

## SPECIAL CONTRIBUTION

## Ethics

# Ethical issues and obligations with undocumented immigrants relying on emergency departments for dialysis

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**Abstract**

Undocumented immigrants with end-stage renal disease in the United States are uniquely disadvantaged in their ability to access dialysis. This article examines the unique circumstances of the medical condition and healthcare system, including the relevant legal and regulatory influences that largely relegate undocumented immigrants to relying on emergency-only dialysis through a hospital's Emergency Medical Treatment and Labor Act obligations. We explore the ethical implications of this current state, emphasizing the adverse effects on patients and staff alike. We also review necessary actions that range from the actions an individual emergency physician to changes needed in federal policy.

**KEYWORDS**

dialysis, emergency-only dialysis, EMTALA, end state renal disease, ethics

## 1 | INTRODUCTION

End-stage renal disease (ESRD) among undocumented immigrants (UIs) presents a unique challenge within the United States healthcare system. Although difficult to assess—because UIs are excluded from the US Renal Data System—it is estimated that there are currently between 5500 and 8857 undocumented patients in the United States with ESRD.<sup>1</sup> The standard of care for ESRD is scheduled 3-times-a-week outpatient hemodialysis or renal transplantation. Because of the funding structure of dialysis care, UIs do not routinely receive this standard of care.

UI patients with ESRD rely on the 1986 Federal Emergency Medical Treatment and Labor Act (EMTALA) as the primary way to secure dialysis. EMTALA obligates hospitals to provide stabilizing treatment (eg, dialysis) to all patients who present to the hospital's emergency department (ED) with an emergency medical condition. EMTALA confers no explicit obligation to provide regular dialysis for patients in a stable condition, however. Further, no additional legal or regulatory

requirements exist at the federal level to facilitate or mandate the standard of care for these patients, who experience frequent and foreseeable critical decompensation without regularly scheduled dialysis.

The narrow scope of EMTALA, coupled with unique aspects of ESRD, warrant an in-depth evaluation of the moral dilemma confronted by emergency physicians when UIs with ESRD present to the ED. This article provides a description of the problem at hand, explains how it is distinct from other issues of UI patients' medical care and EMTALA responsibilities, provides an ethical analysis of this dilemma, and finally proposes actions that individual practitioners, health systems, and public officials should take to address the issue.

## 2 | DEFINING THE PROBLEM

A foundational, governing federal statute in the care of UIs with ESRD is EMTALA. Passed in 1986, this law requires EDs to provide an emergency medical screening exam and stabilizing treatment for all patients

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presenting within 250 yards of the hospital. Emergency-only hemodialysis (EOHD) is the practice of providing dialysis care to patients through the ED only when their illness severity rises to the level of an emergency medical condition as defined by EMTALA—usually dictated by hyperkalemia, uremia, or volume overload. This law is explicitly not intended to be a federal “malpractice statute,” and hence it confers no obligation to provide the standard of care to ED patients, but only evaluation of the patient, stabilizing treatment of any emergent condition, and a transfer if further stabilization is needed at a higher level of care. As such, even though a patient with ESRD will predictably be in an emergent condition after 72 hours without dialysis, no EMTALA obligation exists if an emergent condition does not exist in that moment. Although the 250-yard rule extended the EMTALA obligation geographically beyond the front door of the ED, no such extension exists temporally. The law only speaks to conditions that require immediate medical attention without addressing conditions that will require immediate attention if left untreated in their currently stable state.<sup>2</sup>

Patients with ESRD use several different dialysis methods, ranging from continuous dialysis in the hospital to overnight peritoneal dialysis at home. The most common method is intermittent hemodialysis, typically scheduled 3 times per week at an outpatient dialysis center. Health insurance coverage for patients requiring renal replacement therapy (RRT), or dialysis, has undergone multiple changes in the last 50 years. In 1962, the Migrant Health Act signed by President John F. Kennedy allowed for medical care to be given to people immigrating to the United States to provide labor. Ten years later, Public Law 92-603 extended health insurance coverage to ESRD patients who had worked long enough to receive social security benefits or had a spouse who had done so.<sup>3</sup> Neither of these federal statutes includes UIs, who remain only covered by EMTALA. The unfunded EMTALA treatment mandate does not apply to outpatient dialysis centers. Two major for-profit companies, Fresenius and DaVita, own dialysis centers that provide nearly 75% of all US dialysis treatments.<sup>4</sup> These companies coordinate some charity services, but there remains no systemic solution to UI patients needing regular dialysis. These charity-supported dialysis services are typically through a third-party non-profit organization, such as the American Kidney Fund, supporting nearly 15% of US dialysis patients.<sup>5</sup> However, concern has been raised about the for-profit motivations and kickback relationships between the nonprofit charities and for-profit corporate dialysis companies.<sup>6</sup>

The cost of dialysis (typically up to \$90,000 per year) poses a substantial obstacle for UI patients with ESRD.<sup>7</sup> Because ESRD automatically qualifies Medicare-eligible patients for treatment, including dialysis and kidney transplantation, US ESRD patients have Medicare coverage for these services.<sup>8</sup> UIs do not, however, qualify for Medicare and hence most UIs have no reliable funding source for their dialysis care.

Individual states and health systems differ significantly in their approach to the care of UI ESRD patients. In California, for example, both documented and undocumented patients with ESRD can receive scheduled dialysis under the Welfare Reform Act of 1996. Arizona initially did not allow UI ESRD patients to receive outpatient dialysis through Medicaid. In 2002, 3 dialysis patients sued to overturn this

law in *Padilla v Rogers*. Ultimately, in 2007, Arizona granted outpatient dialysis to UI patients with ESRD.<sup>9</sup> Texas, in contrast, does not provide Medicaid coverage for routine dialysis of UIs with ESRD, putting a further burden on EDs, local hospitals, and public healthcare systems.<sup>10</sup> These are just a few examples of the vastly different standards of care and practice patterns for UI patients with ESRD. One in-depth analysis of the cost and impact of such a system identified nearly \$21.8 million dollars of hospital care associated with this approach annually.<sup>11</sup> Although the Affordable Care Act, enacted in 2010, extended health insurance coverage to millions of Americans, it did not extend medical coverage to UIs with ESRD, further underscoring and perpetuating this problem.

In contrast to most other medical conditions, ESRD—like type 1 diabetes mellitus—is a chronic medical condition only because a life-sustaining treatment is available. Without RRT or insulin, both are uniformly fatal. When these treatments are regularly provided, they transform rapidly fatal diseases into stable chronic conditions that can be managed for years. This paradoxically means that patients can be in a stable condition that will predictably and rapidly progress to an emergent condition if not treated. The expected and rapid (typically over the course of days) decline from a stable condition to an emergent condition that can be treated effectively through dialysis, but at substantial cost to patients of profound morbidity and risk of mortality. This situation raises significant questions about emergency physicians' ethical obligations to UI patients with ESRD. The following section examines those moral questions.

### 3 | ETHICAL ISSUES

#### 3.1 | Bioethical principles

Since the inception of intermittent maintenance hemodialysis as a treatment modality in the 1960s, access to this expensive and life-saving technology has posed ethical issues.<sup>12</sup> Early ethical dilemmas were about allocating the absolutely limited access to dialysis machines among multiple ESRD patients. Legislative enactment of Medicare coverage for ESRD treatment and the subsequent proliferation of dialysis centers eased those early moral dilemmas of rationing ESRD care.

In essence, hospital EDs have become de facto emergency dialysis centers for UI patients with ESRD in most US jurisdictions. However, emergency dialysis is inferior to maintenance dialysis in 2 major respects: it is both more expensive and it provides lower quality care with poorer long-term outcomes.<sup>13</sup> Yet, institutions that facilitate access and funding for outpatient dialysis by UI patients risk attracting a disproportionate share of these expensive patients and assuming a major financial burden. Given the duty under EMTALA to provide at least emergency dialysis to UI patients, we contend that the responsibility for providing quality ESRD care for these patients should not fall on individual institutions, but should be shared equitably. Failure to do so results in an inequitable and hence unjust distribution of the financial burden of caring for these patients and, in fact, penalizes those

institutions that provide higher quality care. Considerations of distributive justice thus provide a rationale for regional and national plans to distribute the cost associated with unfunded and uninsured dialysis care equitably. Piecemeal approaches result in unjust imbalance of cost and promote denying and deferring care.

In addition to justice, beneficence and non-maleficence are widely recognized principles of bioethics.<sup>14</sup> These principles guide the practice of medicine to always strive to provide the most beneficial care and to avoid harm. Yet there are often practical constraints to providing the best possible care: a lack of staff, a full waiting room, an MRI not available at night. In such practical limitations to optimal care, there are often equally practical approaches to mitigate the harm that render the ethical injury minimal (eg, triaging acuity in a full waiting room, observing, or transferring the patient requiring an unavailable MRI). In the care of UI dialysis patients, the lack of a plan covering a non-emergency option causes harm with no viable alternative strategy to limit harm. UIs receive lower quality of care, missing such standards as regular assessment by nephrologists, screening tests, typical dialysis access surgery, or frequent dialysis treatments.<sup>15</sup> Accessing essential care can dominate these patients' lives, making it difficult to work and care for family, and creating a mental burden and lack of a sense of control of basic life activities. Patients are forced to guess when they are sick enough to qualify for emergent dialysis, and a wrong guess can have fatal consequences. The imminent and anticipated decline of a patient in need of dialysis but not receiving it until under EMTALA obligation is an egregious example of directly permitting harm and withholding benefits for UI patients, in a way that is more direct and immediate in its cause and effect than the other ways in which uninsured patients' care is compromised. Thus, limiting access to dialysis for UIs is clearly inconsistent with the principles of beneficence and non-maleficence. These policies identify UI patients as unworthy of basic standards of care due solely to a lack of legal residency. Individual physicians and health systems lack sufficient resources to address this problem, and thus its correction requires a change at the broader policy level.

### 3.2 | Emergency-only hemodialysis

EOHD is often referred to as "compassionate dialysis," a doublespeak euphemism for cyclically providing treatment only when failing to do so would result in imminent death.<sup>16</sup> On its surface, it may seem like a beneficent effort within a broken system, but EOHD has been described as a "cruel carousel" that is far from compassionate. It is comparable to treating patients for diabetic ketoacidosis in the ED and then discharging them with no provision for, or anticipation of, access to insulin, and advising them that they should try to return to the hospital when they are once again near death, but not before. When transitioning from EOHD to scheduled hemodialysis, patients reported significant improvements in their chronic symptoms: 100% improvement in nausea, 57% for pain, 94% for appetite and shortness of breath, 87% for anxiety, 86% for depression, 65% for tiredness, and 60% for drowsiness.<sup>17</sup> Caregivers experienced higher levels of stress, greater caregiver burdens, more unpredictability, greater harmful

effects on children, and more reliance on faith in God when their loved ones with ESRD were receiving emergency-only hemodialysis.<sup>18</sup>

Although meeting immediate EMTALA obligations for care, EOHD fails to deliver care that is medically equivalent to regular outpatient dialysis. The probability of death for patients receiving EOHD begins diverging from patients receiving standard dialysis at 1 year and is 14-fold higher by 5 years from dialysis initiation.<sup>19</sup> In addition, EOHD results in patients experiencing persistent severe physical symptoms and psychosocial distress and is 3–5 times more expensive annually than standard dialysis treatment.<sup>20</sup> Because hyperkalemia is both largely asymptomatic and the most easily verifiable indication for emergent dialysis, patients sometimes intentionally supplement potassium before presentation to the ED. This is done to ensure that they are able to get dialysis that day and are not turned away despite their distressing, but not yet emergent, uremic or volume overload symptoms. The combined result is a higher cost treatment with significantly worse outcomes, creating both physical and psychosocial distress, which encourages life-threatening risk-taking behavior. These are all substantive harms of EOHD. EOHD is therefore an ethically fraught stopgap solution.

### 3.3 | Moral distress

In addition to the above ethical arguments delineated, health care professionals may experience moral distress associated with poorly caring for patients. Moral distress occurs when one knows the ethically correct action to take, but feels powerless to take that action.<sup>21</sup> Participation in EOHD has been found to be a source of moral distress and professional burnout for involved clinicians<sup>22</sup>. Emergency physicians may be particularly vulnerable to this source of moral distress and its manifestation as burnout because of their role as gatekeepers to EMTALA services such as EOHD. For the individual emergency physician, repetitively stabilizing and discharging UIs through EOHD, without a greater plan or institutional support, may feel like participating in neglect or abandonment.

Forty percent of emergency physicians demonstrate high levels of symptoms consistent with burnout, and burnout results in adverse effects on all types of patient care, healthcare costs, and physician health.<sup>23</sup> Although the obligation to address social determinants of health (eg, undocumented status) that affect the health of ED patients is typically construed as a patient-centered moral argument,<sup>24</sup> in this case it is also a workforce wellness, safety, and longevity concern.

### 3.4 | Ethical resolution

The ethical and moral problems created by EOHD cannot be solved at the individual patient level. The issues require system-level solutions and should involve burden sharing rather than burden shifting. Practices where the intent is to discourage future visits by undocumented ESRD patients, such as placing and removing a new temporary hemodialysis catheter at each visit, should be avoided. Advocating for

patients to return to their country of origin or relocate to a state with more robust ESRD services are not reasonable or long-term practical solutions to this growing challenge and are examples of burden shifting to avoid confronting the ethical problem. Furthermore, repatriation has the added harm of relocating a patient to a country with even fewer resources for dialysis. Although that may be a permissible political consideration, it is not an ethical one.

In short, the current approach to caring for these patients (namely, EOHD) that knowingly increases their mortality and morbidity, in direct conflict with the patient's expressed preference to comply with regular outpatient dialysis, is a morally questionable solution. It directly compromises respect for principles of justice, beneficence, and non-maleficence by conditioning care on patients' ability to pay, citizenship status, and race or ethnicity. It is, in fact, indefensibly participating in a form of systemic injustice and discrimination.

## 4 | NECESSARY ACTIONS

Advocacy for UIs with ESRD should start in the ED and extend to the hospital, local community, state, and nation. Stakeholders should consider the following actions, as outlined in Table 1.

### 4.1 | Individual emergency physicians

Individual physicians, taking care of specific UIs with ESRD should, in addition to their usual medical care of these patients, advocate for a regularly scheduled, outpatient dialysis strategy. This should include raising awareness of these cases in the community and highlighting the issues to local leaders, given the gravity of perpetuated harm and minimized benefit of EOHDs. Individual emergency physicians should recognize the important role they play in the care of these vulnerable patients and seek effective solutions beyond stabilization of their emergent condition during each ED visit. Taking these actions may help address feelings of the moral distress for tacit complicity in the injustice of EOHD.

### 4.2 | Hospitals

Hospitals should consider providing scheduled dialysis rather than EOHD for their UI patients. In jurisdictions where public funding is available for EOHD only, hospitals can seek other sources of support, including from charitable or kidney patient support programs. Regardless of external financial support, hospitals should pursue scheduled dialysis for their UI patients with ESRD. They should first be reassured that this is the most cost-effective option. The adjusted costs were \$4316 versus \$1452 per month.<sup>25</sup> As emphasized in this discussion, it is also the best outcome for patients; one hospital in Texas compared 105 patients with scheduled dialysis to 76 patients with EOHD and found significantly reduced 1-year mortality at 17% versus 3% with a

**TABLE 1** Actions to take for undocumented patients with ESRD

Level of response	Obligation	Ethical justification
Individual physician	Advocate for regularly scheduled dialysis Identify and highlight problem to local leaders	Minimizing the harm of emergency-only dialysis; intolerance of injustice; responding to moral distress
Hospital	Schedule regular dialysis	Minimizing harm to each patient
Local/regional	Collaborate to equitably distribute undocumented ESRD needs among community	Maximize benefit in the community
State	Cover undocumented ESRD costs under Medicaid	Eliminate injustice
National	Cover undocumented ESRD costs under Medicare	Eliminate injustice

number needed-to-treat (NNT) of 7. This may be attributable to the increased rates of bacteremia in EOHD patients.<sup>26</sup> These facts provide concrete support, in addition to the moral argument, that hospitals should take action to provide high quality care for their dialysis patients, regardless of their funding status.

### 4.3 | Local and regional institutional collaboration

Hospitals and health systems in the same community or region should consider inter-institutional collaboration to distribute ESRD care for UI patients equitable with one another, recruiting third party arbiters if necessary. Competitive healthcare markets and financially strained organizations will be tempted to retain an EOHD approach to UI patients with ESRD. This may be especially likely when one organization in a community takes the medically preferable approach of scheduling these patients for regular outpatient dialysis. As has been discussed, this expensive care, is not currently covered by our healthcare insurance system, and local healthcare organizations should seek to collaborate with one another to avoid local medical tourism between institutions for the most hospitable dialysis provider.

### 4.4 | State governments

At the state level, EPs should advocate for Medicaid coverage of patients with ESRD regardless of citizenship status. As of 2019, only 12 states provided this coverage for UIs.<sup>27</sup> One general internist was able to succeed at accomplishing this change at the state level in Colorado.<sup>28</sup> She has now become a recognized expert on the effects of regularly scheduled dialysis on both patient outcomes and the patients' family caregivers.

## 4.5 | Federal policy

The United States needs a comprehensive, national solution to this problem. Interventions at each of the preceding levels make improvements, but there would remain legitimate concerns about cost and disparities in care between communities and states. For example, if Medicare would cover ESRD for UIs in the same manner as it does for US citizens, this would constitute a stable solution to the problem. Coupled with such a comprehensive change, immigration policies could be designed to limit medical tourism and cover UI patients with established residence in the United States. Only this approach would be in keeping with the World Health Organization recommendations for ethical care of patients with kidney disease, in light of the 17 sustainable development goals adopted by the United Nations, which strive for equity and access.<sup>29</sup>

## 5 | CONCLUSIONS

Although EMTALA has been successful in curbing “patient-dumping” behaviors that prompted its enactment, reliance on its obligation in the care for UI patients with ESRD requiring dialysis is not sufficient. This analysis of the unique problem of UIs with ESRD highlights the medical and moral shortcomings of EOHD.

Most immediately, emergency physicians should recognize an obligation both to advocate for their UI patients’ access to regular dialysis (rather than EOHD) within their institutions and to local and state leaders. Hospitals, health care systems, and state and federal governments should accept comparable obligations. Tolerance of an emergency-only dialysis approach should be recognized as a moral failing at every level of the healthcare continuum.

### CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

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