New Opportunities for Funding Dialysis-Dependent Undocumented Individuals

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Abstract

The cost of dialysis for the estimated 6500 dialysis-dependent undocumented individuals with kidney failure in the United States is high, the quality of dialysis care they receive is poor, and their treatment varies regionally. Some regions use state and matched federal funds to cover regularly scheduled dialysis treatments, while others provide treatment only in emergent life-threatening conditions. Nephrologists caring for patients who receive emergent dialysis are tasked with the difficult moral dilemma of determining "who gets dialysis that day." Without a path to citizenship and by exclusion from the federal marketplace exchanges, undocumented individuals have limited options for their treatment. A novel opportunity to provide scheduled dialysis for this population is through the purchase of insurance off the exchange. Plans purchased off the exchange must still abide by the 2014 provision of the Patient Protection and Affordable Care Act, which prohibits insurance companies from denying coverage based on a preexisting health condition. In 2015 and 2016, >100 patients previously receiving only emergent dialysis at the two largest safety-net hospital systems in Texas obtained off-the-exchange commercial health insurance plans. These undocumented patients now receive scheduled dialysis treatments, which has improved their care and quality of life, as well as decompressed the overburdened hospital systems. The long-term sustainability of this option is not known. Socially responsive and visionary policymakers allowing the move into this bold, new direction deserve special appreciation.

Clin J Am Soc Nephrol 12: 370–375, 2017. doi: 10.2215/CJN.03680316

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"In the long history of humankind (and animal kind, too) those who learned to collaborate and improvise most effectively have prevailed." Charles Darwin (1809–1892)

Opening Scenario: December 3, 2015

SL is a 49-year-old Kenyan woman with kidney failure who has been dialysis dependent since 2002. She had come to Houston in 2001 on a visitor's visa, with her husband and 2-year-old son. She became acutely ill during this visit and was initiated on dialysis. Since then and for the past 14 years, SL has presented to the Emergency Department (ED) with uremic symptoms at least once a week, asking to be dialyzed. Her family drops her off by 4:30 a.m. The ED screening physician then makes a decision based on a rudimentary physical examination and a set of basic screening tests: serum electrolytes, blood oxygenation, and a 12-lead electrocardiogram. If she has pronounced hyperkalemia (>6.1 meq/L) or hypoxia (oxygen saturation <92%) due to volume overload, then she is considered to qualify for one emergent dialysis treatment. Otherwise, she is sent home and told to return another day. For now, SL waits patiently in the ED alongside 10–15 other similar patients, all of whom are hoping for one thing: a single dialysis treatment that day.

Background

Of the 12 million undocumented individuals living in the United States, an estimated 6500 individuals have kidney failure requiring chronic dialysis (1). About 65% of practicing nephrologists in academic and private centers provide care to these individuals; much of this service is uncompensated or inadequately reimbursed (2). Nephrologists caring for these patients face unique challenges that include: inadequate predialysis care, inability to obtain permanent vascular access, incapability to schedule dialysis treatments, and powerlessness to provide affordable access to medications. Although for many patients dialysis is a bridge to transplantation, sadly, undocumented individuals are often excluded from transplantation despite the fact that several of them are excellent transplant candidates due to their better overall health, younger age, and available potential donors (3).

Public policies to provide health care for noncitizens began with the Migrant Health Act, signed by President John F. Kennedy in 1962. This authorized delivery of health care to the 4.6 million individuals who came to the United States to provide inexpensive labor following the Second World War (Figure 1). This act subsequently led to the development of Federally Qualified Health Centers. Currently, >1000 such centers provide comprehensive primary care to >20 million uninsured or undocumented individuals annually (4). Unfortunately, when these individuals develop chronic illnesses that fall under neither primary nor emergency health care (such as chemotherapy, joint replacement for severe arthritis, or dialysis), there is no uniform or rational solution—only difficult ethical predicaments (5).

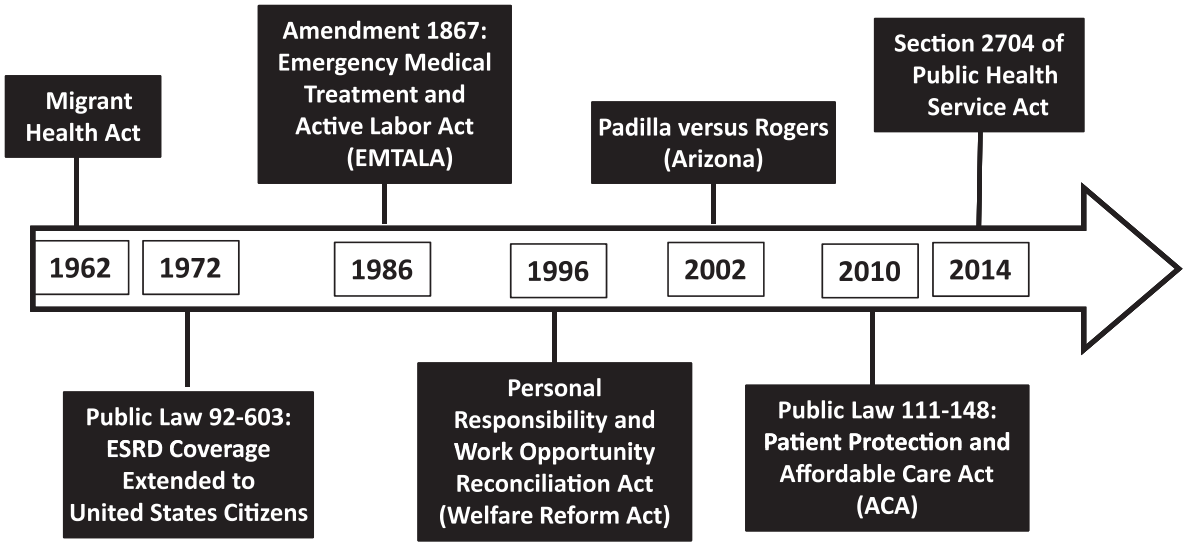

Figure 1. | **Timeline of pertinent legislation and events related to dialysis-dependent undocumented immigrants**.

In 1972, Congress passed Public Law 92–603 amendment to the Social Security Act, extending ESRD coverage to all individuals who had (or were the spouse or dependent of someone who had) worked long enough to qualify for Social Security benefits (Figure 1). This singular act covering dialysis and kidney transplantation has led to longer and more productive lives for millions of Americans. Undocumented individuals, even those who may have contributed to social security, are excluded from this coverage. The origin of emergent dialysis stems from amendment Section 1867 to the Social Security Act (Figure 1). This amendment, passed in 1986 and referred to as the Emergency Medical Treatment and Active Labor Act, requires that a patient who comes to an ED with an emergent medical condition be provided with treatment (such as dialysis) until stable or transferred to another hospital. It is under this provision that undocumented individuals have qualified for emergent dialysis (6).

A major and disconcerting ethical quandary is the practice of emergent dialysis, which forces care providers into making difficult and unjustifiable ethical decisions, such as "who deserves treatment that day." Nephrologists caring for this population advocate for their patients often by bending the rules or "working" the system (7). Providers and hospital systems are tempted to persuade patients dependent on dialysis to relocate to another state or to their home country (repatriation). Although this is often done with good intent, it separates patients from their loved ones and communities, while simultaneously straining existing overburdened health care systems elsewhere.

In some states, notably California, undocumented patients receive regularly scheduled dialysis treatments that are covered by state and matched by federal resources (Medicaid). California chooses to provide dialysis to the undocumented as a result of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, also referred to as the Welfare Reform Act (Figure 1), the federal law that allows individual states to decide what outpatient services to provide noncitizens.

Regional variation has also been influenced by legal action. In 2002 in Arizona, a trio of undocumented dialysis-dependent individuals filed suit to overturn a state policy that disallowed outpatient dialysis for undocumented individuals (Figure 1). A preliminary injunction was granted, and in 2007 Arizona restored its policy of providing regularly scheduled outpatient dialysis to undocumented individuals with kidney failure (8).

Cost of Emergent Dialysis for Undocumented Patients

The cost of patients receiving emergent dialysis in Houston is nearly four times more than those receiving scheduled dialysis: $285,000 versus $77,000 per year (9). Undocumented patients admitted to two safety-net hospitals in New York City to initiate dialysis incurred a 29% higher cost when compared with United States citizens admitted for the same reason (10). The Centers for Medicare and Medicaid Services classifies such cases as superutilizers, defined as "a patient who accumulates large number of ED visits and hospital admissions which might have been prevented by relatively inexpensive early interventions and primary care." From 2011 to 2012, 3% of superutilizers at the primary safety-net hospital in Denver, Colorado, accounted for 30% of total charges. Not surprisingly, recipients of emergency dialysis were identified as superutilizers and their average annual cost ($400,000 per patient) was the highest of the superutilizer subgroups (11).

In the absence of a federal policy to revise or reform the 1996 Welfare Reform Act or ratify comprehensive immigration reform, nearly all dialysis-dependent undocumented individuals will remain excluded from the standard avenues of care. Given the current political climate, the likelihood of such policy changes occurring is minimal. It is against this backdrop of expensive, local, patchwork solutions for providing care to a vulnerable population that an unexpected solution has emerged: private insurance purchased off the marketplace exchange.

Health Insurance for Undocumented Individuals Requiring Dialysis

Undocumented individuals are ineligible for all federal insurance programs because they are not legal residents or citizens of the United States. Approximately 29% of undocumented individuals acquire private health insurance through their employer. The remaining 71% comprise a large portion of the 33 million uninsured individuals in this country (12). Of the four states with the most undocumented residents (California, Texas, Florida, and New York), Texas has the highest rate of uninsured undocumented individuals at 75%.

The federal Patient Protection and Affordable Care Act (ACA; Public Law 111–148) was adopted on March 23, 2010 (Figure 1). As it stands, the ACA marketplace exchanges are government sponsored and specifically disallow anyone who is not a legal United States citizen to purchase insurance. Although there have never been federal regulations prohibiting the sale of private insurance to undocumented individuals, insurers previously denied those with certain chronic illnesses from purchasing a commercial insurance plan. Beginning January 1, 2014, Section 2704 of the Public Health Service Act (added by the ACA; Figure 1), prohibited health plans and health insurance issuers offering group or individual health insurance coverage from imposing any preexisting condition exclusion (13,14). It is this provision that made it possible for dialysis-dependent undocumented individuals to purchase insurance plans off the marketplace exchange.

Off-exchange plans can be purchased directly from a carrier or through an agent or broker. Legal residents rarely purchase off-exchange ACA plans, since these plans are ineligible for the government subsidies that significantly reduce the monthly premiums. The monthly premiums for most off-exchange plans range from $250 to $900 per person, a price that varies by state, individual income level, and by tier of plan purchased. In general, this is prohibitively expensive for undocumented individuals, 40% of whom have annual incomes that are 138% below the Federal Poverty Level of <$16,000 for an individual or <$34,000 for a family of four. Nearly 81% of the undocumented individuals without health insurance are within this income range (12).

The American Kidney Fund (AKF) is a publically supported, nonprofit organization that provides financial assistance to cover expenses related to dialysis treatment and CKD prevention programs. The AKF currently assists nearly 93,000 (one in five) patients on dialysis in this country (15). According to their publicly available annual report, the AKF spent $206 million on direct patient care in 2013 (15). The third party payment system by the AKF makes it possible for needy dialysis patients to afford the premiums and retain their commercial insurance plan. Nearly all of the dialysis-dependent undocumented individuals with new off-exchange insurance plans qualify for charitable support from the AKF due to low income levels. The AKF continues to provide support as long as the patient remains under the care of participating dialysis centers, which in turn are financial supporters of the AKF. The reimbursement is sent directly from the third party to the insurance company on behalf of the needy patient; in some instances, the check is sent to the patient, who uses this to pay the insurance premium.

Starting in 2014, major insurance carriers in many states began to reject third party insurance premium payments, citing concerns that charitable assistance to chronically ill individuals skews the marketplace exchange risk pool. If major insurance carriers deny patient assistance from third party payers, such as the AKF, this will have far-reaching consequences for thousands of patients on dialysis. The Centers for Medicare and Medicaid Services (CMS) plan to address nonprofit premium payments in future rulemaking (16).

This occurrence of undocumented dialysis-dependent individuals purchasing off-exchange insurance was first described in Illinois in 2014; and in conversations with nephrologists around the country, it occurs elsewhere but is neither widely publicized nor utilized (17).

The Texas Experience with Off-Exchange Plans

Parkland Health and Hospital System in Dallas and Harris Health in Houston represent the two largest safety-net hospital systems in Texas, and two of the five largest in the United States (18). Both cities have a large undocumented immigrant population and an already overburdened hospital system. In the Harris Health safety-net system, undocumented individuals account for 14% of total operating and up to 25% of uncompensated care costs (19). Since 2002, the average monthly census of emergent dialysis patients in Houston has been about 90 patients, who account for about 16 dialysis treatments and up to 15% of hospital admissions each day. Each patient on emergent dialysis receives an average of three to four treatments per month.

The Texas experience with off-exchange plans is new, but very exciting. During the 2015 open enrollment period (November of 2014 to February of 2015), >100 undocumented individuals dependent on emergent dialysis in Dallas purchased insurance off-exchange. The purchased commercial plan was through one major insurance carrier, Blue Cross Blue Shield of Texas. Remarkably, 1 year later, there has been no reported defaulting on the policies of these patients. In January of 2016, after learning of this policy, >30 undocumented emergent dialysis-dependent individuals in Houston, including SL, were enrolled in the same plan. In both cities, all patients were placed in Fresenius Medical Care dialysis units close to their homes. Many of these patients, like SL, had been receiving infrequent dialysis treatments for years. Because open enrollment typically occurs between November and February, all remaining emergent dialysis patients as well as new undocumented patients that commence dialysis in 2016 will only receive emergent treatments until the 2017 open enrollment period. However, patients may enroll in a plan off-cycle with the occurrence of certain life events, such as marriage or loss of current employer-based insurance.

Table 1 details the improvement in processes of care among the 32 Houston patients who began to receive scheduled dialysis between December 1, 2015 and February 1, 2016. The significant reduction in blood transfusions, ED visits, and

Table 1. Significant reduction in care utilization after insuring dialysis-dependent undocumented individuals in Houston, Texas

Background	September 1, 2015 to May 1, 2016	
No. of patients	32	
Average age (years)	43.6	
Hispanic (%)	97	
Men (%)	59	
Time on emergent dialysis	1.4 yr (511 d)	
Processes of care[a]	September 1 to December 1, 2015	February 1 to May 1, 2016
Emergency Department visits[b]	596	5
Total days hospitalized	101	19
Number of blood transfusions	33	3

Thirty two undocumented dialysis-dependent individuals previously receiving emergent dialysis obtained commercial health insurance and began to receive scheduled, maintenance hemodialysis on February 1, 2016. This resulted in a statistically significant reduction in utilization of Harris Health hospital resources. All comparisons are statistically significant (P value <0.05) using inverted β-binomial comparison testing.

[a]Insurance was obtained between December 15, 2015 and January 22, 2016. All 32 patients received only emergent dialysis for the 3 months preceding December 1, 2015.

[b]Only includes Emergency Department visits related to dialysis or anemia.

days admitted represent major cost savings to the county hospital system. In personal communication with several newly insured patients, their quality of life is now vastly improved.

To cite this experience with one example: EL is a 56-year-old man who had been on emergent dialysis since 2013. In a 3-month period between September 1, 2015 and December 1, 2015, he was admitted to the hospital three times, incurred 26 ED visits, and received four blood transfusions. After being enrolled in the new program in January of 2016, he has been receiving dialysis thrice weekly at an outpatient dialysis unit. In the 3 months following this change (February 1, 2016 to May 1, 2016), he has had zero admissions, ED visits, or blood transfusions. His current hemoglobin level is 11.2 g/dl due to regular treatment with erythropoietin stimulating agents. In his own words, "*Tengo mucha más energía. Por primera vez en años, me siento casi normal*" (I have so much more energy. For the first time in years, I feel almost normal).

Approximately 90% of the patients in Dallas and Houston who have taken advantage of this option receive in-center hemodialysis; the remainder have chosen peritoneal dialysis or home hemodialysis. Some vascular surgeons in the community accept these plans and have placed fistulas in patients previously dialyzing with a tunneled cuffed catheter. In communication with representatives from the dialysis organization, the negotiated reimbursement in Texas with this policy varies between $350 and $500 per treatment. The unadjusted published Medicare rate in 2014 was $240 per treatment (20).

Sustainability of Commercial Insurance Coverage for this Population

Insurance coverage for the very sick is based on the principle that large numbers of healthy individuals are in the risk pool and pay premiums. If individuals with advanced kidney disease disproportionately purchase a particular insurance plan that covers dialysis, then an insurer may stop offering, limit the product, or raise rates to cover the costs of dialysis. The purchase of off-exchange plans by undocumented individuals to cover dialysis services is a novel and creative solution to the national problem but is susceptible to market changes. Its sustainability will need to stand the test of time.

Undocumented individuals in Texas have been able to purchase insurance because enrollment in these specific plans did not require any of the following documentation: a valid work visa, passport, or social security number. Though the ACA is a federal policy, its legislation was based on 2006 health reform initiated in Massachusetts. Bulletin 2011–19 from the Division of Insurance (DOI) in Massachusetts explicitly states, "Carriers shall not refuse to issue or renew coverage to an applicant or a member solely because an applicant or member chooses not to provide a social security number" (21). The DOI in each state regulates all fully insured plans. An individual carrier has discretion in its underwriting guidelines to change or remove a policy, but such decision could face repercussions at the state level by the DOI. Fully insured policies are guaranteed for either a 6- or 12-month period; if an insurer does not renew the policy at the conclusion of this period, the patient is tasked with finding another policy.

For example, in 2015, the off-exchange policy purchased by the undocumented patients in Dallas was a Preferred Provider Organization plan. This policy was not available for new or renewing patients in 2016. Hence, patients enrolled into a Health Maintenance Organization plan offered by the same carrier that had a more limited choice in providers and services due to contractual agreements. Vigilance and creativity by dialysis facility administrators and social workers are essential for the continued coverage of these new plans.

Administrators at these dialysis units remain apprehensive that these policies could be terminated at any time. Two examples from personal experience that

threaten sustainability of this option for the undocumented population are: (*1*) the policies of nine of the 32 Houston patients did not begin to pay for dialysis treatments until 3 months after the enrollment date, hence, the dialysis center absorbed the cost during this time; and (*2*) if the premiums were not received by the insurance company due to third party processing delays or the patient retaining the money and not sending payment, the policy was terminated.

For now, this has been a life-changing experience for these patients who describe feeling like they are "*en un sueno*" (in a dream) from which they are afraid to wake up.

Finally, there is concern over undocumented patients' continued purchase of commercial plans to receive scheduled dialysis, particularly if dialysis centers and hospital systems currently providing charity or Medicaid-funded treatments decide to coerce their undocumented patients to obtain private coverage. If so, large numbers of chronically ill patients enrolling in one particular off-exchange plan could threaten its sustainability. One solution that has been proposed to this eventuality in California is the creation of a separate exchange specifically for undocumented individuals (22).

If these policies are no longer available for purchase or renewal in the 2017 enrollment period, what will be the ethical responsibility and moral commitment of the dialysis unit to continue providing dialysis treatments to their patient? The answer to these concerns is the reason for an urgent, sustainable solution to this national problem.

Conclusions

The United States is a nation of immigrants. Undocumented individuals are members of the community in which they live and there is a moral and fiscal obligation to provide them with adequate health care. As our nation scrutinizes its health care system and wrestles with immigration reform, the care of undocumented individuals with chronic diseases epitomizes the crux of the proposed national agendas. The burden has traditionally been shouldered by hospital systems in large cities, particularly those in close proximity to our southern border. Without a path to citizenship and by exclusion from the ACA marketplace exchanges, undocumented individuals have limited options. Herein, the novel ability to purchase private insurance off the marketplace exchange shifts costs away from overburdened hospital systems and provides a more humane way to treat dialysis-dependent undocumented individuals. The Texas experience has alleviated serious ethical dilemmas; it has been positive and rewarding to both patients and nephrologists. While economics and politics at both local and national levels will determine the long-term sustainability of this option, policymakers allowing the move into this bold, new direction deserve special thanks.

Closing Scenario: February 1, 2016

SL now receives scheduled hemodialysis, three times a week at a for-profit outpatient dialysis center that is conveniently located near her home. As of May 1, 2016, SL has neither visited the ED nor been hospitalized. With her new dialysis schedule, she is now able to provide better care for her family, intends to resume working, and now lives a life that is closer to normalcy and not governed by her agonizing ED visits.

Acknowledgments

The author thanks Ms. Sharon Philips and Ms. Lakeesha Charles, Licensed Master Social Worker (LMSW) of Parkland Health and Hospital System in Dallas; and Ms. Virginia Manuel, LMSW-Advanced Practice of Harris Health for information used in this manuscript; and Dr. Jingbo Niu of the Baylor College of Medicine, Section of Nephrology, for statistical analysis.

Disclosures

R.R. did not receive any financial support.

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Published online ahead of print. Publication date available at www.cjasn.org.