

**ACCESS TO LIFE: ADVANCED HEART FAILURE THERAPIES FOR
UNDOCUMENTED IMMIGRANTS**

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ABSTRACT

The U.S. healthcare system systematically excludes undocumented immigrants (UIs) from life-sustaining treatments for advanced heart failure (AHF), creating profound ethical violations and health disparities. This thesis demonstrates how excluding UIs from AHF therapies breaches justice, autonomy, beneficence, and non-maleficence by restricting access to mechanical circulatory support, inotropic therapy, and heart transplants. Analysis of Medicaid restrictions, legal barriers, and a representative patient case study reveals how current policies institutionalize preventable harm. Contrasting these failures with successful state-level expansions for end-stage renal disease (ESRD), the work proposes actionable solutions to redress inequities exacerbated by immigration policies. The findings underscore that structural reform is both ethically imperative and financially viable, with critical implications for public health, equity, and clinician moral distress. This thesis calls for immediate policy changes guided by the ESRD model and further research to address healthcare exclusion.

For JJ, his family, and the undocumented
communities of Philadelphia.

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CHAPTER 1

INTRODUCTION

Living with Heart Failure and Without Papers

All names and locations have been anonymized.

My first encounter with JJ was just a name on a long list of patients. I received sign-out from the team regarding his chief complaint, his current symptoms, and our treatment plan. I learned that he had end-stage heart failure and came to the hospital with a condition known as a “heart failure exacerbation and volume overload.” On paper, this looked like one of many clinical situations that I had seen several times before, but little did I know that JJ’s situation was anything but routine.

By the time I met JJ, this was far from his first encounter with the medical system. His heart failure had progressed so severely that his ejection fraction (EF) was estimated to be 5%. This means that only 5% of the blood in his heart was being squeezed out with each heartbeat. I watched the flickering of his heart muscle, nearly motionless, as the echocardiogram looped on repeat. Before I had even seen the patient, I knew his health was in jeopardy.

To my surprise, when I walked into JJ’s room and saw him for the first time, I saw a lively man in his early 60s, looking remarkably comfortable, staring back at me. I was shocked. I walked in expecting the worst based on the picture that I had painted in my mind, but his heart failure had progressed slowly enough that his body had time to compensate for his low EF. I would soon learn that these are the patients whose stability is the most fragile.

The definitive treatment for advanced heart failure is a transplant. Despite his weak heart, JJ had been denied a transplant evaluation on the grounds that he was an undocumented immigrant without insurance. This was the first time I had heard this rule. Other patients I had seen in the same situation would have been immediately evaluated and possibly listed for a new heart. But for JJ, we treated him with diuretic medications to remove excess fluid from his body, refilled his maintenance medications, and discharged him. These were merely stabilizing treatments, and as such, this was not the last time our paths would cross.

Approximately three months later, JJ returned to the hospital after running out of his medications. However, what had started as another heart failure exacerbation had progressed to cardiogenic shock. His heart was unable to pump enough blood to adequately supply his vital organs, and this was a medical emergency. He was transferred to the ICU and started on a continuous IV medication called milrinone which helped his weakened heart muscle to squeeze harder with each heartbeat. Once stabilized, he looked like the same pleasant man I had met less than three months ago—always without complaints, never wanting to burden anyone, and just wanting to go home. But now he was attached to the IV medication that was maintaining his heart's ability to beat effectively. This was when I learned that, without insurance, he would never be able to leave the hospital with the milrinone. I will never forget being in his room, countless doctors standing over him as he looked up at us from his hospital bed, and hearing the doctor tell him, "Because you are undocumented, there is nothing else for us to do in the hospital. But to send you home, we need to stop the milrinone." Not a day has passed that

I have not thought about this massive failing to our undocumented patients with end-stage heart failure.

Undocumented Immigrants in the Cardiac Care Gap

There are approximately 11 million people currently residing in the United States who fall into the category of “undocumented immigrant” (UI) (Passel & Krogstad, 2024). Undocumented is a status that can be broadly applied to anyone residing in the United States without legal status (Immigrants Rising, 2023). This includes, but is not limited to, those who entered illegally, those whose legal status has expired, current or previous Deferred Action for Childhood Arrivals recipients, as well as those in the process of applying for legal status but without current legal documentation (Immigrants Rising, 2023). In the United States, UIs have historically been excluded from receiving health insurance benefits through marketplace and federal programs (Medicare and Medicaid), resulting in substandard, fragmented, and psychologically stressful healthcare interactions (Kuczewski, 2017).

While emergency Medicaid covers urgent, stabilizing treatment regardless of immigration status, it does not ensure long-term care or management of chronic conditions (U.S. Department of Health and Human Services, 2003). For patients with serious illnesses such as advanced heart failure (AHF), this gap in coverage can mean the difference between life-sustaining treatment and preventable death. This is more than a bureaucratic failure—it is a violation of human rights, an ethical injustice, and a systemic shortcoming that forces doctors to practice medicine in ways that contradict the very principles they have sworn to uphold.

This thesis demonstrates how excluding undocumented immigrants from AHF therapies breaches justice, autonomy, beneficence, and non-maleficence. Through a representative case study, I contrast these ethical failures with successful end-stage renal disease (ESRD) reforms to propose actionable solutions to address inequities exacerbated by current immigration policies.

CHAPTER 2

BACKGROUND

Health Insurance in the United States

The United States is notorious for its complex healthcare and insurance systems as well as its lack of universal health care, but this was not created overnight. In this section, I will explore the historical and political context that led to the current system for U.S. health insurance and how those circumstances led to a lack of coverage and greater health disparities for those who are undocumented.

The United States was one of the last western countries to adopt health insurance. Prior to this, “sick pay” was provided as a means of income stabilization, and any other financial assistance for the poor was distributed primarily from local parishes (Starr, 1982). The rise of industrialization and capitalism in America drew increasing concerns about how “poor relief” would affect incentives for work and the free circulation of labor—ultimately leading to abolishment of government assistance. This forced low-income people to either work or emigrate. When the idea was reintroduced in the 19th century, the new conception of health insurance was divorced from charity and rebranded as a “benefit,” requiring the financial contribution of the individual (Starr, 1982). The impacts of early 20th century liberalism can still be felt in modern political views toward social services, low-income populations, and the value of people relative to their ability to contribute to the labor force. The political and economic uncertainty of The Great Depression along with years of lobbying pressure from progressive organizations such as the American Association for Labor Legislation continued to push the discussion of

health insurance into the public eye. Eventually, the rise of group hospitalization plans like Blue Cross laid the foundation for what would become modern private health insurance. For more information about the historical and political context leading to American health insurance, see book two, chapter one, of Peter Starr's *The Social Transformation of American Medicine* (Starr, 1982).

Viewing health insurance as a benefit as opposed to charity incentivized people to remain in the labor force. This created a system in which health insurance is linked to employment in the United States. However, this left many people, both U.S. citizens and otherwise, without adequate coverage. In 2010, the Affordable Care Act (ACA) was introduced, allowing those without employer-based health insurance to purchase private plans through subsidized exchanges (Patient Protection and Affordable Care Act, 2010). The ACA, although significantly decreasing the uninsured rate amongst the very poor, explicitly excluded some legal and non-legal residents—further widening the health gap between citizens and non-citizens in the U.S (Evans & Arbeit, 2017; Tuohy, 2020). This gap still exists today, and from here I will explore the history of Medicaid and its role in providing coverage to UIs.

The Rise of Medicaid and Limitations for Undocumented Immigrants

Introduced in 1965 as part of the broader Social Security Act, Medicaid serves as a government sponsored insurance option for those who face poverty, joblessness, or certain disabilities. In the United States, many UIs fall into this category, opening the new possibility for them to receive health insurance coverage. However, in 1996, the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) was signed into law—marking one of the most comprehensive welfare reform bills in

American History. PRWORA denied nearly all welfare benefits, including non-emergent Medicaid, to UIs. This permanently classified UIs as “ineligible” for most public benefits. This shift was a departure from the assumption—rooted in earlier rulings like *Plyler v. Doe*—that all individuals residing in the U.S., regardless of legal status, were entitled to basic services, including healthcare (Chesler, 2008). This bill substantially limited states’ ability to provide coverage to UIs and further exacerbated existing inequities (Chesler, 2008).

Policy Barriers to Healthcare for Undocumented Immigrants

Emergency Medicaid & PRWORA

The complex history of health insurance in the U.S. has created painful ripple effects felt by everyone living in America. However, this section will highlight certain policies that have made accessing these services even more difficult for those who are undocumented.

As mentioned, PRWORA significantly restricted Medicaid access for UIs, but with one exception: the Emergency Medical Treatment and Active Labor Act (EMTALA). Enacted in 1986, EMTALA mandates that hospitals receiving Medicare funding must treat patients with emergency conditions—regardless of immigration status or ability to pay—until they are stabilized (DC Department of Health Care Finance [DHCF], n.d.; Park et al., 2023). An emergency medical condition is defined as an acute illness or injury (including severe pain) that, without immediate care, would: (A) place the patient’s health in serious jeopardy, (B) result in serious impairment of bodily functions, or (C) result in serious dysfunction of any bodily organ or part (Park et al., 2023). However, EMTALA excludes non-emergency care, including lifesaving

procedures like organ transplants. Once stabilized, patients lose emergency Medicaid coverage, once again leaving many UIs to delay further care until their conditions become critical (Chesler, 2008; DHCF, n.d.).

Insurance Exclusion and Financial Strain

Beyond PRWORA, systemic barriers—such as insurance restrictions, high costs, and legal deterrents—worsen healthcare inequities for UIs. Without legal status, it can be difficult for UIs to get legitimate jobs that pay well and offer insurance benefits. Additionally, exclusion from ACA marketplace plans leaves them with insurance options that are often prohibitively expensive (Ibarra, 2022). Many UIs rely on community health and federally qualified health centers for primary care. Despite these options, the lack of access to routine care results in a higher dependence on already strain emergency departments (Samra et al., 2019).

The lack of health insurance exposes undocumented immigrants to severe financial strain. Out-of-pocket costs for chronic disease management average 1.5-3 times higher for uninsured people than insured rates, compounding the economic hardship faced by this already vulnerable population (Agency for Healthcare Research and Quality [AHRQ], 2022). This financial burden often leads to insurmountable medical debt which can further discourage engagement with the healthcare system—either due to fear of unaffordable bills or because providers deny follow-up treatment for unpaid medical debt (National Consumer Law Center [NCLC], 2023).

Weaponizing Immigration Policies

The U.S. political climate has increasingly weaponized healthcare access as a tool of immigration enforcement, creating systemic barriers for undocumented patients. The

2019 Public Charge Rule, which penalized Medicaid use in residency applications, created widespread fear throughout immigrant communities (U.S. Department of Homeland Security [DHS], 2019). Health advocates report this policy could cause dramatic drops in program participation as families avoid care rather than risk immigration consequences (Haq et al., 2020). While later rescinded, the confusion that it sparked, as well as the rule's potential return, continues to loom over healthcare decisions for UIs.

In 2025, the Trump administration rescinded a Biden-era policy that had protected sensitive locations like hospitals, schools, and churches from immigration enforcement (NILC, 2025). For UIs already facing limited healthcare options, this change will likely intensify fears of encountering immigration authorities at medical facilities. The increased risk of enforcement at hospitals and community health centers threatens to further deter UIs from seeking essential medical care, potentially leading to worse health outcomes.

CHAPTER 3

CASE STUDY: LIVING WITH ADVANCED HEART FAILURE

A Case Study Analysis: JJ's Story

This chapter examines the challenges of managing heart failure within the context of structural barriers faced by UIs in the U.S. healthcare system. Centering patient voices through a case study, it demonstrates how immigration status dictates access to guideline-directed care.

As discussed in Chapter One, JJ faced significant legal, social, and systemic barriers to healthcare. He lacked access to primary care, did not speak English, and could not afford his heart failure specific guideline-directed medical therapy (GDMT) medications. These challenges led to suboptimal disease control and frequent hospitalizations. During our first encounter, his care was limited to temporizing measures: diuretics, optimization of his GDMT, and discharge with instructions for when he would inevitably need to return to the hospital. At this stage, the standard of care would have included offering mechanical circulatory support (MCS), such as an Impella device or a left ventricular assist device (LVAD), and potentially life-sustaining inotropic medications (see Figure 1). However, the stark disparity in access to care between insured U.S. citizens and UIs like JJ becomes most apparent at this critical juncture.

Inotropic medications, while often life-sustaining, require extensive support and follow-up care, including permanent intravenous access and home infusion services—resources JJ lacked due to his uninsured status. For insured patients, these therapies can serve as a bridge to transplant or, when transplantation is not feasible or desired, as palliative care. However, JJ's undocumented status made him ineligible for a transplant

and even palliative inotropes. This left him with no options for escalating his care, effectively denying him the standard heart failure therapies routinely offered to insured patients (Figure 1).

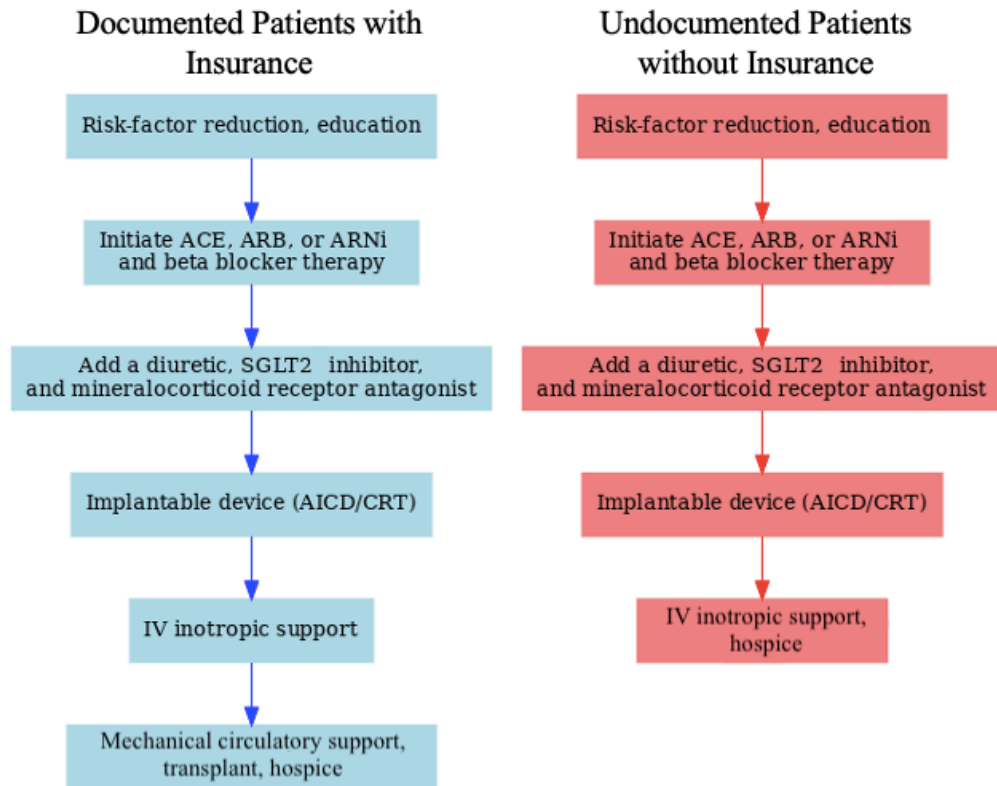


Figure 1. Systolic heart failure standard of care progression for those who are documented and insured versus those who are undocumented and uninsured.

The worsening of JJ’s condition, necessitating advanced interventions, was a feared outcome during his previous hospital admissions. Despite clear clinical indications and potential benefits, he was never started on inotropic therapy because his care team knew he would be unable to continue the treatment at home. Initiating inotropes would have left him medically stabilized but indefinitely confined to the ICU, tethered to an IV pole and hospital bed, with no insurance or clear path toward discharge. However, these

conversations were fraught with challenges, including language barriers, limited medical and legal literacy, and JJ's lack of a support system. Despite these obstacles, he understood that no further therapies were available to him.

Despite several palliative care consultations and social work interventions, JJ's cycle of fragmented hospitalizations continued until he eventually presented again to the emergency department in cardiogenic shock—a life-threatening complication of AHF characterized by dangerously low blood pressure and insufficient oxygen delivery to vital organs. This medical emergency made him eligible for Medicaid under EMTALA, finally allowing him to receive inotropic therapy (see Figure 2). After several days in the ICU, his symptoms improved, and his vitals stabilized, as expected with evidence-based treatment. However, this stabilization came with a cruel irony: by improving his condition, he no longer qualified for Medicaid. The very treatment that saved his life also stripped him of the coverage needed to sustain it. Without Medicaid, JJ lost access to the inotropic medications that had been maintaining his stability, leaving him trapped in a cycle of unmet medical needs and systemic inequities (Figure 2).

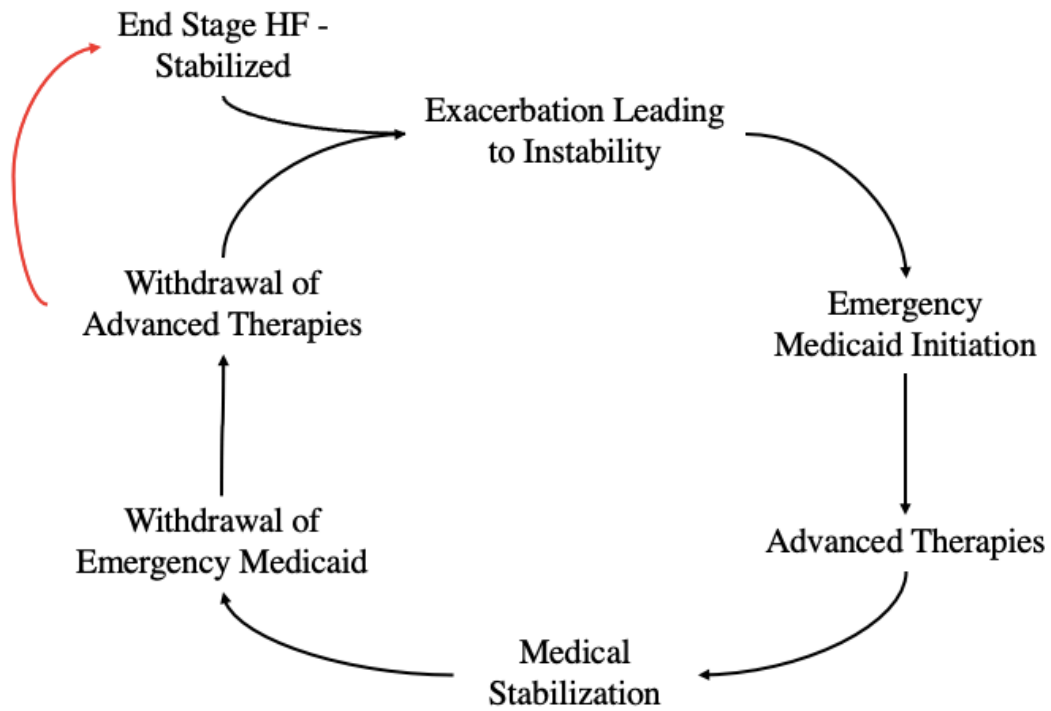


Figure 2. Cycle of care barriers for uninsured, undocumented immigrants.¹

At this point, JJ found himself in an impossible situation with no viable options to continue with adequate care. Despite his improvement on inotropic therapy, the medication had to be discontinued for him to be discharged home. There were no further interventions available to him, and nothing else required his continued hospitalization. Both JJ and his medical team knew the consequences of stopping inotropic therapy, and the evidence did not support discontinuing it. Yet, with no alternative, the medication was slowly weaned, risking the possibility of sending him back into cardiogenic shock. Fortunately, he tolerated the gradual taper, and the therapy was eventually discontinued entirely. He was discharged home with yet another few months' supply of his

¹ This excludes a few states who have expanded their Medicaid programs to provide greater coverage for UIs (Rizzolo, 2023)

medications, instructions for his inevitable need to return to the hospital, and a follow-up appointment. However, this decision jeopardized his medical stability, leaving him vulnerable and effectively returning him to the same precarious position he had been in before—a cycle of instability and unmet needs.

Standard of Care for Heart Failure

Heart failure is a complex disease characterized by the heart's inability to meet the body's metabolic demands and requires consistent, multidisciplinary care to slow disease progression and improve quality of life. Structural inequities and limited access to care for UIs often result in delayed diagnoses, inadequate treatment, and preventable complications, underscoring the urgent need for policy reforms that address these disparities (Castañeda, 2015).

For individuals at risk of heart failure, primary prevention strategies focus on lifestyle modifications, including dietary changes, regular exercise, smoking and alcohol cessation, and management of chronic conditions such as hypertension (Heidenreich, 2022). However, heart failure is a chronic, progressive disease requiring lifelong treatment and consistent follow-up care. The high prevalence of cardiovascular disease has driven extensive research, leading to the development of evidence-based, standardized recommendations known as guideline-directed medical therapy (GDMT). These guidelines serve as the foundation for delivering high-quality cardiovascular care (Heidenreich, 2022). Non-pharmacologic interventions, including implantable cardioverter-defibrillators (ICDs), may also be utilized to reduce the risk of sudden cardiac death (Figure 1).

For patients whose condition progresses despite these measures—particularly those with worsening ejection fraction—advanced therapies become necessary. These include intravenous inotropic medications (e.g., dobutamine, epinephrine, and milrinone) to improve cardiac contractility, mechanical circulatory support (MCS) devices such as left ventricular assist devices (LVADs) and Impellas, and ultimately cardiac transplantation (Heidenreich, 2022) (Figure 1). While these interventions can significantly extend life for patients with end-stage heart failure, they are resource-intensive and require comprehensive psychosocial support, close cardiology follow-up, and consistent access to health insurance—all of which are too often lacking amongst our most vulnerable populations.

Inferior Care for Undocumented Immigrants with Advanced Heart Failure

Clinical and systemic barriers not only deter UIs from accessing routine healthcare but also exacerbate the management of chronic, progressive conditions such as heart failure. In the United States, marginalized populations experience disproportionately higher rates of heart failure, with approximately 5-10% of HF patients progressing to advanced stages (Heidenreich, 2022; Kogan et al., 2025). When combined with lack of insurance and systemic barriers to preventative care, UIs face particularly high risks for developing AHF and its devastating complications. Without access to early interventions, they often miss critical opportunities for lifestyle modifications and GDMT—despite clear evidence that timely pharmacologic interventions can slow HF progression, prevent cardiac remodeling, and reduce mortality (Cotter et al., 2023).

For those who do obtain diagnoses, the financial barriers prove insurmountable. Recent data reveal crushing cost disparities. The average out of pocket cost for the

recommended quadruple therapy is \$253/month—those with private insurance paying \$292/month, and those with public insurance paying \$159/month. For those who are uninsured—including many UIs—they face costs averaging \$975/month (Alhassan et al., 2022). Without these medications, disease progression accelerates dramatically.

The consequences are predictable and dire: delayed diagnoses mean many UIs remain unaware of their condition until they present with severe symptoms. By then, they often meet criteria for Stage C HF or progress directly to Stage D HF—a preventable tragedy when early care exists but remains inaccessible.

CHAPTER 4

DISCUSSION

Ethical Implications

Justice

Access to healthcare for all is a fundamental principle of distributive justice, yet the struggles faced by UIs highlight glaring inequities in the U.S. healthcare system. Even among citizens with insurance, healthcare is not distributed equally, as evidenced by disproportionate rates of morbidity and mortality across racial and socioeconomic groups (Bosworth, 2018). While gaps in preventative care affect all populations, U.S. citizens are often shielded by safety net programs like Medicaid. In contrast, UIs without insurance face the same—if not greater—barriers to primary care, compounded by the severe consequences of being uninsured and undocumented when they require urgent medical attention.

These disparities become even more pronounced when life-saving interventions are needed. As discussed in Chapter 2, UIs have historically been excluded from social safety net programs like Medicaid, severely limiting their access to affordable care for non-emergent yet life-threatening conditions, including chronic diseases such as cancer, renal failure, diabetes, and heart failure. EMTALA was designed to address this gap, ensuring that no one in the U.S. dies due to lack of care during a crisis. However, this protection is only extended to undocumented patients once they are already in a medically precarious situation, effectively prioritizing emergency care over preventative or ongoing treatment.

Access to primary care is well-documented to reduce morbidity, mortality, and long-term healthcare costs (U.S. Department of Health and Human Services [HHS], n.d.). For patients with HF, early access to primary and preventative care could prevent the progression to advanced stages, reducing the need for emergency interventions. Yet, UIs are systematically excluded not only from preventative care but also from life-saving therapies such as organ transplantation at the federal level. In fact, 3% of organ donation comes from immigrants, despite being only 0.4% of all recipients (National Academies of Sciences, Engineering, and Medicine [NASEM], 2022, Chapter 4). This exclusion results in preventable deaths, as UIs are denied access to transplants solely based on their legal status.

The denial of advanced heart failure therapies to UIs is not merely a social or economic issue—it is a profound ethical violation of justice. By systematically excluding UIs from life-saving interventions, the healthcare system perpetuates inequities that disproportionately harm vulnerable populations. Addressing these injustices requires a reevaluation of policies and practices to ensure that all individuals, regardless of immigration status, have equitable access to the care they need to survive and thrive.

A common argument against expanding healthcare access to UIs is the fear that they will become “freeloaders” of the system, a concern underpinning policies like the Public Charge Rule. Critics often claim that UIs do not contribute equally via taxes or to the economy and therefore should not benefit from public assistance funded by American taxpayers. However, this argument overlooks the reality that as many as 80% of UIs in the U.S. are employed, often in essential but undesirable jobs that sustain key sectors of the economy (Brenner et al., 2021). Despite their high rates of employment, only about

54% have access to health insurance, and even those plans are often prohibitively expensive (Ibarra, 2022). Moreover, UIs pay income taxes, sales taxes, and contribute to payroll taxes, including those that fund Medicare. A 2009 study found that while UIs accounted for 5% of the U.S. population, they incurred only 1.4% of personal health expenditures (Brenner et al., 2021; Flavin et al., 2018). During the same period, their contributions to the Medicare Trust Fund exceeded withdrawals, generating an annual surplus of \$11.1 billion to \$17.2 billion between 2002 and 2009 (Brenner et al., 2021; Zallman, et al., 2013). These findings challenge the narrative that UIs are a burden on the system and instead highlight their significant economic contributions and disproportionate lack of access to care.

Despite these contributions, UIs face systemic barriers that deny them access to life-saving medical interventions, as exemplified by JJ's case. The denial of transplant eligibility based on his immigration status represents a clear violation of justice. While U.S. law does not explicitly exclude UIs from receiving transplants, the system effectively bars them by requiring insurance coverage—a requirement that immigration policies make nearly impossible for UIs to meet. This systemic exclusion was evident in JJ's experience: he was denied transplant eligibility at multiple institutions due to his lack of insurance. His legal status not only barred him from transplantation but also limited his access to other life-saving therapies, such as MCS. Unfortunately, this is not an isolated case. A 2020 cohort study found that Medicare, Medicaid, and uninsured patients were significantly less likely to receive LVADs compared to privately insured patients. Even among those with legal status, Black and Hispanic patients faced disparities in access to

LVADs and higher rates of in-hospital mortality when they did receive them (Heidenreich et al., 2022).

The standard treatment for cardiogenic shock in patients with reduced ejection fraction, like JJ, is inotropic therapy. According to the 2022 AHA guidelines, the use of inotropes in a patient refractory to GDMT and MCS can be used as a bridge until definitive therapy (e.g., transplant) can be obtained or as palliative therapy for those who are ineligible for further interventions (see Table 1) (Heidenreich et al., 2022). JJ's case—cardiogenic shock secondary to Stage D heart failure with reduced ejection fraction, refractory to GDMT—disqualified him from Class 2a recommendations for inotropes. While he qualified for palliative inotropes (Class 2b), his lack of insurance made even this option inaccessible.

Crucially, JJ's exclusion from these recommendations was not due to his medical condition but his legal status. An American citizen with the same medical history would have been eligible for temporary inotropic therapy at home while awaiting definitive treatment, such as a transplant. Instead, JJ was forced to settle for care substandard to evidenced-based recommendations, highlighting how structural inequities tied to immigration status systematically deny UIs access to life-saving therapies. This case underscores the urgent need to address the intersection of legal status and healthcare access as a matter of justice.

2022 ACCF/AHA Guideline for the Management of Heart Failure Recommendations for Inotropic Support	
Class of Recommendation ²	Recommendation
2a	In patients with advanced (stage D) HF refractory to GDMT and device therapy who are eligible for and awaiting MCS or cardiac transplantation, continuous intravenous inotropic support is reasonable as “bridge therapy.”
2b	In select patients with stage D HF, despite optimal GDMT and device therapy who are ineligible for either MCS or cardiac transplantation, continuous intravenous inotropic support may be considered as palliative therapy for symptom control and improvement in functional status.
3: Harm	In patients with HF, long-term use of either continuous or intermittent intravenous inotropic agents, for reasons other than palliative care or as a bridge to advanced therapies, is potentially harmful.

Table 1. 2022 ACCF/AHA Guideline for the Management of Heart Failure (Heidenreich et al., 2022).

Autonomy

Autonomy grants patients the right to make informed decisions about their bodies and healthcare. However, for UIs like JJ, autonomy is often compromised by social determinants of health, such as language barriers and systemic inequities. As a Spanish speaker, JJ relied on translation services, which can be inconsistent, prone to errors, and culturally insensitive. This hindered his ability to give informed consent and advocate for himself throughout his illness. Despite these challenges, his care team had multiple conversations with him prior to his ICU admission about the structural barriers preventing him from accessing life-saving treatments, such as transplantation and other

² The Class of Recommendation indicates the strength of recommendation, encompassing the estimated magnitude and certainty of benefit in proportion to risk.

advanced therapies. These discussions highlighted the futility of pursuing such options due to his lack of insurance, emphasizing the limited choices available to him.

However, when JJ entered a state of medical emergency, the dynamics of communication and decision-making shifted dramatically. In emergencies, patients are often unable to speak for themselves, and the informed consent process is frequently waived to prioritize timely, life-saving interventions. For JJ, this meant that despite prior conversations about the limitations of his care, milrinone—a life-sustaining inotropic therapy—was initiated during this time of crisis. It was only after he was stabilized that the care team and JJ could fully process what had occurred and confront the implications for his ongoing care.

After the milrinone was initiated, JJ was informed that he could not continue the treatment—not due to medical guidelines or necessity, but because of his lack of insurance. This decision was not rooted in clinical judgment but in systemic inequities that denied him access to care. By restricting UIs like JJ from advanced heart failure therapies, the healthcare system not only undermines their autonomy but also perpetuates a cycle of injustice, where life-saving interventions are offered only to be withdrawn due to factors beyond the patient's control. This abrupt initiation and subsequent withdrawal of treatment underscored the violation of his autonomy at every stage.

Beneficence

Beneficence, the ethical obligation to act in the best interest of others, is a cornerstone of medical practice. Yet, for UIs with advanced heart failure, systemic barriers routinely prevent access to the standard of care, including life-saving therapies like LVADs, transplantation, and long-term inotropic support. These treatments, which

are considered definitive for end-stage heart failure, are often inaccessible to UIs due to their lack of insurance and legal status. This denial of care not only undermines the principle of beneficence but also relegates UIs to substandard or palliative measures, directly contradicting the ethical duty to prioritize patient well-being.

If physicians are expected to uphold beneficence, structural changes must align with this ethical imperative. This includes expanding access to preventative care for UIs, who face compounded barriers such as fear of discrimination, deportation, language challenges, and financial constraints. In the U.S., low-income individuals, including UIs, rely on a fragmented safety-net system comprising public hospitals, federally qualified health centers (FQHCs), and migrant health centers (Gusmano, 2012; Zuckerman et al., 2011). While these resources provide crucial care, they are insufficient to address the systemic inequities that leave UIs without comprehensive preventative care. Chronic conditions like diabetes, hypertension, and heart disease—key contributors to heart failure—are manageable and preventable, yet UIs are systematically denied the care needed to address these conditions effectively (Alarcón, 2022).

JJ's case starkly illustrates the violation of beneficence. Both he and his medical team, supported by medical evidence, advocated for the continuation of inotropic therapy to manage his AHF. However, systemic barriers—rooted in his lack of insurance, which is itself a consequence of his undocumented status—forced physicians to prioritize outdated and inhumane policies over his well-being. This conflict placed physicians in a position where they were forced to weigh patients' dignity and rights against decades-old systems of oppression that prevent them from acting in their patients' best interests. Such systemic failures not only harm patients like JJ but also erode trust in the medical system,

contribute to physician burnout, and violate the foundational ethical principles of medicine. To truly uphold beneficence, the healthcare system must address these inequities and ensure that all patients, regardless of immigration status, have access to the care they need.

Non-Maleficence

The line between beneficence and non-maleficence is often blurred, as some acts may fall into both categories. This was the case for JJ. While the initiation of inotropic therapy during his cardiogenic shock could be viewed as an act of beneficence, its subsequent withdrawal exposed the systemic harms that violate the principle of non-maleficence. Structural barriers, such as lack of insurance and exclusion from transplant eligibility due to legal status, force healthcare providers to resort to temporary fixes for chronic conditions like AHF. These stopgap measures, while sometimes lifesaving in the short term, often lead to suboptimal care and worse long-term outcomes. For JJ, this meant starting inotropic therapy without a sustainable plan—only to withdraw it later when systemic barriers made continuation impossible. This approach not only failed to address his underlying condition but also placed him in physical and psychological jeopardy, directly violating the core principle to “do no harm.”

Physically, inotropic medications are a form of life support. Withdrawing them from a dependent patient risks immediate hemodynamic instability which can lead to shortness of breath, organ failure, altered mental status, or even death. For JJ, the decision to start milrinone, knowing it could not be continued long-term exemplifies how structural barriers force providers into ethically fraught decisions. These barriers result in care that is reactive rather than proactive, addressing crises without resolving the

underlying chronic condition. This approach not only fails to improve health outcomes but often exacerbates them, as patients like JJ are caught in a cycle of temporary fixes and preventable harm.

Psychologically, the strain of being undocumented compounds the challenges of living with a chronic, life-threatening condition. Systemic barriers force UIs to delay care until their conditions reach a critical stage, leading to worse medical outcomes, prolonged hospitalizations, and higher morbidity and mortality (Kisa & Kisa, 2024). For patients with AHF, whose clinical stability is often tenuous, frequent near-death experiences and emergency hospitalizations likely exacerbate this psychological burden, as similar findings have been noted for other chronic diseases (Cervantes et al., 2018). The psychological toll of living in constant medical instability, compounded by fears of deportation and underlying distrust of the medical system, represents a profound violation of non-maleficence. These harms are not inevitable but are the direct result of structural inequities that prioritize temporary fixes over sustainable care.

End-Stage Renal Disease as a Framework for Advanced Heart Failure Therapies

Implementing the changes necessary to provide equitable access to AHF therapies for UIs will require substantial shifts in federal and state policies, as well as a broader recognition of legal status as a critical social determinant of health. While this is a daunting task, there are precedents that offer a roadmap for reform. One notable example is the policy framework developed for end-stage renal disease (ESRD), which can serve as a model for expanding access to AHF therapies.

Patients with ESRD require routine hemodialysis (HD) three times per week to maintain fluid and electrolyte balance and prevent complications such as pulmonary

edema, cardiac arrhythmias, and death. However, prior to 1972, HD centers were both scarce and costly, leaving most individuals without access to this life-saving treatment. The Social Security Amendments of 1972 attempted to address this inequity by expanding Medicare coverage to include kidney replacement therapies for all U.S. citizens and permanent residents with ESRD, regardless of age. These policy changes not only projected coverage for an additional 10,000 individuals but also significantly improved survival rates (Mendu & Weiner, 2020). Later, the ACA further expanded Medicaid, providing low-income Americans—including those with ESRD—access to not only dialysis but also primary care to manage chronic conditions like hypertension, diabetes, and heart failure, which often exacerbate ESRD (Trivedi & Sommers, 2018).

State Medicaid Expansions for End-Stage Renal Disease

These legislative changes marked a significant advancement in ESRD treatment equity for low-income patients and patients of color (Trivedi & Sommers, 2018). However, UIs were still excluded from these benefits, as they remained ineligible for Medicaid and Medicare at the federal level. This exclusion meant UIs could not access the diagnostically based Medicare entitlement for HD, leaving them without reliable access to life-sustaining treatment (Cervantes et al., 2023). Instead, UIs were forced to rely on emergency-only HD (EOHD) once they developed crisis-level symptoms (Cervantes et al., 2019). Recognizing this inequity, 20 states and the District of Columbia have expanded access to outpatient HD by expanding state Medicaid coverage as well as redefining ESRD as an emergency medical condition to allow for coverage under EMTALA (Rizzolo et al., 2023).

While far from a perfect solution, this approach represents one of the few instances where Medicaid has been expanded to cover ongoing medical care for UIs with chronic conditions. The expansion of dialysis coverage for UIs demonstrated both ethical and economic benefits. Research shows that emergency-only hemodialysis (EOHD) generates significantly higher costs—approximately \$2,000 per emergency department visit compared to \$250 for a single outpatient session—while delivering inferior clinical outcomes (Cervantes et al., 2023). This approach creates unnecessary inefficiencies, as each emergency visit requires repeated diagnostic assessments to justify treatment. More critically, the intermittent nature of EOHD leads to dangerous complications, prolonged hospital stays, excess financial burdens on patients and healthcare systems (West et al., 2020).

The success of these state-level Medicaid expansions for ESRD demonstrates that progress is possible when there is political will to address systemic inequities. By applying a similar framework to AHF therapies, policymakers can extend life-saving treatments—such as LVADs, transplantation, and long-term inotropic support—to UIs who are currently excluded from care. Just as ESRD was redefined as a medical emergency to justify Medicaid coverage, so too can AHF be recognized as a condition requiring urgent and ongoing intervention. This precedent offers a clear path forward for achieving equitable access to advanced therapies for all patients, regardless of immigration status.

Renal Failure Vs. Heart Failure

Disease Progression

Much like AHF, ESRD represents a progressive and lethal condition that disproportionately burdens marginalized communities, with striking similarities in their clinical trajectories and systemic barriers to care (Trivedi & Sommers, 2018). Both conditions share common risk factors including hypertension, diabetes, and obesity, while their progression follows a disturbingly familiar pattern among UIs: preventable risk factors go unmanaged due to lack of primary care, silent progression occurs without monitoring, critical symptoms emerge only at advanced stages, and emergency interventions replace comprehensive care—all exacerbated by structural inequities in health literacy, financial access, and immigration fears. The ESRD experience has demonstrated that targeted policy changes can interrupt this vicious cycle, as evidenced by states successfully classifying ESRD as a medical emergency qualifying for Medicaid coverage, thereby creating pathways for UIs to receive life-sustaining HD (Cervantes et al., 2019). For AHF, applying this model would require recognizing that LVADs and transplantation hold equivalent life-sustaining value as HD for ESRD patients, and that denying such interventions based on immigration status constitutes both medical and ethical failure.

Therapies for End-Stage Disease

The parallels between ESRD and AHF reveal a devastating treatment paradox for undocumented immigrants, where lifesaving therapies become inaccessible despite absolute physiological dependence. In ESRD, thrice-weekly hemodialysis is non-negotiable—replacing renal function to prevent fatal hyperkalemia or pulmonary

edema—just as LVADs and inotropes sustain circulatory function in AHF (Heidenreich et al., 2022; West et al., 2020). Yet systemic barriers transform these medical necessities into unreachable privileges: federal policies exclude undocumented patients from transplant waitlists, while Medicaid restrictions routinely deny coverage for outpatient dialysis and cardiac therapies (Cervantes et al., 2019; Rizzolo et al., 2023). The consequences are clinically significant and ethically untenable. Undocumented ESRD patients experience 14-fold higher mortality rates when relegated to emergency-only dialysis, while AHF patients face threefold faster disease progression without guideline-directed care (Nguyen et al., 2019; Rodriguez et al., 2012). This forced reliance on crisis intervention creates a cycle of psychological trauma, with 40% of undocumented dialysis patients requiring CPR during emergency treatment and AHF patients enduring repeated ICU admissions (Alhassan et al., 2022; Cervantes et al., 2023). Identical patterns of exclusion—barring patients from both curative transplants and maintenance therapies—expose how immigration status dictates survival for organ failure patients, rendering advanced medical technology simultaneously essential and inaccessible.

CHAPTER 5

CONCLUSION

Summary

"Give me your tired, your poor, your huddled masses yearning to breathe free" (Lazarus, 1883). These words, inscribed on the Statue of Liberty, declare America's founding promise. The tension between America's ideals and its policies crystallizes in the systematic exclusion of UIs from evidence-based AHF therapies—a violation of medicine's foundational principles: justice, autonomy, beneficence, and non-maleficence. Such exclusions are not only ethically indefensible but fiscally irrational, as they replace cost-effective chronic care with costly emergency interventions and preventable hospitalizations.

The blueprint for change already exists. States have successfully expanded dialysis and kidney transplants for UIs with ESRD—a condition mirroring AHF in its chronicity and resource needs. This precedent proves equitable care is clinically sound, economically rational, and morally non-negotiable. However, increasing anti-immigrant hostility in the U.S. demands urgent advocacy—not only to expand AHF therapies through ESRD-inspired reforms, but to dismantle the structural determinants of health that disproportionately harm undocumented communities. We must advocate for comprehensive primary care, equitable treatment of all chronic illnesses, and ultimately, a healthcare system that aligns with Lazarus' vision of refuge. Realizing this vision requires confronting the systems that exclude UIs from the very prosperity their labor sustains—because justice in healthcare cannot wait for immigration reform.

Navigating Healthcare Access for Undocumented Immigrants in a Hostile Political Era

There has never been a more critical moment to defend healthcare access for undocumented communities. In the first few months of Trump's second administration, countless executive orders have been issued—weaponizing healthcare exclusion as a tool of immigration enforcement, and abandoning medicine's duty to protect vulnerable populations (Executive Order No. 14159, 2025). The full implementation of these orders is difficult to predict, but its potential consequences are alarmingly clear: states that have expanded Medicaid to provide even minimal healthcare access—including essential services like primary care, dialysis, and transplants—now face federal retaliation. Simultaneously, provisions allowing termination of non-governmental organizations funding threaten to dismantle the fragile networks delivering healthcare and other vital services to immigrants (Executive Order No. 14159, 2025).

For undocumented patients with AHF, these changes could mean the difference between life and death—arbitrarily denying access to LVADs, transplants, and guideline-directed therapies not based on medical need, but immigration status. Physicians are conscripted as unwilling agents of a system that elevates immigration enforcement over clinical judgment, where deportation risks outweigh discharge planning. The moral injury inflicted when a patient dies from treatable heart failure due to federal policies is not collateral damage—it is the intended outcome of dehumanizing rhetoric made manifest through medical neglect.

The stakes transcend cardiology clinics. When ICE surveillance deters a mother from bringing her child to the pediatrician, when fear prevents a construction worker

from seeking care for crushing chest pain, when dialysis patients skip treatments to avoid checkpoints—we witness the human cost of policies designed to punish through healthcare deprivation. Our profession’s historical ambivalence toward these injustices must end. If "first, do no harm" means anything, it must mean resisting the politicization of healing with every tool at our disposal: clinical advocacy, institutional protections, and unwavering moral witness.

From Bystanders to Agents of Change: A Call to Action

A recent essay in *The Hastings Center's Bioethics Forum*, by Adelaida Jasper, highlights this urgent need for transformation and the vital role physicians and bioethicists must embrace (Jasperse, 2025). She argues that medical and bioethics communities can no longer remain in advisory roles but must instead demonstrate proactive leadership in defending healthcare access for immigrant populations. She also makes careful note that silence in the face of systemic exclusion constitutes complicity—a fundamental betrayal of the ethical principles these professions pledge to uphold. During these unprecedented times, authentic commitment to justice, autonomy, beneficence, and non-maleficence requires courageous advocacy that transcends hospital corridors and academic discourse, demanding engagement with the lived realities of marginalized communities.

This transformation begins with grounding ethical frameworks in lived experience. Bioethicists and clinicians must engage directly with the social determinants shaping undocumented patients’ health—whether food insecurity exacerbated by ICE surveillance or transportation barriers due to driver’s license restrictions (Asad & Clair, 2018; National Immigration Law Center [NILC], 2024). Patient narratives about

rationing medications to avoid clinics, or hiding symptoms until crisis strikes, reveal the human consequences of policies that bioethics too often theorizes about from a distance.

The call to action is unambiguous: professionals cannot witness preventable suffering while remaining passive. Courage proves contagious when clinicians testify at state Medicaid hearings, when ethicists partner with community organizations to document healthcare discrimination, and when institutions declare their facilities sanctuaries from immigration enforcement. The ESRD expansion movement proved such advocacy works—not through abstract debate, but through relentless insistence that ethical principles must manifest in actual care.

For UIs with AHF, this means fighting not just for transplant access but for systems that honor their humanity. It requires research that quantifies both the clinical benefits of equitable care and the moral costs of exclusion. Most critically, it demands rejecting the false comfort of neutrality. When a patient dies from treatable heart failure because policies deem them "undeserving," bioethicists and physicians share responsibility if they chose silence over action.

Areas for Further Study

Further research should explore the multifaceted consequences of limiting healthcare access for UIs with heart failure, building on existing studies of conditions like ESRD. The financial and ethical costs of treatment denial warrant rigorous analysis, including the downstream economic burden of preventable hospitalizations and the moral implications of withholding life-sustaining care. Equally important is examining the psychological toll of recurrent heart failure exacerbations on this vulnerable population, whose experiences may mirror the documented trauma and distress seen in ESRD

patients facing similar barriers (Cervantes, 2018). The ambiguous standard of "stabilization" under EMTALA also requires particular scrutiny, especially regarding whether this emergency mandate adequately covers chronic disease management and complications arising from emergency interventions. Simultaneously, the healthcare system must confront the professional and ethical dilemmas faced by clinicians forced to practice under policies that conflict with their moral obligations, as the mental health impacts of such moral injury remain understudied. These interconnected issues—spanning clinical outcomes, healthcare economics, ethical frameworks, and provider well-being—collectively underscore the urgent need for reforms that align medical practice with both humanitarian principles and evidence-based public health objectives.

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