IMMIGRANT HEALTH & BIOETHICS: ON THE SIGNIFICANCE OF LOCAL CONTEXT

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ABSTRACT

Local context should be considered a significant social determinant of health for immigrant communities, particularly those with precarious legal status. In this thesis I use a study done by Lilia Cervantes, MD and collegeaues of undocumented immigrants with end-stage renal disease attempting to access healthcare in three different US states to expand on my argument. Due to the lack of comprehensive federal immigration reform since 1986, many immigrants depend on the Emergency Medical and Active Labor Treatment Act (EMTALA) to access healthcare, which provides emergency-only care. Without federal mandates, further healthcare for this population is dependent on local laws and/or safety-net services. As a result, this local context impacts their medical outcomes, healthcare utilization and economic costs and acts as a potential moral hazard to family, patients and providers of and serving immigrant communities.

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CHAPTER 1: INTRODUCTION

As of April 2023, the World Health Organization's (WHO) website described social determinants of health (SDH) as "the non-medical factors that influence health outcomes." They are the conditions shaping one's daily life and are an "important influence on health inequities – the unfair and avoidable differences in health status." The WHO includes income and social protection, working life conditions, education, and access to affordable health services of decent quality as examples of social determinants of health. This last one, "access to affordable health services of decent quality" I believe is significantly influenced by local context for immigrant communities, especially those of precarious legal status.

Although there are several health conditions that can demonstrate the significance of local context as a social determinant of health for immigrant communities in the US, in this paper I will be using the example of undocumented immigrants suffering from end-stage renal disease (ESRD). Lilia Cervantes, MD of the University of Colorado has led much of the research showing that significant variation in hemodialysis care for undocumented immigrants exists between states leading to differences in mortality, healthcare utilization and moral distress.

Part One of Chapter 1: Undocumented & Uninsured

According to an article published by Rachel Fabi and colleagues in 2021, there are approximately 10.7 million undocumented immigrants living and working in the United States, which equates to roughly 3.3% of the US population (Fabi, Saloner and

Taylor 2021, 694). However, undocumented immigrants constitute 27% of the United States' uninsured population (Welles and Cervantes 2019, 615). Undocumented immigrants compose a disproportionate amount of the uninsured population due to exclusion from almost all federally funded health insurance programs and a lack of comprehensive federal immigration reform since 1986.

Due to these policy barriers to care, most undocumented immigrants are left to rely on the Emergency Medical Treatment and Active Labor Act (EMTALA) to access healthcare. Reliance on emergency departments for health care is substandard and unsustainable. Emergency departments are incapable of, and frankly not intended to provide adequate primary and preventative care (Katz, and Wei 2019, 693). As is evidenced by multiple studies, when undocumented immigrants are forced to rely on emergency-only care for healthcare they suffer poorer medical outcomes, higher mortality rates, and accrue higher medical costs (Welles, and Cervantes 2019, 615).

CHAPTER 2: EMTALA

The "emergency-only care" that undocumented immigrants rely on is provided through EMTALA. The Emergency Medical Treatment and Active Labor Act (EMTALA) was enacted by Congress in 1986 in response to the common practice of "patient dumping" (Zhou, Amanatullah, and Frick 2019, 1 – 2). Patient dumping referred to the practice of refusing to provide emergency care to patients, most often due to their lack of insurance and/or inability to pay for care. Instead, these patients were transferred to other hospitals, usually public or university hospitals. A study published in 1986 looking at transfers to Cook County Hospital in Chicago found that "87% of patient transfers were because of lack of insurance." At that time, patient transfer was deemed necessary due to inability to pay. A patient's clinical stability in order to be safely transferred was not always accounted for. In fact, this same study found that 24% of these patients were unstable at the time of transfer, and subsequently their mortality was three times greater than non-transferred patients (Zhou Amanatullah, and Frick 2019, 2). At this time, similar practices and clinical outcomes were demonstrated in most large cities across the country with public hospitals.

EMTALA is a federal mandate that hospitals who receive Medicare funding are required to abide by. It requires three distinct obligations of these hospitals. First, a medical screening exam must be performed on all persons presenting to the hospital requesting care in order to determine if an emergency medical condition exists. Second, the hospital is required to stabilize that emergency condition to the best of their ability or transfer that patient to another hospital with the appropriate resources. Finally, the

hospital receiving a transferrable patient due to their facility's resources is required to accept said patient (Zibulewsky 2001, 349). The law provides a definition for both "emergency medical condition" and "stabilized." However, the language of both leaves room for ambiguity and interpretation at the state and local level.

Part One of Chapter 2: Federal Access, Or The Lack Thereof, To Healthcare

In 1965 the federal government tacitly acknowledged the importance of the access to healthcare for all when they passed the Social Security Amendments of 1965 into law, creating both Medicare and Medicaid. Medicare was established to provide healthcare to all individuals over the age of 65 regardless of financial need. It originally included Part A (hospital insurance) and Part B (Medical Insurance). However, in 1972 Medicare expanded to cover disabled individuals and those with end-stage renal disease requiring dialysis or a kidney transplant regardless of age, recognizing the burden disabilities and ESRD may place on an individual's life and their ability to work. Under the Medicare Prescription Drug Improvement and Modernization Act of 2003 private health plans could become approved under Medicare, known as Medicare Part C or Medicare Advantage Plans. Finally, in 2006 Medicare expanded to include Part D, an optional prescription drug plan (CMS.gov 2021). Since its inception in 1965, Medicare has been amended several times to meet the evolving needs of this population of individuals.

Along with Medicare, Medicaid was also passed in 1965. It was intended to provide medical insurance to those with a financial need. It has since been expanded to included low-income families, pregnant women, people of all ages with disabilities and those in need of long-term care (CMS.gov 2021).

Federal access to health care was again reformed in 1997 with the Children's Health Insurance Program (CHIP). CHIP was created to provide health insurance and preventative care to uninsured children. And in 2010 the Affordable Care Act created a Health Insurance Marketplace with access to federally subsidized private health insurance plans (CMS.gov 2021) in order to further reduce the number of uninsured individuals in the United States.

Since 1965, our federal government has continued to reform policies governing health insurance access. However, the same cannot be said for immigration reform. The last time Congress passed federal immigration reform was in 1986, and in the nearly 40 years since there have been several failed but ultimately unsuccessful attempts at immigration reform. Due to this lack of immigration reform, undocumented immigrants continue to be excluded from most federal healthcare programs with the exception of the Emergency Medical Treatment and Active Labor Act (EMTALA) of 1986. Medicare, Medicaid, CHIP and the ACA Marketplace all explicitly exclude undocumented individuals, with the exception of those financially capable of purchasing a private unsubsidized health insurance plan from the ACA Marketplace. For most, this is prohibitively expensive. As a result, most undocumented immigrants are left to rely on emergency healthcare only, which is provided through EMTALA.

Due to the ambiguous language of the Emergency Medical Treatment and Active Labor Act (EMTALA), each state is left to interpret what an "emergency medical condition" and "stabilization" are leading to local variations in clinical practice (Welles, and Cervantes 2019, 615). For instance, both California and New York consider the diagnosis of end-stage renal disease (ESRD) to be an emergency medical condition.

Defining it as such allows them to provide standard outpatient hemodialysis to these individuals three times a week (Welles and Cervantes 2019, 616). However, Texas does not consider the diagnosis of ESRD to be an emergency medical condition. Instead, uninsured, undocumented individuals suffering with ESRD living in Texas must present to the emergency room in critical condition, most often a direct result of untreated ESRD. If they are deemed ill "enough," they are admitted to the hospital and receive one session of emergency-only hemodialysis (Welles, and Cervantes 2019, 616).

As undocumented immigrants living and working in the United States are explicitly excluded from all forms of federal public health insurance, with the exception of EMTALA, the state in which they live dictates their access to the healthcare system. And as the WHO pointed out, access to affordable health services of decent quality is a social determinant of health. For undocumented immigrants with ESRD this local context should be considered a significant social determinant of health.

CHAPTER 3: END-STAGE RENAL DISEASE

More than 500,000 people living and working in the United States suffer from end-stage renal disease (ESRD) (Hashmi, Benjamin and Lappin 2023, 1). Of those, approximately 6,480 are undocumented immigrants (Cervantes, Fischer and Berlinger 2017, 529). Kidney disease, which includes ESRD, is the ninth leading cause of death in the United States and its prevalence is increasing by about 20,000 new cases each year (Hashmi, Benjamin and Lappin2023, 1). ESRD is the final stage of chronic kidney disease and is life-threatening if left untreated. However, dialysis or kidney transplant are life-saving treatments.

A number of chronic diseases can lead to end-stage renal disease, including hypertension, recurrent kidney stones and at times acute kidney injuries. However, the leading cause of CKD progressing to ESRD is diabetes (Hashmi, Benjamin and Lappin2023, 1). Once CKD has progressed to ESRD patients may present to the ED with persistent nausea and vomiting, hyperkalemia, volume overload refractory to diuretics and poorly controlled hypertension. Their volume overload can cause dyspnea, described by patients as a feeling of 'drowning' as fluid fills their lungs (Cervantes, Fischer and Berlinger 2017, 530) and hyperkalemia can lead to deadly arrythmias. These symptoms present as an emergency need for dialysis, and without dialysis ESRD is fatal.

Although emergent hemodialysis can be used in an emergency, it is not the standard of care. Standard of care for someone with CKD involves aggressive monitoring for signs of disease progression, with the goal of preventing progression to ESRD. However, once someone has kidney failure, also known as ESRD, dialysis or

transplant is required. Standard hemodialysis is given three times a week via an arteriovenous fistula or hemodialysis tunneled catheter; however, a fistula is preferred for long-term treatment. A catheter is almost always used just until a fistula can be surgically placed and matured.

Of the three hospitals that Cervantes and colleagues included in the study, hemodialysis access as well as vascular access varied for undocumented immigrant patients depending on where they lived and received their care. At Harris Health in Houston, Texas undocumented immigrants received emergency-only hemodialysis through the emergency room via a temporary tunneled dialysis catheter. It is EMTALA that allowed these individuals to access this care in Texas. However, Texas does not consider the diagnosis of ESRD to be a qualifying "emergency medical condition." Instead, patients must become critically ill secondary to their kidney failure in order to demonstrate an emergent medical condition. Critically ill for an individual with ESRD may be defined as "the presence of any of the following: elevated potassium, low bicarb, low oxygen saturation, uremic symptoms including confusion, substantial nausea and vomiting, mental status changes or other neurological signs and symptoms and/or shortness of breath" (Cervantes et al. 2018, 188). They then would receive one session of hemodialysis after which they would be discharged without access to the standard of care for an individual with ESRD - hemodialysis three times a week in an outpatient clinic in order to prevent critical illness.

At Denver Health (at the time of the study) in Denver, Colorado an arteriovenous fistula was placed for undocumented immigrants with ESRD as they will continue to have a need for dialysis. However, in order to access this dialysis they are required to

present to the emergency department critically ill. At that time they are provided with 2 consecutive hemodialysis sessions on 2 consecutive days, which will hopefully further delay their need to present to the emergency department critically ill for their next dialysis session. Again, without consistent hemodialysis individuals with ESRD will die.

Finally, at the study's third site, Zuckerberg-San Francisco General Hospital in San Francisco, California, an arteriovenous fistula is placed for these patients and standard three times per week hemodialysis in an outpatient setting is provided because California chose to include the diagnosis of ESRD as a "emergency medical condition" providing the standard of care for this disease through EMTALA.

Of the three states included in Cervantes et al. work, California is the most progressive in terms of expanding healthcare access to undocumented immigrants and the uninsured at large. In January 2020, California extended their state-funded Medicaid program, known as Medi-cal, to cover low-income young adults ages 19 to 26 regardless of immigration status. In May 2022, this coverage expanded to all low-income adults ages 50 and older regardless of immigration status. And effective early 2024, all low-income individuals regardless of immigration status will be eligible for Medi-cal coverage. (KFF 2022) The state had previously covered both children and pregnant women regardless of immigration status. Without a federal mandate to cover undocumented individuals, California chose to expand their state's Medicaid program to provide healthcare access to this population. Not only is this the morally right thing to do in order to work towards eliminating health inequities exacerbated by the exclusion of undocumented immigrants from federal healthcare programs, it is the right thing to do for

the population of California, which is home to the most undocumented immigrants of any state in the country.

CHAPTER 4: IMPLICATIONS OF LOCAL CONTEXT

As explained earlier in this paper, for undocumented immigrants with end-stage renal disease access to life-sustaining hemodialysis depends on state policy and local safety-net services (Cervantes, Fischer, and Berlinger 2017). This is best exemplified by the work of Lilia Cervantes and colleagues as they compared access to hemodialysis for this population in Texas, California and Colorado. The results of their work highlighted the significant impact that local context can make on one's health, further supporting my argument that local context is a significant social determinant of health for immigrant communities, especially those with precarious legal status. Their work showed that state policies significantly impact the medical outocomes for undocumented immigrants with ESRD, their associated healthcare utilization and economic costs and act as a potential moral hazard to family, patients and providers of and serving immigrant communities, especially those with precarious legal status.

Part One Chapter 4: Medical Outcomes

The study found that patients who received emergency-only hemodialysis, like those at Harris Health in Houston, Texas, were at a 14-fold higher mortality risk than those who received standard hemodialysis after five years. The direct causes of the higher mortality rates for undocumented immigrants with ESRD receiving emergency-only hemodialysis have been shown to be due to "acute, unexpected events, such as cardiac arrest or cardiac arrhythmias" (Welles, and Cervantes 2019, 616). The majority of these patients who died in the hospital from an acute cardiac event had elevated

potassium levels and documented rhythm disturbances from this hyperkalemia. On average, their last dialysis session was 6 days prior to their final admission and this elevated potassium was secondary to ESRD, meaning that their deaths may have been prevented with consistent access to standard hemodialysis in order to prevent such elevations in potassium leading to cardiac arrhythmias and sudden cardiac death (Welles, and Cervantes 2019, 617).

Part Two Chapter 4: Healthcare Utilization & Costs

The number of acute-care hospital days for those treated with emergency-only hemodialysis was nearly 10-fold greater than those with access to standard hemodialysis (Welles, and Cervantes 2019, 616). When individuals are forced to rely on emergency-only hemodialysis as opposed to standard outpatient thrice weekly dialysis sessions, they are essentially forced to forgo preventative care and instead put their bodies through continuous cycles of critical illness. The emergency-only dialysis for undocumented immigrants, like that provided in Texas, ends up being nearly 4 times more costly than the standard hemodialysis due to more emergency room visits and an increased number of hospital admissions due to the repeated acutity of illness these individuals are forced to put their bodies through (Cervantes et al. 2018, 188 - 195). One study of patients in Houston, Texas found that "compared with undocumented immigrants receiving standard dialsysis, those receiving emergency-only hemodialysis spent more days in the hospital (162 versus 10 days), had more emergency department visits (26.3 versus 1.4), more blood transfusions (24.9 versus 2.2), fewer dialysis treatments per year (98 versus 154), more physical pain, a lower level of physical function, and higher annual costs ($284,655

versus $76,906)" (Welles, and Cervantes 2019, 616). This is all evidence that in states that choose to prohibit undocumented immigrants with ESRD from accessing standard thrice weekly hemodialysis and instead forcc these individuals to rely on emergency-only hemodialysis they receive "less efficient care with worse clinical outcomes, all at a higher cost" (Welles, and Cervantes 2019, 616).

Part Three Chapter 4: Moral Distress

As mentioned previously, undocumented immigrants suffering from ESRD with access only to emergency-only hemodialysis due to state policies are forced to live through cycles of critical illness instead of receiving adequate healthcare, which places undue physical and mental distress on patients, their families and healthcare providers. Lilia Cervantes, MD, Stacy Fischer, MD and Nancy Berlinger, PhD explored the illness experience of undocumented immigrants with ESRD, but without access to scheduled thrice weekly hemodialysis. Through their qualitative study interviewing undocumented Latino patients with ESRD and no access to standard hemodialysis they found common themes of the illness experience including "distressing symptom burden and unpredictable access to emergent-only-hemodialysis" and "death anxiety associated with weekly episodes of life-threatening illness" for both themselves and their families.

Without access to consistent hemodialysis, the symptoms of kidney failure begin to accumulate quickly. Perhaps the most noticeable is the accumulation of fluid in the body, specifically in the chest causing patients to experience shortness of breath described by many in this study as "a weekly feeling of drowning." Not only is it

physically distressing, but the psychological burden of feeling unable to breathe harms both the patient and their families (Cervantes, Fischer, and Berlinger 2017, 531).

CHAPTER 5: CONCULSION

Undocumented immigrants suffer from poorer health outcomes and our healthcare system carries a greater financial burden when healthcare access for these patients is limited to that provided through EMTALA only. California, along with several other states, have provided one model of how to provide full healthcare access to undocumented immigrants, which is both the ethical thing to do and the most financially prudent, when the federal government has failed to do so.

Several ethical theories, including Utilitarianism, can be used to demonstrate that providing undocumented immigrants with emergency-only healthcare is morally wrong. Utilitarianism is an ethical theory that states that moral rights from wrongs can be determined by focusing on outcomes. It is most ethical from a utilitarianism perspective to choose the path that will produce the greatest good for the greatest number (Stone 2018, 18). As demonstrated by the work of Lilia Cervantes et al. providing emergency-only hemodialysis for undocumented inividuals suffering from ESRD causes direct harm to a large number of individuals, without a corresponding beneficial outcome for others. Limiting undocumented immigrants access to healthcare to that provided by EMTALA only, and leaving it up to states to interpret the scope of such care, fails to produce a greater good for the greatest number.

The failure of the federal government to pass immigration reform means that healthcare access for undocumented individuals is limited to emergency-care only via EMTALA, unless a state takes it upon itself to expand coverage to this population. Many undocumented individuals living in states, like Texas, that have not expanded their access

to healthcare suffer worse health outcomes, increased healthcare costs and moral distress. As a future emergency physician, I have a duty to not only provide the highest quality care to all individuals regardless of their documentation status, but to work towards eliminating healthcare disparities through advocacy and policy change. Appreciating that the local context is a significant social determinant of health for immigrant communities, especially those with precarious legal status, is the first step towards such change.

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