Kidney Care for Vulnerable Populations

Executive Summary

The challenge of providing optimal kidney disease care to all individuals living in the U.S. persists and continues to grow. This position paper discusses the characteristics of the uninsured and underinsured citizen and non-citizen populations receiving end-stage kidney disease (ESKD) treatment, outlines the current status of public benefits available to these individuals on the national and state level, and explores the ethical issues these circumstances present to nephrologists and dialysis facilities treating these patients.

The RPA believes that the federal government has a responsibility to provide care for all patients within the borders of the United States, and that the financial burden of uncompensated care provided to citizens and non-citizens should be a shared national responsibility. The RPA also believes that a growing body of evidence suggests the patchwork pattern of state coverage policies has, in aggregate, led to poor health outcomes including increased mortality, in these vulnerable patients—while simultaneously burdening states with exorbitant health care costs. In order to remedy this problem, the RPA believes all citizens and non-citizens afflicted with ESKD should be eligible for Medicaid to cover optimal care if they do not have insurance coverage or resources to pay for it otherwise. This approach, though currently applied in a minority of states, has been proven to result in improved health outcomes, cost savings and adheres to the ethical principles of justice and beneficence.

Principles

1. All health care professionals and health care systems are obligated to treat the sick.
2. The federal government has the ethical and fiscal responsibility to provide health care for people within U.S. borders.
3. The financial burden of ESKD patient care should be a shared national responsibility and not fall disproportionately on those states with the greatest population of uninsured / underinsured citizens or non-citizens.
4. All citizens and noncitizens with ESKD who do not have insurance or resources to pay for healthcare should be eligible for federal funding to allow them to receive the same care as would be available to people with Medicaid.
5. Because of the confidential nature of the patient-physician relationship, nephrologists should not be expected to act as agents for the U.S. Immigration and Customs Enforcement Agency by reporting undocumented non-citizens.
Background

As the consequences of the profound changes in federal budgetary priorities in the United States have continued to evolve in the early 21st century, many members of society who are already financially disadvantaged have become increasingly marginalized, further increasing disparities in access to care. Among these at-risk populations are citizens who either cannot afford or choose not to obtain health insurance, and the portions of the nation’s non-citizen population, including undocumented immigrants, minors born in the U.S. to undocumented immigrants, temporary workers, students on visas, and visitors. Legislative initiatives such as the Affordable Care Act (ACA) have significantly reduced the number of uninsured individuals in the U.S. and the amount of uncompensated care provided. However, fragmented implementation of the law has limited its potential positive impact. In addition, the ACA specifically excludes payment for the care of non-citizens.

For U.S. citizens and non-citizen patients with chronic kidney disease (CKD), including ESKD, the limitations in health care coverage can have grave consequences. Moderate and even advanced CKD is a silent disease that disproportionately affects marginalized segments of society who do not receive preventive healthcare. As a result, under or uninsured individuals with CKD condition are more likely to suffer progressive CKD, eventuating in ESKD. The primary treatment modalities for patients with ESKD are dialysis or kidney transplantation. Dialysis is prescribed for those with irreversible kidney failure and is not an elective procedure. Patients with ESKD must receive this therapy to survive. Once diagnosed, patients with ESKD typically undergo several dialysis treatments per week in an outpatient setting for the remainder of their lives, if they cannot receive a kidney transplant. Impeded access to or denial of scheduled outpatient dialysis services has been linked to a five-fold increase in mortality in the first year of ESKD and a fourteen-fold increase over five years compared to those with insurance and regular access to dialysis care.¹,²

Treatment of these uninsured patient populations results in significant financial hardship for dialysis facilities and hospitals, and may threaten their financial stability. The care of these patients falls disproportionately on to public, non-profit health systems and to a lesser extent on for-profit hospital systems, as for-profit dialysis providers have generally not provided this form of uncompensated care. These issues are morally complex, time consuming and may place the physician at odds with hospital and dialysis center administrators.

Analysis

Citizens Receiving Uncompensated Care

Uncompensated care is health care that is delivered, but not paid for by either a patient or a third-party payer. Citizens receiving uncompensated care generally fall into two groups: those with annual incomes above 138% of the federal poverty level (FPL), and people living at or below the poverty level. Some people in the first category, will be unable to
obtain private health insurance, because of the rapidly rising costs. When those individuals become ill, health care costs are absorbed by providers, taxpayers, and state governments. Costs are then shifted to the insured and governments resulting in higher premiums and/or taxes.

In states that have chosen to expand Medicaid enrollment under the ACA, citizens earning up to 138% of the FPL are eligible to enroll. Unfortunately, estimates suggest that 27% of potential Medicaid enrollees in expansion states (currently 37 including the District of Columbia) do not choose to enroll. This population of “eligible but uninsured” is disproportionately impoverished, persons of color and employed. Though eligible for insurance, these individuals end up contributing to the cost-shift or “hidden tax,” which results in higher premiums for the insured.

Overall, the ACA has significantly reduced the number of uninsured persons in the United States. The most recent U.S. Census report states that 8.5% or 27.5 million individuals were without health insurance for 2018. By contrast, in 2013, that number was 13.4% or 43 million. The exact degree to which the ACA is responsible for this change is unclear, but some estimates suggest that expansion states reduced the uninsured portion by ~ 6% due to the ACA.

Most uncompensated care is delivered to the very ill during or after a visit to an emergency department, and hospitals provide the bulk of uncompensated care. The American Hospital Association (AHA) reports a total of $38.4 billion in provided uncompensated care in 2017, using a conservative cost basis metric. This is a significant reduction from 2013, the year prior to Medicaid expansion under the ACA, when uncompensated care cost $46.8 billion. A report from the Commonwealth Fund suggested hospitals in Medicaid expansion states serving the uninsured saw the greatest reduction in uncompensated care costs. While the overall picture post ACA suggested reduced uninsured rates and an arrest in the rise of uncompensated care costs, the percentage of uninsured actually rose slightly in 2018 versus 2017. This suggests that ACA effects have likely peaked barring significant further expansion of Medicaid in the remaining 14 states. Also concerning is the tenuous political future of the ACA with persistent threats of repeal and the absence of a viable alternative coverage plan.

Non-Citizens Receiving Uncompensated Care

The non-citizen population is made up of legal permanent residents (defined as aliens who have been legally accorded the privilege of residing permanently in the U. S. as an immigrant in accordance with the immigration laws), and undocumented alien residents (aliens residing in the U. S. who have not entered as immigrants in accordance with the immigration laws). The nation’s undocumented non-citizen population peaked at 12.2 million in 2007 and, in the wake of the financial crisis of 2008 and changes in U.S. immigration policies, declined to 10.5 million in 2017 according to the Pew Research Center’s most recent published data. Additional Pew Research Center data shows that 6.5 million or 61% of these non-citizens are concentrated in 20 major metropolitan areas. This concentration has been consistent over the prior ten years and demonstrates that the burden for care for these non-citizens is focused in these
metropolitan centers. Estimates are that about 6,500 of those undocumented immigrants have ESKD, which typically developed after more than 10 years in the U.S.\textsuperscript{11}

The Emergency Medical Treatment and Active Labor Act (EMTALA) enacted in 1986, requires every U.S. hospital emergency department to treat anyone who enters with an “emergency”, which can include conditions ranging from a headache to cardiac arrest. Subsequently, the Personal Responsibility and Work Opportunity Act of 1996 (the Welfare Act) allowed emergency services such as outpatient dialysis for undocumented immigrants to be paid through state Medicaid programs. However, in 2001 the federal government reversed course and mandated that emergency care to undocumented immigrants would only be paid for in emergency departments via EMTALA. The result of these policy twists and turns is that outpatient dialysis payments were eliminated in most states for this patient population. Though state Medicaid reimburses emergent dialysis under EMTALA, only a small minority of states provide payment of outpatient, non-emergent dialysis to undocumented immigrants. Even in the latter case, however, these payments are often to the dialysis facility only - providers may not be compensated for patient care. This cycle of suboptimal care leading to predictable poor health outcomes creates “moral distress” for practitioners and is a significant contributor to their “burnout”.\textsuperscript{12}

Public Benefits for U.S. Citizens: Current Situation

Public coverage includes Medicaid, which is administered by the states within broad federal guidelines, with financing being shared by states and the federal government. As a jointly funded venture between federal and state governments, CMS allows each state, within federally-established national guidelines, to: 1) establish its own Medicaid eligibility standards; 2) determine the type, amount, duration, and scope of Medicaid-covered services; 3) set the rate of payment for such services; and 4) administer its own program. Medicaid coverage is primarily available to low income children, parents, pregnant women, people with disabilities, and the elderly. Most nondisabled adults under age 65 who do not have dependent children are not eligible for Medicaid. Due to the Supreme Court ruling in 2012, Medicaid expansion under the ACA was made optional for states. As of late 2018, 34 states plus Washington, DC, had expanded Medicaid under the ACA, and three states have approved expansion via ballot initiative but have not yet implemented.\textsuperscript{13} As noted previously, significant reductions in uninsured non-elderly adults have occurred from the 2010 peak of 46.8 million to the current 38.4 million.\textsuperscript{4} States adopting ACA Medicaid expansion outpaced non-adopters in terms of percentage reduction of prevalent uninsured.

The effects of Medicaid expansion relative to ESKD patient outcomes have largely been understudied. However, three recent studies have attempted to evaluate the effects of ACA Medicaid expansion programs. The first of these observational studies reviewed mortality in incident ESKD patients in Medicaid expansion states versus non expansion. In this study, expansion was associated with a relative mortality reduction of 11.5% with younger and minority patients seeing the largest gains.\textsuperscript{14} Similarly, Harhay compared transplant listing rates and actual transplants performed in Medicaid expansion states versus non-expansion states and found significant increases in both transplant listings and actual performed transplants in
expansion states.\textsuperscript{15, 16} While these studies are observational in nature, this is the first evidence that expanded insurance benefits patients in the dangers transition to ESKD period as well as provides enhanced access to the superior therapy of kidney transplant.

Inherent characteristics of the Medicaid program make providing effective health care to marginalized patient populations difficult; this applies to both citizens and non-citizens. As noted above, variability in state determinations of eligibility, benefits, and reimbursement have resulted in a patchwork public safety net. Theoretically, this arrangement is intended to provide each state with the flexibility to provide health care to its neediest patients as it deems appropriate. However, use of such a patchwork system hampers efforts to address improving health care for these vulnerable individuals on a national level. This situation is exacerbated in states that have chosen to not expand their Medicaid programs.

Individuals with coverage through a state Health Insurance Exchange Qualified Health Plan (QHP) can remain in that plan when they develop ESKD. Language from the Exchange Final Rule, released in March 2012, states: “We note that neither the proposed nor final rule state that individuals will automatically be terminated from Exchange coverage should they be found eligible for Medicare.” Individuals who choose to remain in their QHP and enroll in Medicare should be aware that they may lose their eligibility for premium subsidies. However, premium subsidies should be maintained until actual Medicare enrollment.

Public Benefits for Non-Citizens: Current Situation

Providing health care to non-citizen patient populations in the U.S. is more complex than for other populations due to a variety of societal and demographic factors, as well as the nature and guidelines of the Medicaid program itself. Among the societal circumstances complicating care delivery to these individuals are language barriers, poor nutritional status, and fear of deportation. The lack of funding for medications and essential allied services results in suboptimal care for complex conditions. The non-uniform, nodal distribution of the non-citizen population disproportionately burdens a small but growing number of states and localities. Health care coverage options are further limited by the ACA which explicitly excludes coverage to undocumented immigrants.

In 1996, the aforementioned Welfare Act, and the “Illegal Immigration Reform and Immigration Responsibility Act of 1996” (the Immigration Reform Act) altered the landscape by dramatically restricting access to public benefits by legal and undocumented immigrants, by raising the admissibility standards for prospective immigrants and by increasing the financial responsibility of petitioners for family and employment based immigrants.

The Welfare Act: 1) renders illegal immigrants explicitly ineligible for a broad set of federal public benefit programs, and for state and local public benefit programs; 2) requires states to pass legislation in order to provide benefits to illegal immigrants; and 3) allows states to decide to bar from entry into the Medicaid program qualified aliens (category of aliens including lawful permanent residents, refugees, asylees, and others). The Welfare Act not only bars undocumented immigrants from receiving federal public benefits, but also creates barriers
preventing other governmental entities from providing these services. The combined effects of
the Welfare Act and the Immigration Reform Act was the reduction of access to the public
benefit safety net even for documented aliens.

For non-citizen patients requiring dialysis for ESKD, the cumulative effect of the Medicaid
program’s state-specific eligibility requirements and the Welfare Act’s restrictions has been to
create wide state to state variability in the level of kidney care. Access to dialysis through the
use of expanded emergency Medicaid (permissible under the Welfare Act) has allowed
noncitizen dialysis patients in 12 states and the District of Columbia to receive outpatient
dialysis care. However, policies such as these are present in a minority of states and many, if
not most non-citizens, receive dialysis in emergency-only situations as dictated by EMTALA with
the attendant poor health outcomes noted previously. These legislative and regulatory
restrictions have created life-threatening double standards of care, not only on a state-by state
basis but also within jurisdictions such that some members of at-risk patient groups receive
regular maintenance dialysis treatments while others do not.

Other consequences of limited federal responsibility for non-citizen health care include shifting
both costs and health care coverage eligibility decisions to state and local entities. The net effect
is to put nephrology practitioners between the rock of their ethical obligation to treat all patients
to the highest standard and the hard place of few or no resources to do so.

Pediatric Patients with ESKD

These complex coverage issues are amplified when one considers the situation of
uncompensated care for children with ESKD. While the pediatric dialysis population is small,
there is substantial difficulty in providing ESKD services for children, especially infants and
young children, who have no access to health care coverage (e.g., undocumented immigrants).
Their care is best provided in pediatric dialysis facilities, which are generally part of a hospital,
and often a free-standing children's hospital. The cost of providing dialysis for children is
greater than for adults, so even if emergency Medicaid funding were available, it would cover a
small fraction of the actual cost of a child's care. In addition, only hemodialysis is covered by
emergency Medicaid, thereby denying children access to peritoneal dialysis, which is often a
superior form of renal replacement therapy for pediatric patients.

Ethical Issues Facing Nephrologists and Dialysis Facilities

While legislative changes limiting health care access and restricting public benefit eligibility for
citizens and non-citizens have some impact on all health care providers, the dilemma
nephrologists face is particularly profound. The outpatient population treated by nephrologists is
the most medically complex of all specialty patient populations, and without dialysis, these
patients will die once their kidneys fail.

Among the ethical questions facing nephrologists and dialysis facilities are:
• Is it ethical to essentially compel the provider to deny dialysis services to uninsured citizens and non-citizens?

• Is it ethical to provide substandard care to one group of patients just because they are unable to pay for their care?

• Should a provider of dialysis services deny care to an individual based on that person’s ability to pay?

• Does the nephrologist or dialysis facility have a responsibility to report information regarding a patient’s citizenship status to governmental entities?

Regarding the last question, the AMA *Code of Medical Ethics* states that “Physicians … have an ethical obligation to preserve the confidentiality of information gathered in association with the care of the patient.” The trust thereby engendered is essential to the therapeutic relationship. If the patient’s immigration status is divulged by the patient to the physician and is included in the medical record, transmission of that information to anyone without a need to know for purposes of medical care must be considered a breach of medical ethics. California’s Proposition 187 would have required physicians to divulge their patients’ immigration status to state authorities but was declared unconstitutional for other reasons.

There are compelling reasons to provide both dialysis and the full range of renal-related services to all patients with ESKD, regardless of ability to pay or citizenship status. Perhaps the most basic is the humanitarian claim that a just society is responsible for caring for those who are in need, and that patients with ESKD should receive dialysis and all essential related care based on their medical need. One might argue that, notwithstanding these fundamental ethical principles of beneficence and justice, undocumented alien status disqualifies those patients from such consideration because they are not full-fledged members of society. Denying life preserving treatment to this population in our midst, however, may be seen as the ethical equivalent of permitting death by “starvation or murder”. Others might argue that, in a just society, benefits accrue to those who contribute. In that regard, it is worth noting that undocumented immigrants contribute more than $11 billion a year in state, local and federal taxes, and utilize fewer public resources than citizens.

The humanitarian and ethical values that guide nephrologists and dialysis facility staff to provide life-saving therapy to all individuals with ESKD who want it needs to be balanced; however, by the pragmatic concern that some dialysis facilities or hospitals, especially those in low income or high intensity immigration areas, cannot remain financially viable if they accept all individuals regardless of ability to pay. Dialysis facilities or hospitals that jeopardize their financial status by providing a high volume of uncompensated care do a disservice to their paying patients who have a legitimate claim to receive dialysis treatments and other health care services. Thus, while the ethical principle of justice requires that nephrologists, hospitals, ancillary care providers and dialysis facilities provide state-of-the art care for financially disadvantaged patients, the principle of prudence requires that they be adequately compensated for this care so they preserve their ability to provide quality dialysis care for their other patients.
On a pragmatic level, providing the standard level of ESKD care to non-paying citizens and noncitizens will prove to be a prudent decision in the long run. Already, providing standard outpatient dialysis has resulted in significant cost-savings versus emergency only dialysis. In addition, the undocumented immigrant population has a high employment rate; more than 90% of working-age men are employed and those with ESKD skew younger with fewer comorbidities / barriers to employment than U.S. citizens with ESKD. Providing improved health outcomes will allow these patients to return to work sooner and care for their dependents – the unrealized aim of the original 1972 landmark ESKD coverage legislation.

In conclusion, the ESKD population remains one of the most medically complex and expensive populations in health care. Vulnerable populations – both citizens and non-citizens without adequate insurance coverage, continue to make up a significant portion of the ESKD cohort. These patients suffer unacceptable mortality rates versus insured peers. Either as a component of the ACA or without, expansion of Medicaid programs to cover outpatient dialysis services has proven to be lifesaving while also reducing costs for taxpayers through reduction of expensive inpatient services. RPA believes the federal government is obligated to provide the framework to implement these common-sense policy approaches nationwide.

References


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