

# Informing Evidence Based Policy Making: Changing access to care for Undocumented Immigrants with Data

Lilia Cervantes, MD

Associate Professor

Division of Hospital Medicine & Office of Research



@Cervantes\_Lily1



Division of Hospital Medicine

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

# Disclosures

- **No Conflicts of Interest**
- **Opinions are my own and do not represent those of funders**

# Outline

- **Review our research and advocacy approach to expand access to dialysis for undocumented immigrants**
- **Describe similar pathway to expand access to outpatient COVID-19 care for undocumented immigrants**
- **Outline ongoing research and approach to expand access to cancer treatment for undocumented immigrants**

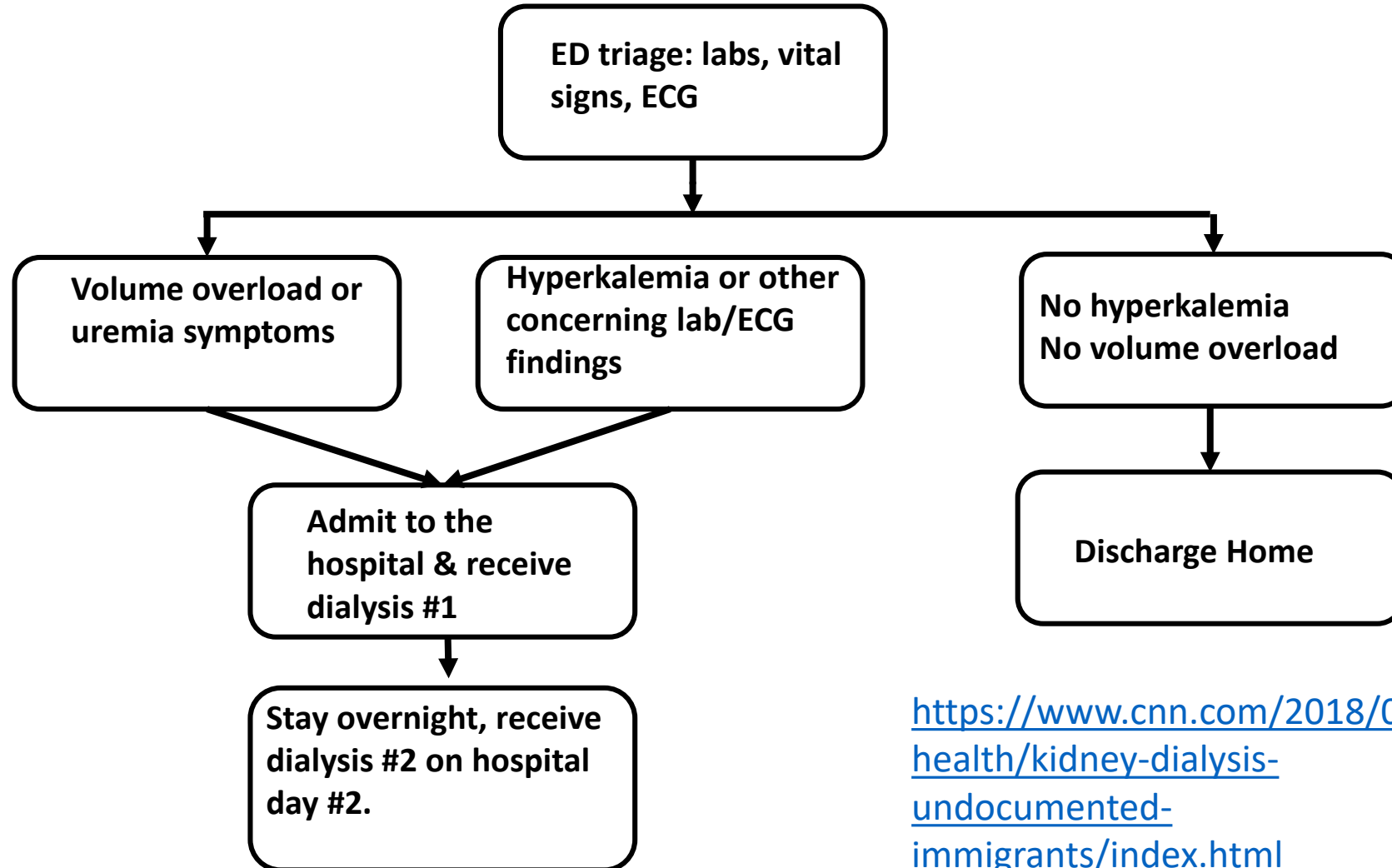


# Portrait of Latinx Community



Hilda

# Denver Health experience



<https://www.cnn.com/2018/08/02/health/kidney-dialysis-undocumented-immigrants/index.html>

# Undocumented Immigrants with ESKD

- Estimated 6 to 9 thousand undocumented immigrants with kidney failure
- Latino, male, employed, resided in the US >5 years prior to ESKD diagnosis
- Kidney replacement therapy is the standard of care for persons with kidney failure and is widely supplied across the U.S
- Availability of kidney replacement therapy varies across the country for undocumented immigrants



# Emergency Medical Treatment and Active Labor Act

## Emergency Medical Treatment and Active Labor Act Social Security Act § 1903(v)(3)

“a medical condition (including emergency labor and delivery) manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in

- (A) placing the patient’s health in serious jeopardy,
- (B) serious impairment to bodily functions, or
- (C) serious dysfunction of any bodily organ or part.”

# Emergency Medicaid

## Washington State

**Alien Emergency Medical Program:** An emergency medical program for individuals who do not meet the citizenship or immigration status requirements of other Apple Health programs.

**Who is eligible:** Individuals with a qualifying medical condition, which includes at least one of the following:

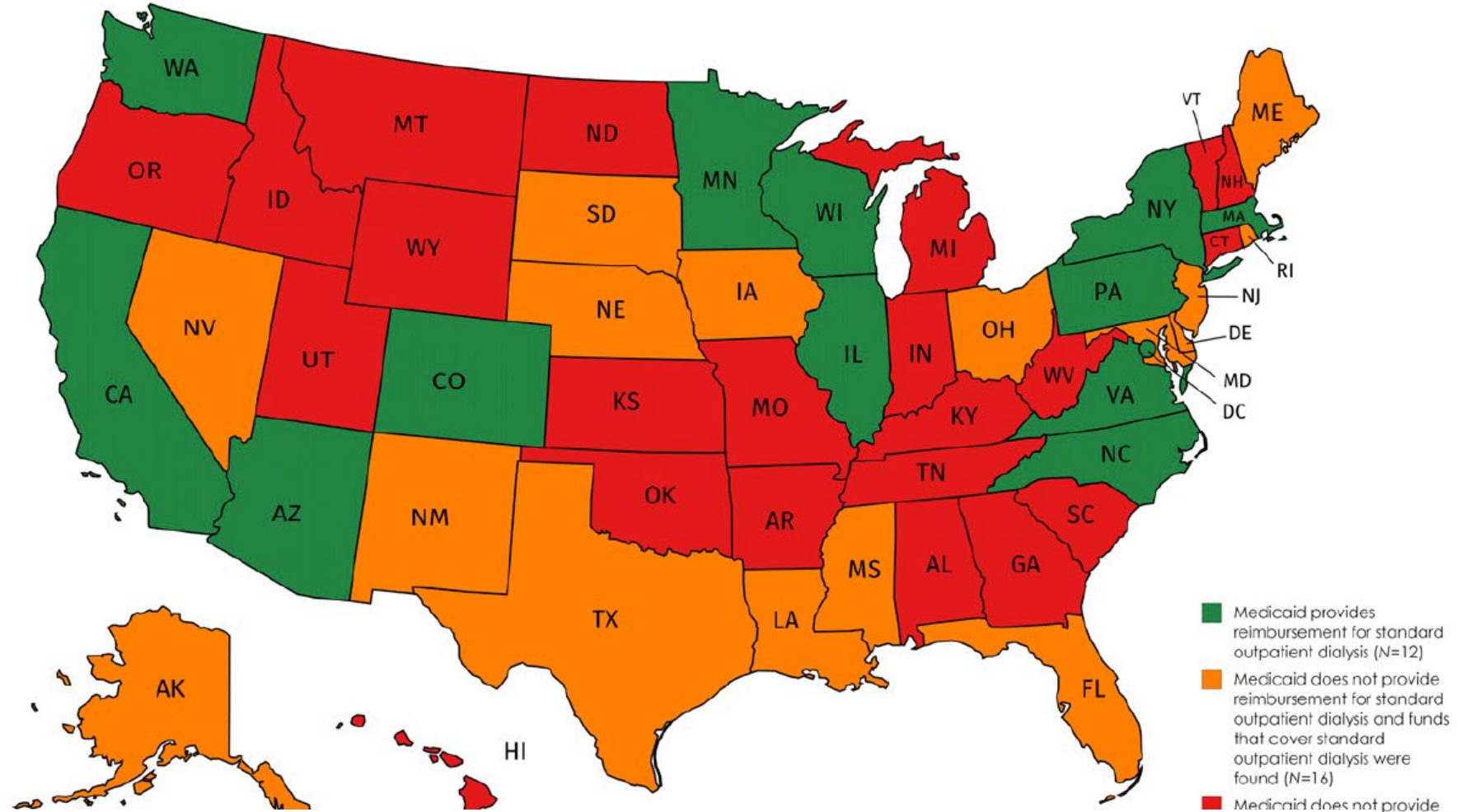
Emergency room care, inpatient admission, or outpatient surgery;

A cancer treatment plan;

Dialysis treatment;

Anti-rejection medication for an organ transplant

# Provision of Standard Dialysis for Undocumented Immigrants



Lilia Cervantes,<sup>1,2</sup> William Mundo,<sup>3</sup> and Neil R. Powe<sup>4,5</sup>



Hilda Cortez was an amazing mother, friend and patient. She loved her boys fiercely, more than anything in the world, even more than her own life. She modeled true courage, even in the face of death. Hilda lived her life full of passion, reckless abandon, humility, and sincerity. She refused to shrink back from who she was created to be. Hilda dreamt of leaving a lasting legacy behind for her sons, and transformed the lives of everyone who knew her. Hilda continues to inspire others to make the very most of the life they have been given. When thinking of Hilda Cortez, it is so easy to remember her contagious laugh, her sense of humor, her strength, the incredible bond she had with her boys, and her ability to make others want to better themselves. We love and miss you every day.



# Qualitative Research – Patient stakeholders



JAMA Internal Medicine | [Original Investigation](#)

## The Illness Experience of Undocumented Immigrants With End-stage Renal Disease

Lilia Cervantes, MD; Stacy Fischer, MD; Nancy Berlinger, PhD; Maria Zabalaga, BA; Claudia Camacho, BA; Stuart Linas, MD; Debora Ortega, PhD

**IMPORTANCE** The exclusion of undocumented immigrants from Medicare coverage for hemodialysis based on a diagnosis of end-stage renal disease (ESRD) requires physicians in some states to manage chronic illness in this population using emergent-only hemodialysis. Emergent-only dialysis is expensive and burdensome for patients.

**OBJECTIVE** To understand the illness experience of undocumented immigrants with ESRD who lack access to scheduled hemodialysis.

**DESIGN, SETTING, AND PARTICIPANTS** A qualitative, semistructured, interview study was conducted in a Colorado safety-net hospital from July 1 to December 31, 2015, with 20 undocumented immigrants (hereinafter referred to as undocumented patients) with ESRD and no access to scheduled hemodialysis. Demographic information was collected from the participants' medical records. The interviews were audiorecorded, translated, and then transcribed verbatim. The interviews were analyzed using inductive qualitative theme analysis by 4 research team members from March 1 to June 30, 2016.

**MAIN OUTCOMES AND MEASURES** Themes and subthemes from semistructured interviews.

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**Author Affiliations**  
Hospital Medicine, I

# Qualitative Research – Primary caregiver stakeholders



## The Experience of Primary Caregivers of Undocumented Immigrants with End-Stage Kidney Disease that Rely on Emergency-Only Hemodialysis

Lilia Cervantes, MD<sup>1,2,3</sup>, Alaina L. Carr, MA<sup>4</sup>, Christine C. Welles, MD<sup>1</sup>, Jeff Zoucha, MD<sup>1</sup>, John F. Steiner, MD MPH<sup>5</sup>, Tracy Johnson, PhD<sup>6</sup>, Mark Earnest, MD, PhD<sup>3</sup>, Claudia Camacho<sup>1</sup>, Kithika Suresh, PhD<sup>7</sup>, and Romana Hasnain-Wynia, PhD<sup>2</sup>

<sup>1</sup>Division of Hospital Medicine, Denver Health, Denver, CO, USA; <sup>2</sup>Office of Research, Denver Health, Denver, CO, USA; <sup>3</sup>Division of General Internal Medicine, University of Colorado, Denver, CO, USA; <sup>4</sup>University of Colorado, Denver, CO, USA; <sup>5</sup>Institute for Health Research, Kaiser Permanente Colorado, Denver, CO, USA; <sup>6</sup>Ambulatory Care Services, Denver Health, Denver, CO, USA; <sup>7</sup>University of Colorado School of Public Health, Denver, CO, USA.

**BACKGROUND:** Undocumented immigrants with end-stage kidney disease (ESKD) who rely on emergency-only hemodialysis (dialysis only after an emergency department evaluation) face psychosocial distress. Emergency-only hemodialysis (EOHD) is likely burdensome for primary caregivers as well.

**OBJECTIVE:** To understand the experience of primary caregivers of undocumented immigrants with ESKD who rely on emergency-only hemodialysis.

**DESIGN, SETTING, AND PARTICIPANTS:** A qualitative, semi-structured interview study to assess the experiences of primary caregivers of undocumented immigrants with ESKD at a safety-net hospital in Denver, Colorado from June 28 to November 15, 2018. Applied thematic analysis was used to analyze interviews.

**MAIN OUTCOMES AND MEASURES:** Themes and

assessing the consequences of excluding undocumented immigrants from public insurance programs.

**KEY WORDS:** health services research; immigrants; undocumented; health disparities; hemodialysis.

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### INTRODUCTION

Undocumented immigrants in the USA are ineligible for Medicare or full Medicaid benefits. In most US states, their



# Qualitative Research –Clinician stakeholders



Annals of Internal Medicine

ORIGINAL RESEARCH

## Clinicians' Perspectives on Providing Emergency-Only Hemodialysis to Undocumented Immigrants

### A Qualitative Study

Lilia Cervantes, MD\*; Sara Richardson, RN\*; Rajeev Raghavan, MD; Nova Hou; Romana Hasnain-Wynia, PhD; Matthew K. Wynia, MD; Catherine Kleiner, PhD, RN; Michel Chonchol, MD; and Allison Tong, PhD

**Background:** In the United States, nearly half of undocumented immigrants with end-stage kidney disease receive hemodialysis only when they are evaluated in an emergency department and are found to have life-threatening renal failure ("emergency-only hemodialysis" [EOHD]). These patients experience psychosocial distress and much higher mortality than patients receiving regularly scheduled hemodialysis, but little is known about how providing EOHD affects the clinicians involved.

**Objective:** To understand clinicians' experiences providing EOHD.

**Design:** Qualitative study using semistructured interviews.

**Setting:** A safety-net hospital in Denver, Colorado, and a safety-net system in Houston, Texas.

**Participants:** Fifty interdisciplinary clinicians experienced in providing EOHD.

**Measurements:** Interviews were analyzed using thematic analysis. Outcomes included themes and subthemes.

**Results:** Four themes and 13 subthemes (in parentheses) were identified: 1) drivers of professional burnout (emotional exhaustion from witnessing needless suffering and high mortality, jeopardizing patient trust, detaching from patients, perceived lack of

control over EOHD criteria, and physical exhaustion from overextending to bridge care), 2) moral distress from propagating injustice (altered care based on nonmedical factors, focus on volume at the expense of quality, and need to game the system), 3) confusing and perverse financial incentives (wasting resources, confusing financial incentives, and concerns about sustainability), and 4) inspiration toward advocacy (deriving inspiration from patients and strengthened altruism).

**Limitation:** Whether the findings apply to other settings is unknown, and social desirability response bias might have reduced reporting of negative perceptions and experiences.

**Conclusion:** Clinicians in safety-net settings who provide EOHD to undocumented patients describe experiencing moral distress and being driven toward professional burnout. The burden of EOHD on clinicians should inform discussions of systemic approaches to support provision of adequate care based on medical need.

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For author affiliations, see end of text.

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\* Dr. Cervantes and Ms. Richardson contributed equally to this work.

Annals.org

# Quantitative Research – Decision-maker stakeholders



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## Association of Emergency-Only vs Standard Hemodialysis With Mortality and Health Care Use Among Undocumented Immigrants With End-stage Renal Disease

Lilia Cervantes, MD; Delphine Tuot, MD; Rajeev Raghavan, MD; Stuart Linas, MD; Jeff Zoucha, MD; Lena Sweeney, MD; Chandan Vangala, MD; Madelyne Hull, MPH; Mario Camacho, MD; Angela Keniston, MSPH; Charles E. McCulloch, PhD; Vanessa Grubbs, MD; Jessica Kendrick, MD; Neil R. Powe, MD

[+ Author Audio Interview](#)

[+ Supplemental content](#)

**IMPORTANCE** Undocumented immigrants with end-stage renal disease have variable access to hemodialysis in the United States despite evidence-based standards for frequency of dialysis care.

**OBJECTIVE** To determine whether mortality and health care use differs among undocumented immigrants who receive emergency-only hemodialysis vs standard hemodialysis (3 times weekly at a health care center).

**DESIGN, SETTING, AND PARTICIPANTS** A retrospective cohort study was conducted of undocumented immigrants with incident end-stage renal disease who initiated emergency-only hemodialysis (Denver Health, Denver, Colorado, and Harris Health, Houston, Texas) or standard (Zuckerberg San Francisco General Hospital, San Francisco, California) hemodialysis between January 1, 2007, and July 15, 2014.

**EXPOSURES** Access to emergency-only hemodialysis vs standard hemodialysis.

**MAIN OUTCOMES AND MEASURES** The primary outcome was mortality. Secondary outcomes were health care use (acute care days and ambulatory care visits) and rates of bacteremia. Outcomes were adjusted for propensity to undergo emergency hemodialysis vs standard hemodialysis.

# Quantitative Research – Decision-maker Stakeholders

- **Objective:** To determine whether mortality, utilization, costs differs between undocumented ESRD patients receiving EOHD vs standard HD (private insurance)
- **Design, setting, participants:** Observational cohort study
- **Results:**
  - Mortality: Adjusted hazard ratio of death at 1 year was 5-fold greater
  - Costs: \$6,000 in savings per person per month

JAMA Internal Medicine | [Original Investigation](#)

## Association of Scheduled vs Emergency-Only Dialysis With Health Outcomes and Costs in Undocumented Immigrants With End-stage Renal Disease

Oanh Kieu Nguyen, MD, MAS; Miguel A. Vazquez, MD; Lakeesha Charles, LCSW; Joseph R. Berger, MD; Henry Quiñones, MD; Richard Fu Joanne M. Sanders, MS; Kandice A. Kapinos, PhD; Ethan A. Halm, MD, MPH; Anil N. Makam, MD, MAS

**IMPORTANCE** In 40 of 50 US states, scheduled dialysis is withheld from undocumented immigrants with end-stage renal disease (ESRD); instead, they receive intermittent emergency-only dialysis to treat life-threatening manifestations of ESRD. However, the comparative effectiveness of scheduled dialysis vs emergency-only dialysis and the influence of treatment on health outcomes, utilization, and costs is uncertain.

**OBJECTIVE** To compare the effectiveness of scheduled vs emergency-only dialysis with regard to health outcomes, utilization, and costs in undocumented immigrants with ESRD.

**DESIGN, SETTING, AND PARTICIPANTS** Observational cohort study of 181 eligible adults with ESRD receiving emergency-only dialysis in Dallas, Texas, who became newly eligible and applied for private commercial health insurance in February 2015; 105 received coverage and were enrolled in scheduled dialysis; 76 were not enrolled in insurance for nonclinical reasons (eg, lack of capacity at a participating outpatient dialysis center) and remained uninsured, receiving emergency-only dialysis. We examined data on eligible persons during a 6-month period prior to enrollment (baseline period, August 1, 2014-January 31, 2015) until 12 months after enrollment (follow-up period, March 1, 2015-February 29, 2016) with an intervening

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+ Supplement

# Community Based Organizations and Decision-Maker Stakeholders



# Impact across the country

## Offering Better Standards of Dialysis Care for Immigrants: The Colorado Example

Lilia Cervantes<sup>1,2</sup>, Tracy Johnson,<sup>3</sup> Aubrey Hill,<sup>4</sup> and Mark Earnest<sup>5</sup>

CJASN 15: ●●●●●, 2020. doi: <https://doi.org/10.2215/CJN.01190120>

On February 1, 2019, the Colorado Department of Health Care Policy and Financing opted to include “ESRD” in Colorado’s definition for “emergency medical condition,” thereby expanding access to scheduled thrice-weekly hemodialysis to undocumented immigrants. Colorado became the 12th state in the country to provide Medicaid reimbursement for scheduled hemodialysis for undocumented immigrants (1). In this perspective piece, we describe emergency-only hemodialysis and provide guidance for other states interested in similarly expanding access to care.

### Undocumented Immigrants with Kidney Failure: An Overview

There are an estimated 5500–8857 undocumented immigrants with kidney failure in the United States (2). Scheduled outpatient dialysis (and/or kidney transplantation) is the standard of care for persons with kidney failure. Access to outpatient dialysis is limited because undocumented immigrants with kidney failure are not eligible for health care coverage under the 1972 Medicare ESRD entitlement program (Public Law 92–603) or the provisions of the Patient Protection and Affordable Care Act (Public Law 111–148) (2). Access to scheduled dialysis varies and depends on the availability of safety-net provisions (public clinics and philanthropy) and each state’s individually administered Medicaid and Emergency Medicaid benefits. To ensure that patients are not turned away from receiving emergency services,

emergency-only hemodialysis at Denver Health, the safety-net hospital that provided care to more than 90% of undocumented immigrants with kidney failure included an elevated potassium level, a low oxygen saturation level, nausea and vomiting, new or worsening neurologic signs/symptoms, clinical findings consistent with heart failure, and electrocardiogram changes (1). A patient meeting any one of these criteria, would be admitted to the hospital to receive two hemodialysis sessions over 2 days, repeated every 6–7 days (1).

Because undocumented immigrants with kidney failure must wait until they are at the brink of death to receive emergency-only hemodialysis, many describe physical and psychosocial distress and, compared with undocumented immigrants with kidney failure that receive scheduled hemodialysis, they have a higher mortality and care is more costly (4,5).

### A State-by-State Solution

The Federal law that creates the Emergency Medicaid program specifies that hospitals provide a medical screening examination when a patient presents with an emergency medical condition defined as “a medical condition (including emergency labor and delivery) manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in (A) placing the patient’s health in serious jeopardy; (B) serious im-

<sup>1</sup>Division of Hospital Medicine and Office of Research, Denver Health, Denver, Colorado

<sup>2</sup>Division of General Internal Medicine and Hospital Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado

<sup>3</sup>Department of Health Care Policy and Financing, Denver, Colorado

<sup>4</sup>Center for Health Progress, Denver, Colorado

<sup>5</sup>Division of General Internal Medicine, University of Colorado Anschutz Medical Campus, Aurora, Colorado

### Correspondence:

Dr. Lilia Cervantes, Denver Health, 601 Bannock, MC 4000, Denver, CO 80204-4507. Email: Lilia.Cervantes@dhha.org



Open Letter to State Medicaid Directors,

On behalf of the undersigned organizations, we urge you to modify your state Emergency Medicaid policy to allow outpatient and home dialysis and directed living donor kidney transplants as covered services.

As you may know, in most states, undocumented immigrants with kidney failure must wait until they are at the brink of death to receive the regular filtration of their blood that is necessary to stay alive.<sup>1</sup> The kidney care these individuals receive is inhumane, extraordinarily expensive, and largely ineffectual. Our organizations believe it is imperative that state policymakers act expeditiously to follow the lead of states like Arizona and Colorado and expand Emergency Medicaid for undocumented immigrants living in the United States.

***Expanding access to care for undocumented people with kidney failure is bipartisan, cost saving, and requires no new statutory authority, requiring only simple changes to a state’s Emergency Medicaid policies.***

Hilda was a young, single mom of two school-aged children who suffered from kidney failure. Because she was undocumented and in Colorado, Hilda was ineligible for scheduled dialysis, receiving it only on an emergency basis. Every 6–8 days, Hilda would appear at the emergency department, near death, to receive two days of dialysis in the intensive care unit. After her third cardiac arrest, Hilda realized she needed to find a family to adopt her boys who had suffered tremendous trauma witnessing their mother’s weekly battle with death. After Hilda identified a family to adopt her sons, she stopped emergency dialysis and passed away on Mother’s Day in 2014.<sup>2</sup> In the wake of Hilda’s death, the interdisciplinary clinicians who were compelled to provide emergency dialysis went on to conduct the research that ultimately supported Colorado Medicaid’s inclusion of the diagnosis of end-stage renal disease (ESRD), also known as end-stage kidney disease (ESKD) as a qualifying condition for Emergency Medicaid. [Colorado Medicaid predicted the policy change would save the state \\$19 million per year.](#)<sup>3</sup> Scheduled dialysis reduces costs as much as \$4316 per patient per month (PPPM). When referenced to the increased costs associated with emergency dialysis, net savings are \$5768 PPPM.<sup>4</sup> In a cohort study of 181

# Transition from Emergency to Scheduled HD

## Patient-Reported Outcomes and Experiences in the Transition of Undocumented Patients from Emergency to Scheduled Hemodialysis

### Patient Selection



30 Patients with kidney failure receiving hemodialysis

- Undocumented immigrants
- > 18 years of age
- Receiving emergency dialysis for 3 months

### Transition from emergency to standard dialysis

#### Emergency dialysis

- Dialysis when critically ill with admission to hospital
- Repeat cycle each week



#### Standard dialysis

- Scheduled outpatient hemodialysis
- Three times a week

### Before and After Transition

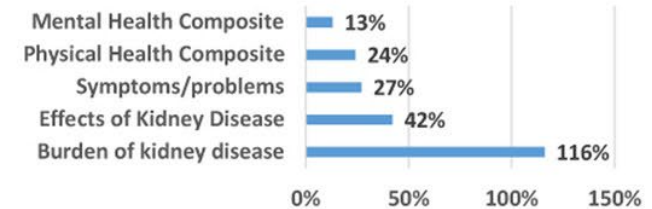


- **Quality of life** KDQOL SF-36
- **Edmonton Symptom Assessment** (pain, tired, drowsy, nausea, appetite, shortness of breath, depression, anxiety, well-being)
- **Trust and satisfaction**
- **Patient Experience:** Semi-structured interview

### Results

#### Patient-Reported Outcomes

% Improvement in KDQoL



- 57-100% improvement in 7 symptoms ( $p < 0.05$ )
- Trust and satisfaction unchanged

#### Patient Experience Themes

- Anxiety about navigating changes in care
- Increased burden on family & employers
- + Relief in receiving consistent care
- + Immediate and remarkable health gains

### CONCLUSION:

Providing health care access to standard dialysis for undocumented immigrants improves quality of life and mitigates debilitating symptoms but brings new challenges in health care navigation.

# COVID-19: Undocumented Immigrants



# Qualitative and Quantitative: Patient and partner stakeholders

Original Investigation | Public Health

## Experiences of Latinx Individuals Hospitalized for COVID-19 A Qualitative Study

Lilia Cervantes, MD; Marlene Martin, MD; Maria G. Frank, MD; Julia F. Farfan, BS; Mark Kearns, MD; Luis A. Rubio, MD; Allison Tong Claudia Camacho, BS; Adriana Collings, MPH; William Mundo, MPH; Neil R. Powe, MD; Alicia Fernandez, MD

### Abstract

**IMPORTANCE** Latinx individuals, particularly immigrants, are at higher risk than non-Latinx White individuals of contracting and dying from coronavirus disease 2019 (COVID-19). Little is known about Latinx experiences with COVID-19 infection and treatment.

**OBJECTIVE** To describe the experiences of Latinx individuals who were hospitalized with and survived COVID-19.

**DESIGN, SETTING, AND PARTICIPANTS** The qualitative study used semistructured phone interviews of 60 Latinx adults who survived a COVID-19 hospitalization in public hospitals in San Francisco, California, and Denver, Colorado, from March 2020 to July 2020. Transcripts were analyzed using qualitative thematic analysis. Data analysis was conducted from May 2020 to September 2020.

**MAIN RESULTS AND MEASURES** Themes and subthemes that reflected patient experiences

### Key

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## Disproportionate Incidence of COVID-19 Infection, Hospitalizations, and Deaths Among Persons Identifying as Hispanic or Latino — Denver, Colorado March–October 2020

Laura Jean Podewils, PhD<sup>1,2,3</sup>; Tori L. Burket, MS<sup>1</sup>; Christie Mettenbrink, MPH<sup>1</sup>; Abigail Steiner, MPH<sup>1</sup>; Allison Seidel, MPH<sup>1</sup>; Kenneth Scott, PhD<sup>1</sup>; Lilia Cervantes, MD<sup>2,4,5</sup>; Romana Hasnain-Wynia, PhD<sup>2,5</sup>

Persons identifying as Hispanic or Latino (Hispanic) represent the second largest racial/ethnic group in the United States (1), yet understanding of the impact of coronavirus disease 2019 (COVID-19) in this population is limited. To evaluate COVID-19 health disparities in the community and inform public health, health system, and community-based interventions, local public health authorities analyzed the sociodemographic characteristics of persons who were diagnosed, hospitalized, and who died with COVID-19 in Denver, Colorado. During the first 7 months of the COVID-19 epidemic in Denver (March 6–October 6, 2020) the majority of adult COVID-19 cases (54.8%), hospitalizations (62.1%), and deaths (51.2%) were among persons identifying as Hispanic, more than double the proportion of Hispanic adults in the Denver community (24.9%) (1). Systemic drivers that influence how Hispanic persons live and work increase their exposure risks: compared with non-Hispanic persons, Hispanic persons with COVID-19 in Denver reported larger household sizes and were more likely to report known exposures to household and close contacts with COVID-19, working in an essential industry, and working while ill. Reducing the disproportionate incidence of COVID-19 morbidity and

close contact, and recent travel), signs and symptoms, symptom onset date, and whether the respondents worked while ill. In early May, the interview form was expanded to include detailed information on industry and occupation according to national guidelines (2) and household size. Because of the large volume of cases and difficulty reaching persons in the hospital, medical chart reviews, rather than telephone interviews, were used to obtain information about persons hospitalized or deceased at the time of COVID-19 diagnosis. Data from case interviews and medical chart reviews were obtained from standardized case report forms, validated for completeness, and entered into a secure REDCap database (3). The analysis used public health surveillance data and was carried out to understand and inform public health actions to control the spread of COVID-19 in the Denver community; the project was determined to be nonhuman subjects' research and exempt by the Colorado Multiple Institutional Review Board.

The analysis focused on adults aged ≥18 years living in noncongregate settings (excluding persons in long-term care facilities, jails, or in shelters for persons experiencing homelessness) at the time of diagnosis and aimed to identify COVID-19 health disparities in the community to inform

# Policy change throughout the country

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## Bennet, Cárdenas, Sánchez Lead 47 Colleagues in Urging Administration to Ensure Undocumented Immigrants Can Receive COVID-19 Care

March 19, 2021

### Bicameral Letter Requests Clarified Guidance from HHS, CMS To Secure Emergency Medicaid Coverage of COVID-19 Testing, Treatment, and Vaccinations

Denver – Today, U.S. Senator Michael Bennet (D-Colo.) and U.S. Representatives Tony Cárdenas (D-Calif.) and Linda Sánchez (D-Calif.) led 10 Senate and 37 House Democratic colleagues in urging the Biden Administration to ensure undocumented immigrants across the country can receive Coronavirus Disease 2019 (COVID-19) testing, treatment, and vaccinations at no cost through emergency Medicaid. In a letter to Secretary of the Department of Health and Human Services (HHS) Xavier Becerra and Acting Administrator of the Centers for Medicare and Medicaid Services (CMS) Liz Richter, the lawmakers requested CMS issue necessary guidance clarifying that emergency Medicaid -- which helps ensure undocumented individuals without health coverage can receive access to critical care -- can provide coverage of COVID-19-related care.

“In light of President Biden’s focus on equity in response to the pandemic, we hope that you will move swiftly to ensure that all individuals can receive COVID-19 care, without worrying how they will pay for it,” wrote **Bennet, Cárdenas, Sánchez, and their colleagues in the letter.**

Despite nearly half of undocumented immigrants lacking health insurance, immigrants have served on the COVID-19 frontlines, with over two-thirds of undocumented workers serving in essential jobs. While the *American Rescue Plan Act*, which President Joe Biden signed into law last week, secured COVID-19 related coverage for uninsured Americans under Medicaid, the lawmakers stressed the need to clarify

# Community- Based Organization Stakeholder engagement



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## Our Team

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CEO/Program Director - Diana Pineda



Diana Pineda is the Founder of VUELA for Health (2018) and Co-Founder of CREAResults (2013). As an immigrant Mexicana who is raising two bicultural girls, she understands that fostering safe, supportive, happy and healthy environments at home are imperative for youth success. Her aim is to empower immigrant families through education, skills building, increasing knowledge and understanding, economic security, and increasing health equity as well as facilitating the intergration of immigrant families into their communitites. As a strong woman who earned her degree in business administration, she

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Maria Elena Rivera  
Diane Medina  
Linda Smith  
Leticia Luna  
Monica Duran  
Maribel Olivas

# Cancer treatment: Undocumented Immigrants

- Qualitative research
- Retrospective cohort study
- Cost-effectiveness analysis

## Policy in Clinical Practice: Emergency Medicaid and Access to Allogeneic Stem Cell Transplant for Undocumented Immigrants

Haley M Simpson, MD, PhD<sup>1\*</sup>, Allison Bock, MD<sup>1</sup>, Lilia Cervantes, MD<sup>1,2</sup>

<sup>1</sup>Division of General Internal Medicine, University of Colorado School of Medicine, Aurora, Colorado; <sup>2</sup>Division of Hospital Medicine and Office of Research, Denver Health, Denver, Colorado.

### CLINICAL SCENARIO

Juan, a 50-year-old man with acute myeloid leukemia (AML), sat on the edge of his bed, dejected. Juan's leukemia had relapsed for a third time, and he was low on options and optimism. Originally from Mexico, he had made the journey to Colorado to work as a mechanic and care for his disabled son. Like millions of other individuals in the United States, he did not obtain a visa and had no affordable options for health insurance. For nearly a decade, that had seemed not to matter, until he became ill. Initially presenting to the emergency department with fatigue and night sweats, Juan was diagnosed with poor-risk AML and underwent emergent induction chemotherapy reimbursed under Emergency Medicaid (Table). Just when his

tion receive appropriate evaluation and stabilizing treatment. An emergency condition is defined as "manifesting itself by acute symptoms of sufficient severity ... such that the absence of immediate medical attention could reasonably be expected to result in (A) placing the patient's health in serious jeopardy; (B) serious impairment to bodily functions; or (C) serious dysfunction of any bodily organ or part" (Table).<sup>3,4</sup> The Centers for Medicare & Medicaid manual restates the EMTALA definition and notes that services for an emergency medical condition cannot include care related to organ transplantation. Most state Emergency Medicaid programs have adopted the federal definition of what constitutes a medical emergency.<sup>5</sup> As a result, undocumented individuals who qualify for Medicaid

# Cancer treatment: Undocumented Immigrants

## Policy Brief

### Expanding Access to Comprehensive Cancer Care for Coloradans: Hematopoietic Cell Transplant for Undocumented Immigrants

*"If I had money, I would live, but if I don't have money, I would die. It's hard when you see human life reduced to this." -35 year old man with Hodgkin's Lymphoma, an undocumented immigrant*

**Background:** In 2019, Colorado expanded access to standard of care dialysis for kidney failure to undocumented immigrants through Emergency Medicaid. This change saved the state millions of dollars and reduced mortality and improved quality of life for patients. Similar to kidney failure, undocumented immigrants with cancer end up in the revolving door of the emergency department, receiving sub-standard care that is more expensive to the state than standard of care. For example, for patients with high-risk blood cancers, Hematopoietic Cell Transplant (HCT) is the only curative treatment option. HCT decreases the chance of relapse from a 70% chance of the cancer coming back to around a two-thirds chance of being cured.<sup>1</sup>

Despite the effectiveness of HCT and other cancer treatments, undocumented immigrants do not have healthcare coverage for cancer treatment and they are instead left in the revolving door of the emergency department when they are critically ill, relying on Emergency Medicaid. HCT is associated with up-front expenses, but the long-term costs to the state for untreated cancer, hospitalizations, and terminal care for these individuals are also high. *Indeed, the cost of HCT can be recouped in as little as two years by a cured immigrant's return to the labor force and contributions to the country's economic productivity.*<sup>2</sup> Using our data-driven estimates, of the 160,000 undocumented immigrants living in Colorado, this would impact at least 1,300 individuals.<sup>3</sup>

**The Solution--**States are beginning to realize the benefits of providing comprehensive cancer care to undocumented immigrants, including Washington State, which added "cancer treatment", including HCT, to their qualifying services for Emergency Medicaid. *We propose that Colorado follow Washington's example and expand coverage of lifesaving cancer care including HCT for uninsured immigrants by adjusting the qualifying services to include cancer treatment for Emergency Medicaid.*

#### Overview of Target Population in the US and CO:

- Nationwide, there are 11.4 million undocumented immigrants comprising 4.6% of the workforce. In Colorado, there are 162,000 undocumented immigrants, comprising 5% of the workforce.<sup>3,4</sup>
- There are no published estimates of the number of undocumented immigrants that have hematologic malignancies, but given 75% of undocumented immigrants in the US generally are from Mexico, Central America, and South America<sup>5</sup> and the incidence of leukemia is 11.4 per 100,000 among Latinx populations<sup>6</sup>, we can estimate that there are approximately 1,300 new cases of leukemia each year among undocumented immigrants. Using the same method, we can expect 832 cases of multiple myeloma (MM) and 2,040 of non-Hodgkin lymphoma (NHL).<sup>6</sup> In Colorado, where 84% of

#### Fiscal Impact and Considerations:

- Using AML as an example, estimates show there is a cost difference of approximately \$68,000 to treat a patient with HCT than to care for them repeatedly while critically ill with chemotherapy.<sup>2</sup> This estimate does not account for lost economic activity of undocumented immigrants who die as a result of AML.
  - An undocumented immigrant worker contributes \$45,000/year to the US GDP.<sup>10</sup>
  - In  $\leq 2$  years, an undocumented immigrant who was cured after treatment with HCT would recoup the difference in cost through their return to the workforce and economic contributions.<sup>2</sup>
- Lost contribution to state and local taxes
  - A 2016, non-partisan analysis showed that undocumented immigrants in CO contributed \$134,582,000 in state and local taxes (through a combination of sales, property, and income taxes) each year.<sup>11</sup> Since many undocumented immigrants live in mixed-status families<sup>12</sup> and cancer of one person significantly impacts the whole family, the economic activity and tax revenue of multiple people could be lost each year.
- Cost-effectiveness and economic value:
  - The Incremental Cost Effectiveness Ratio (ICER) equation estimates the value of an intervention from a cost-effectiveness standpoint, comparing the cost per "quality-adjusted life-years" of an intervention to an alternative. A "quality-adjusted life-year" is a frequently used tool to estimate the cost-effectiveness of an intervention.
  - The ICER for HCT compared to no transplant for acute leukemia is \$16,346 to \$34,360, depending on the type of transplant and other treatment regimens provided with it.<sup>13</sup> The treatment is considered a favorable intervention if the value of the ICER is  $< \$50,000$ . This means the costs associated with the intervention (in this case HCT) are outweighed by the improvement in the individual's return to societal contribution.
- From 2000-2011, undocumented immigrants contributed \$2.2-3.8 billion more to the Medicare Trust Fund (by paying federal taxes on their income) than they used each year (almost no Medicare funds can go to undocumented immigrants), providing for a program that they cannot benefit from.<sup>14</sup>
- California provides cancer care, including HCT, to undocumented immigrants at lower costs than for US citizens on Medicaid.<sup>2,15</sup>

#### How would this impact healthcare providers?

- There is no data on how healthcare providers feel when forced to withhold life-saving treatment to patients with cancer. However, we know the grave impact on providers who could not provide standard of care treatments for end-stage kidney disease.
  - In Colorado, healthcare providers limited to offering emergency-only dialysis to undocumented immigrants (as opposed to standard three times weekly dialysis) had moral distress, higher burnout,

# Take home messages

- Read the bill and understand the policy pathway
- When you are motivated to conduct research to change policy, consider first engaging your patient and partner stakeholders to understand their perspective of what the solution might be.
- Include qualitative research and/or mixed methods
- Engage opponents and understand the data they need to support your cause

**“Success is not about abstracts, papers, awards, or titles. It is about having a positive impact on the lives of others, about meaningful change”**

**- Dr. Barbara T. Murphy**



**@Cervantes\_Lily1**

