Emergency-Only Hemodialysis Policies: Ethical Critique and Avenues for Reform

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Introduction

An estimated 10.7 million undocumented immigrants resided in the United States in 2016.[1] In 2015, it was estimated that approximately 6,480 of these immigrants were dialysis-dependent, termed end-stage renal disease (ESRD).[2] The appropriate medical treatment for this population is renal replacement therapy (RRT), which includes hemodialysis, peritoneal dialysis, or renal transplantation.[3] While the majority of United States citizens with ESRD are eligible for coverage for RRT through the federal Medicare program, such coverage does not extend to undocumented immigrants. Consequently, undocumented immigrants, the vast majority (over 70%) of whom lack private insurance, depend on either state or local policies or on charity care to obtain life-sustaining RRT.[4] As over 75% of states do not have a state-level policy to provide RRT to those not otherwise covered by Medicare or private insurance, treatment is typically limited to the provision of 'emergency-only hemodialysis' (EOHD).[5] The practice of EOHD involves a patient presenting to a hospital emergency department with a life-threatening acute complication of kidney failure in order to obtain a single dialysis treatment. These conditions include volume overload or high potassium, both of which can result in imminent death unless urgently treated.[6]

Prior literature has identified both the clinical and ethical shortcomings associated with reliance on EOHD, including adverse health outcomes, comparatively high costs, and moral distress.[7] In 2000, the Renal Physicians Association published a position paper on dialysis for non-citizens, stating that providing access to RRT for all patients, regardless of citizenship status, can be justified on humanitarian and pragmatic grounds.[8] Other professional organizations have since advocated to extend state or federal insurance coverage to dialysis-dependent undocumented immigrants, but these recommendations have not been adopted at the federal level.[9]

In this paper, we introduce the current policy landscape governing RRT for non-citizens, describe the ethical shortcomings presented by the reliance on EOHD for undocumented patients, and explore common arguments opposing expansion of coverage for RRT to this population. We then introduce several state-level efforts to mitigate the ethical shortcomings associated with EOHD for undocumented patients. We argue that, while reform at the federal level would ultimately be a more sustainable long-term solution, these state-based approaches nevertheless are an improvement over current federal policies, and can help mitigate the ethical shortcomings of EOHD.

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Policies on RRT for Non-Citizens

In the United States, nearly all citizens diagnosed with advanced kidney failure requiring dialysis are eligible for federal insurance coverage as the result of the 1972 Public Law 92-603.[9] This law, however, does not extend such coverage to non-citizens, including undocumented immigrants, regardless of duration of residence in this country. Subsequent laws imposed additional restrictions for undocumented immigrants. For example, the Consolidated Omnibus Budget Reconciliation Act of 1986 prohibited the use of federal funds in the care of undocumented immigrants, with the exception of emergency care.[10]

Similarly, the 1996 Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) barred undocumented immigrants from most federal insurance programs and gave states broad latitude in deciding which treatments to cover for undocumented immigrants.[11] PRWORA significantly altered the landscape of health care provision for undocumented immigrants by creating additional barriers to care.[12] Undocumented immigrants were also largely excluded from the Patient Protection and Affordable Care Act (ACA).[13]

The aforementioned policies largely restrict undocumented immigrants from accessing federal health programs to receive RRT. However, EOHD is guaranteed under the Emergency Medical Treatment and Labor Act (EMTALA) of 1986, which mandates that healthcare facilities treat and stabilize all individuals who present to a hospital with emergent conditions.[14] Thus, in some states, dialysis access is limited to EOHD through EMTALA. EOHD is provided through federal Medicaid funds, which cannot be used to reimburse scheduled dialysis and renal transplantation for undocumented immigrants.

Other states have taken action to extend coverage for RRT to undocumented patients. These actions have taken a range of forms. A few states define each dialysis treatment as "emergency care," thus enabling the use of state Medicaid funds to provide thrice weekly scheduled hemodialysis. Others use private insurance plans subsidized by dialysis companies.[15] Alternatively, in several states that have opted not to expand Medicaid under the Affordable Care Act, including Texas, some of the costs for EOHD can be offset by Medicaid waivers, which grant additional federal funding to cover unreimbursed care in safety-net hospitals, including costs incurred by the treatment of undocumented populations.[16] Several cities and local health systems have paid for scheduled dialysis as charity, motivated by data indicating that this is ultimately less expensive than relying on EOHD. However, the sustainability of these models is tenuous. In what follows, we describe the shortcomings of the current federal reliance on EOHD policies, and examine strategies to mitigate these shortcomings.

Several cities and local health systems have paid for scheduled dialysis as charity, motivated by data indicating that this is ultimately less expensive than relying on EOHD. However, the sustainability of these models is tenuous. In what follows, we describe the shortcomings of the current federal reliance on EOHD policies, and examine strategies to mitigate these shortcomings.

Ethical Critique of EOHD Policies

Reliance on EOHD violates several core principles of medical ethics, including failing to uphold fiduciary and professional obligations and violating commitments to resource stewardship. Furthermore, it may contribute to moral distress and burnout. We discuss each of these issues in turn.

Failure to Uphold Fiduciary and Professional Obligations

Healthcare professionals have a fiduciary obligation to protect and promote the well-being of their patients, including obligations of beneficence and nonmaleficence. The practice of EOHD is inconsistent with these recognized principles.

EOHD causes numerous health harms as compared to scheduled dialysis. In one study, the five-year relative mortality hazard was over fourteen times higher for patients receiving EOHD compared to those receiving scheduled dialysis.[17] Similarly, EOHD has been associated with increased emergency department visits, hospitalizations, hospital days, and catheter-related bloodstream infections.[18] Reliance on EOHD also requires nephrologists and emergency physicians to depart from evidence-based medical practice beyond the timing of dialysis. As noted by the Renal Physicians Association, restrictive policies on RRT access lead to double standards in care, with significant variation between states and jurisdictions.[19] Dialysis in

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undocumented patients is usually initiated at a lower level of renal function due to financial constraints.[20] Furthermore, physicians may be restricted from listing otherwise eligible patients for transplants, as very few states allow undocumented immigrants to receive renal transplantation, despite many of these patients having living donor candidates.[21]

EOHD also contributes to non-health harms for both patients and their families. Unpredictable dialysis schedules and long hospitalizations can cause lead to job instability or even loss, resulting in financial harm.[22] Recurrent experiences with near-death events can also produce anxiety and other emotional and psychological harms for patients and their families.[23]

Poor Stewardship of Resources

As described by the American Medical Association Code of Medical Ethics' Opinion on Physician Stewardship, physicians are obligated to be "prudent stewards of the shared societal resources with which they are entrusted. Managing health care resources responsibly for the benefit of all patients is compatible with physicians' primary obligation to serve the interests of individual patients."[24] EOHD undermines this commitment to responsible stewardship in several ways. First, it is low-value, as it is expensive yet also associated with poor outcomes and increased healthcare utilization as compared to scheduled dialysis. According to one estimate, scheduled outpatient dialysis is associated with a net savings of about $72,000 per person per year as compared to emergency-only treatment.[25] EOHD can also contribute to indirect healthcare costs, including increased emergency department visits, length of hospitalizations, and catheter-related bloodstream infections.[26]

Additional failures of stewardship arise from restrictions on coverage for renal transplantation. According to one study, renal transplantation could yield a total savings of $321,000 per undocumented transplant recipient, assuming about eight years of life expectancy.[27] Other studies find both cost benefits and reduced morbidity and mortality among renal transplant recipients compared to those on dialysis, particularly in younger patients.[28] For example, a study comparing transplant outcomes between US citizens and noncitizens on Medicaid found that nonresident aliens had a lower risk of transplant loss and death compared to US citizens and were in general younger, had fewer comorbid conditions, and were more likely to have a potential living kidney donor.[29] Overall, the evidence suggests that providing renal transplantation to undocumented immigrants would result in similar outcomes and cost savings to those seen in US citizens. This is particularly likely because undocumented patients with ESRD tend to be younger and on dialysis for longer than US citizens with ESRD.

Contributor to Moral Distress and Burnout

Furthermore, the inability to provide equal care to undocumented citizens with ESRD and to adequately promote patient well-being can drive moral distress and even burnout in clinicians.[30] Burnout in turn has been associated with negative effects on perceived quality of care and measures of patient safety and patient satisfaction.[31] Consequently, EOHD may negatively impact patients, including but not exclusive to those receiving EOHD.

Interviews with clinicians suggest that the ethical distress posed by EOHD can be a strong catalyst towards becoming involved in advocacy.[32] Such advocacy can advance systemic approaches towards scheduled dialysis funding, and has resulted in the adoption of scheduled dialysis and even renal transplantation coverage in some states.[33] Yet advocacy at the individual level may also result in ethically problematic workarounds, including "bending the rules" or "stretching the truth" to help patients receive services.[34] For example, clinicians may overstate the significance of a patient's lab values or symptoms in order for the patient to receive emergency hemodialysis.[35] While such actions are driven by noble intentions, they nevertheless raise ethical concern for their impacts on physician integrity, as well as issues related to procedural justice.

Common Objections to Expanding RRT Coverage

Several objections are commonly raised in response to proposals to expand RRT coverage for undocumented immigrants. Below, we discuss three: financial constraints, RRT-driven migration, and the finite organ pool. Notably, each relates to a common theme, namely, that of limited resources. We explore each concern and identify counterarguments that we believe weaken the force of these claims.

Financial Constraints

Perhaps the most commonly cited concern regarding expanding RRT coverage is how states and cities should pay for this care.[36] In states providing Medicaid-funded scheduled dialysis, the cost is largely borne by taxpayers. While some have objected to the use of state funds for dialysis, studies have demonstrated that scheduled dialysis is associated with vast cost savings as compared to EOHD, and that renal transplantation is often more cost-effective than dialysis.[37] Thus expanding RRT coverage might, perhaps paradoxically, reduce, rather than increase, the costs associated with ESRD treatment for undocumented immigrants.

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Nevertheless, the financial implications for states and cities can be quite complex. Though studies suggest that EOHD can lead to substantial cost savings, implementing scheduled dialysis programs at the local level can be challenging. Several factors contribute to these difficulties. First, fragmentation in and frequent changes of the United States healthcare system can dampen payers' incentives to provide services like scheduled dialysis to offset future costs, as the patient may not be in the same risk pool when the cost benefits of these services are eventually realized.

Second, restrictions on the use of federal funds for undocumented immigrants can make obtaining even partial reimbursement for local or state-administered programs challenging. For example, a medical center providing EOHD can receive Medicaid payments supported by both federal and state contributions. Yet no federal payments would be permitted for the medical center if it chose instead to offer scheduled dialysis, and state funds would only be provided within those states that have elected to provide dialysis to the undocumented under the terms permitted under the PRWORA. While hospitals and county health systems can nevertheless still elect to provide outpatient scheduled dialysis, such programs generally must rely instead on local taxpayer funds or charity care for their patients, meaning the financial sustainability of such programs can be tenuous and can place health care systems and dialysis centers under financial strain.[38]

In 2009, citing high costs, Grady Memorial Hospital in Atlanta stopped providing outpatient dialysis to undocumented immigrants and several were repatriated back to their home country. The resulting negative publicity forced administration to reopen its outpatient dialysis center to undocumented immigrants in 2010, after reaching a complex deal with multiple private dialysis providers who agreed to provide charity care to a few patients.[39]

RRT-Driven Migration

A second objection is that expanding RRT care to the undocumented will incentivize illegal immigration, either to or within the US. Existing data, however, do not support this objection. Notably, some states providing scheduled dialysis and renal transplantation, such as Illinois and California, saw a decline in the undocumented immigrant population from 2009-2014.[40] Illinois and California have also expanded Medicaid and provide healthcare coverage for undocumented children.[41] These acts have preceded a decrease in the undocumented population in these states, so it is unlikely that dialysis coverage alone will lead to such migration.

The notion that individuals migrate to the United States specifically for ESRD treatment or other health care is also not substantiated by the literature. Most migrants with ESRD move for economic and familial reasons, and generally only become aware of their kidney disease after immigrating to the United States.[42] In California, the number of undocumented immigrants receiving state-funded scheduled dialysis increased between 1998 and 2001 but remained steady from 2001 to 2008.[43] Scheduled dialysis coverage for undocumented immigrants was expanded in California between 1988 and 1990, following a series of legislative actions and the *Crespin v. Kizer* case.[44] Data are not available for the period immediately following this expansion, but data from the following decades suggest that expanded hemodialysis and transplantation programs alone do not result in substantial interstate migration. A national analysis of migration patterns found that expansion of health insurance to recently migrated permanent resident children and pregnant women was not associated with migration from other states.[45]

Admittedly, there are no specific data on the migration patterns of dialysis-dependent undocumented patients. Nevertheless, while it cannot be definitively said that RRT expansion will not lead to individuals moving to states specifically for RRT, the available evidence suggests that migration is fueled by a complex array of socioeconomic factors and is unlikely to be motivated solely by ESRD treatment options.

Finite Organ Pool

A third objection is a nationalist one, namely, that states have no inherent obligations towards noncitizens.[46] This argument is often extended to kidney transplantation, particularly in the context of limited organ availability. However, many undocumented immigrants have potential living kidney donors and would not necessarily be "taking" an organ from the pool.[47] There is thus little reason to restrict undocumented immigrants from receiving live donor transplantations, particularly given the long-term cost savings and overall benefits of transplantation. Furthermore, when considering deceased donor organs, it is true that such organs are indeed finite. Nevertheless, there are justice-based arguments for permitting undocumented immigrants to being able to receive deceased donor organs, given that undocumented immigrants contribute to the available donor pool. While the number of organs donated by undocumented immigrants is unknown, data from the United Network of Organ Sharing (UNOS) and the Organ Procurement and Transplantation Network (OPTN)

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suggest that undocumented immigrants provide more organs than they receive.[48]

Policy Strategies and Potential Solutions

Several federal policy changes could improve the landscape for ESRD treatment for undocumented populations, including allowing reimbursement for non-emergent care for undocumented immigrants through federal Medicaid funds or extending Medicare ESRD coverage to undocumented immigrants. A federal policy on RRT would help alleviate the complexity in obtaining funding for this care at the local or state level and would reduce the burden on states with higher numbers of undocumented immigrants. Scheduled dialysis and renal transplantation both have demonstrated cost savings and health benefits over emergency dialysis, which federal funds currently help pay for.

Nevertheless, such federal reform appears unlikely in the current political climate. Thus, the burden is likely to fall to states to address the ethical shortcomings of ESRD policy. In what follows, we outline recent state-level innovations, including the adoption of scheduled dialysis and renal transplantation coverage for undocumented immigrants. These programs can serve as a blueprint for other states, who frequently look to one another when crafting their own policies.[49]

Colorado

Colorado is the most recent state to classify ESRD as an emergency medical condition, allowing undocumented immigrants to receive scheduled dialysis at dialysis centers.[50] This policy change went into effect on February 1, 2019. Any individual who meets eligibility requirements but not citizenship requirements for full Colorado Medicaid benefits is eligible for scheduled dialysis through Emergency Medicaid. Home dialysis and renal transplantation are not covered under this policy change. Preliminary estimates suggest that switching from EOHD to scheduled dialysis could save about $17 million per year in state Medicaid funds.[51]

Arizona

Arizona more explicitly defines dialysis as an emergency service, stating "emergency services include outpatient dialysis services for a person with End Stage Renal Disease (ESRD) where a treating physician has certified that in his opinion the absence of receiving dialysis at least three times per week would reasonably be expected to result in placing the patient's health in serious jeopardy, serious impairment of bodily function, or serious dysfunction of a bodily organ or part."[52] Thus, as in Colorado, Arizona is able to use Medicaid funding to provide undocumented immigrants with scheduled dialysis.

Illinois

Illinois also classifies ESRD as an emergency medical condition and pays for the treatment of such conditions if the individual meets Medicaid eligibility requirements other than citizenship.[53] In addition, as mentioned previously, Illinois covers renal transplantation for eligible undocumented immigrants through Medicaid funds.[54] A *Chicago Tribune* article following this legislation notes that "the cost savings ultimately persuaded legislators and the Illinois Department of Healthcare and Family Services to support the law."[55]

In addition to the transplant surgery, the program covers necessary care following the transplantation, including immunosuppressant medication and follow-up visits.[56] Some challenges associated with this legislation include the low reimbursement provided for renal transplantation in undocumented patients and the single bundled payment meant to cover post-transplant care regardless of additional hospitalizations or physician visits.[57] This uncertainty in funding and reimbursement is likely to prevent some hospitals from performing these transplants.

California

California covers emergency services, pregnancy-related services, and occasional long-term care for undocumented immigrants through a restricted scope Medi-Cal program for those who meet income and other eligibility requirements but do not meet immigration requirements.[58] By defining dialysis as an emergency service, California is able to use state Medicaid funds to cover scheduled dialysis for undocumented immigrants.[59] As in Illinois, the decision to fund scheduled dialysis for these patients was made because of the potential cost savings.[60] California has also provided renal transplants to some undocumented immigrants, although specific information on transplant eligibility and related coverage is not easily accessible on either the Medi-Cal or California Department of Health Care Services websites.[61]

Texas

Unlike the other states discussed in this section, Texas does not currently have a statewide program for undocumented immigrants with ESRD. However, it is included here because the state has the second largest population of undocumented immigrants with ESRD. In the absence of a state policy, cities and counties have developed a number of innovative solutions to care for

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the undocumented population. These solutions may be a useful guide for health care systems located in states in which state-level legislation providing scheduled dialysis may not yet be politically feasible.

In larger cities, undocumented immigrants can receive scheduled dialysis funded either by city health systems, such as Harris Health in Houston and CareLink in San Antonio, or by off-exchange insurance plans. Though the ACA does not permit undocumented immigrants to purchase health insurance on state exchanges, several cities in Texas have had success in enrolling these patients in off-exchange plans. Financial assistance for premium payment from the American Kidney Fund (AKF) allows low-income undocumented immigrants to enroll in these plans, which are not eligible for financial subsidies.[62]

Challenges in the provision of scheduled dialysis through city funds and off-exchange plans include instability in plan availability, limited number of providers willing to accept this form of insurance, and changes in some states' policies to prevent the use of charitable funds to pay insurance premium costs. Without this assistance, these plans would be unaffordable for the majority of undocumented immigrants.[63]

Takeaways from State Programs

These experiences suggest several lessons from state-based reforms. First, including scheduled dialysis as a covered emergency service can enable undocumented immigrants to access this service through Medicaid funds. This is likely a more stable solution compared to alternate workarounds including reliance on off-exchange ACA plans, state Medicaid waivers, charity dialysis, and county funds, which are all more likely to fluctuate year to year. Furthermore, examples from states with established RRT programs indicate that such programs can be fiscally justifiable. For example, initial data from Colorado suggests cost savings from providing scheduled dialysis. While additional data is needed to assess the longer-term cost implications, that other states such as California have provided scheduled dialysis and renal transplantation to undocumented immigrants for several years suggests these models can be sustainable. Further research is needed to explore the cost-benefit implications from state-level expansions.

Second, while immigration and undocumented immigrants are contentious issues at the local, state, and federal level, progress on RTT coverage for undocumented patients can nevertheless be made in a divided political environment, as demonstrated by Colorado's recent policy change. Evidence of long-term cost savings, if substantiated, would likely advance the bipartisan case for expanding RRT coverage for undocumented immigrants in other states.

Finally, while reform at the state level is ethically preferable to the status quo, the aforementioned complexities related to fragmentation will likely limit the degree to which state-level reforms can provide a comprehensive solution. Consequently, the ultimate remedy will likely require federal action to enact sustainable and equitable coverage for undocumented immigrants. Nevertheless, state-level reforms merit further exploration, both as a temporary remedy, and to provide models for future federal revision.

Going forward, existing statewide programs should provide clear, easily accessible information on implementation and data on costs and savings. Cost-benefit data would be particularly useful for individuals hoping to establish programs in less politically amenable states. Expanded federal coverage for undocumented immigrants with ESRD would help reduce the statewide variation and complexity in funding for dialysis.

Conclusion

Many of the estimated 6,500 undocumented immigrants with ESRD in the United States rely on EOHD. In order to receive care, they must demonstrate severe clinical findings, including high potassium levels and uremia. There is growing evidence that EOHD is associated with poor health outcomes and increased cost compared to scheduled dialysis. This paper discussed several ways in which the practice of EOHD violates several core principles of medical ethics. Physicians providing emergency dialysis are unable to fulfill their fiduciary duty to their patients, practice within established professional guidelines, or follow appropriate resource stewardship. Statewide programs can help address the ethical shortcomings of EOHD policies. In states without these programs, scheduled dialysis cov-

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erage at the local level often relies on county taxpayer funds and charity care. Going forward, existing statewide programs should provide clear, easily accessible information on implementation and data on costs and savings. Cost-benefit data would be particularly useful for individuals hoping to establish programs in less politically amenable states. Expanded federal coverage for undocumented immigrants with ESRD would help reduce the statewide variation and complexity in funding for dialysis.

Note

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