consequences from fragmented care. Patients described accumulating debilitating symptoms between emergency sessions,

resulting in recurrent near-death experiences and constant dread.

They spoke of the trauma of approaching hospitals while intentionally exacerbating their own potassium levels, gambling with death because inflated lab results were their only ticket to hospital admission and lifesaving treatment when resources were scarce. They explained how cramming a week's worth of dialysis into emergency sessions upended work, family, and community life.

While grateful for any care they received, their stories revealed denial of routine dialysis' human costs.

Equipped with these unflinching, powerful patient narratives, Cervantes had shining evidence of the moral imperative for reform. Patients emerged from the shadows, their voices strengthening their joint advocacy. Their perspectives became guiding lights, putting human faces to injustice.

The second brick—the clinician perspective

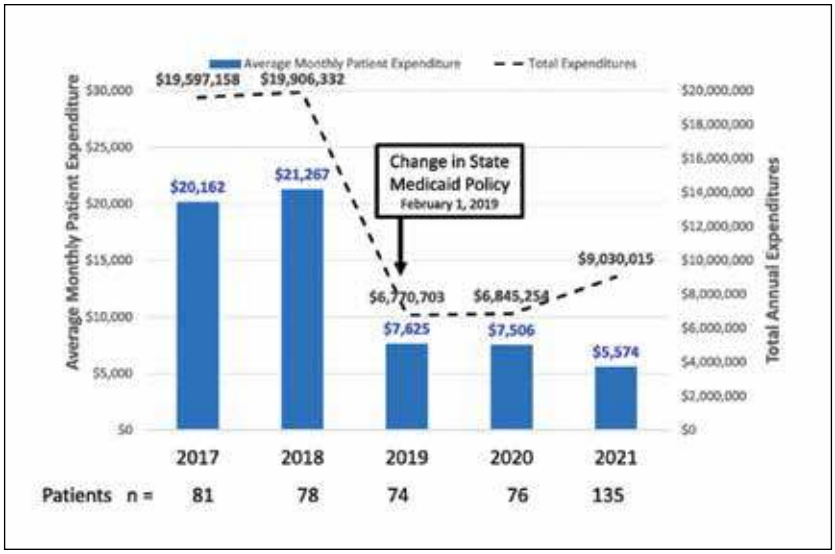
Illuminate diverse viewpoints, including frontline providers. This builds broad coalition for reform.

The next foundational brick was illuminating the clinician viewpoint. Cervantes knew individual doctors expressed outrage, but no research had systematically examined the qualitative experiences of providers administering emergency-only dialysis.

Cervantes rigorously investigated, interviewing 50 interdisciplinary clinicians at two high-volume safety net hospitals.[7] Their experiences were consistent; clinicians experienced profound moral anguish and ethical dilemmas providing fragmented dialysis which they knew and had first-hand knowledge of how it accelerated patient decline. They felt complicit in a system forcing them to deliver inferior care based on immigration status. Many considered quitting medicine altogether due to burnout from witnessing unnecessary suffering, and feeling powerless to provide treatment they felt patients deserved.

Clinicians also expressed frustration with the lack of clear or consistent criteria determining dialysis eligibility. This ambiguity led to conflict among providers and sometimes led to gaming the system, causing self- and professional-doubt. Moreover, the constant life-or-death dilemmas resulted in a rushed focus on emergency care, neglecting patients' multiple other medical needs.

Here was proof that flawed policies harmed both patients and clinicians. Cervantes' data exposed a broken system that failed patients and clinicians. Bolstered by patient and clinician narratives, Cervantes moral foundation for her advocacy grew stronger.



Cost analysis of dialysis expenditures for undocumented immigrants before and after change to Colorado state Medicaid policy. Used with permission from the authors and publisher[11]

The next bricks—symptom burden and circumstances of death

Quantify impacts. Do not rely on anecdotes alone. Data strengthens your case.

The next two pivotal bricks dismantled claims that emergency-only dialysis sufficiently sustained patients. To counter arguments that intermittent treatment did not harm patients, Cervantes' next step was to investigate outcomes.

She assessed symptom burden using a validated scale, finding undocumented patients reported significantly more nausea and symptoms between emergency sessions.[8] Analyzing death also produced damning results —most patients who died did so a median of six days after their last emergency dialysis, often from cardiac arrests with critical electrolyte imbalances (average potassium 6.4 mEq/L).[9]

The data left no doubt that emergency-only dialysis was inferior and resulted in preventable patient suffering and death.

Dialysis coverage 2019, after successful change to include Colorado as the 12th state to provide statewide maintenance dialysis utilizing Emergency Medicaid or Medicaid for undocumented immigrants. (The figure shows 13 states plus Washington D.C. in green because New Mexico uses a unique high-risk pool to provide state-wide dialysis coverage.)[4] Used with permission from the authors and publisher

By quantifying symptom burden and documenting how patients died, Cervantes further exposed the human cost of denying scheduled dialysis. Her data dealt a blow to notions that the status quo was equitable.

The final brick—health care utilization, cost, and mortality

Make both moral and economic cases. Appeal to values and practical realities to convince decision-makers.

Cervantes demonstrated that emergency-only dialysis wasted resources and cost significantly more than routine dialysis. She conducted analyses quantifying the stark dichotomy. She found that patients lacking scheduled access accumulated more ED visits and hospitalizations.[10] Despite using dialysis less often overall, costs related to complications and hospitalizations were exponentially higher.[2]

In Colorado, emergency-only dialysis cost the state $20,267 per patient per month, versus $5,574 for the same patients when they received routine outpatient dialysis.[2,11] After the state expanded coverage for routine dialysis, Colorado Medicaid expenditures for this population decreased four-fold.[11]

Providing routine outpatient dialysis could also free up scarce beds and resources in emergency departments and hospitals that often operate at, or over, capacity.

Most alarmingly, the five-year mortality rate was more than 14 times higher for emergency-only compared to routine dialysis patients.[10] The data proved failing to provide routine dialysis led to preventable deaths, was financially illogical, and crushed remaining justifications for the current state of emergency-only care.

With an impenetrable fortress of evidence cemented, Cervantes had systematically dismantled the barriers, brick by brick, learning and sharing invaluable lessons along the way. Her mission coalesced patients, clinicians, and policy-makers into an unstoppable coalition.

The wall crumbles

When Cervantes received a call from the Colorado Department of Health Care Policy and Financing saying the state planned to expand to include ESKD as a qualifying emergency medical condition, she burst into tears. Her promise to Hilda had been realized.

On February 16, 2019, Colorado became the 12th state to provide statewide maintenance dialysis utilizing Emergency Medicaid or Medicaid for undocumented immigrants.[12,13,14]

Still work to be done

Cervantes continues her mission, publishing and speaking broadly to share a model for reform.[15,16] She has served as a role-model and continues to share the blueprint for enacting such changes.[2, 17]

The pace of progress has accelerated—a 2023 state-by-state review of provision of maintenance dialysis showed that since 2019, five more states now utilize Emergency Medicaid; two explicitly clarified their Emergency Medicaid coverage before 2019; and one state utilizes a high-risk insurance pool.[12]

Cervantes and her extensive coalition continue pushing for health equity, applying lessons to help more people facing disparities.[18,19,20,21] She transforms moral outrage into disciplined action, mastering languages and skills to effectively influence systems. Her inspirational journey teaches that dedication and incremental change can overcome even daunting barriers when passionate leaders commit to advocacy.

An inspirational leader

There are many lessons from Cervantes, but none more powerful than the inspiration to be part of making change. Through her example, change is possible. She shows us that while inspiration fuels the spark, dedicated and disciplined research and advocacy performs the hard work required for meaningful change. Her journey instills the drive to move beyond inspiration toward committed action. There's a bit of Cervantes in all of us. Brick by brick, we can, we must, we shall, break down walls.

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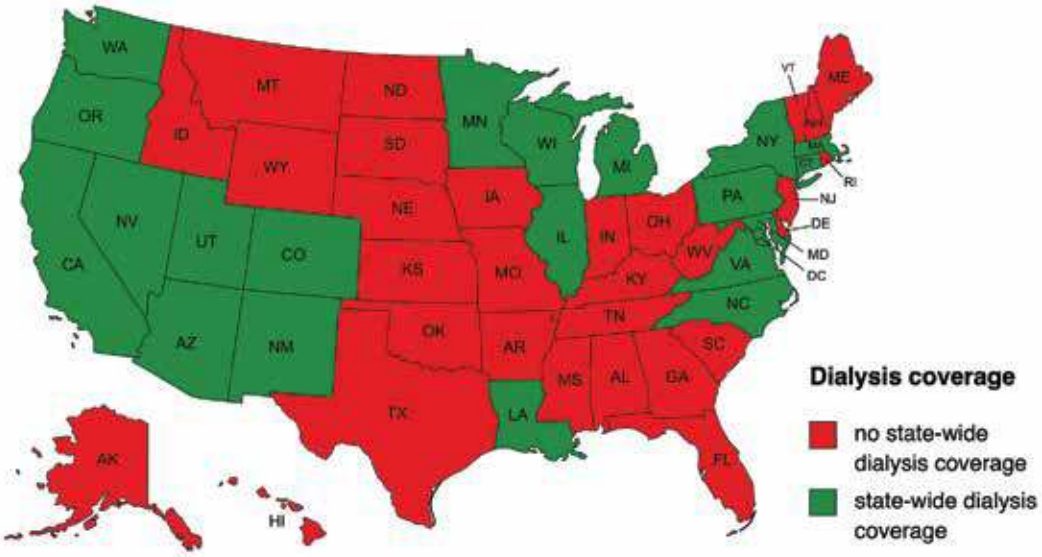

Dialysis coverage 2023. Note addition of five states and District of Columbia that now provide statewide maintenance dialysis utilizing Emergency Medicaid or Medicaid, and two states that clarified existing policy, for undocumented immigrants.[12] Used with permission from the authors and publisher

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The author's E-mail address is juan.lessing@cuanschutz.edu.