Access, Quality, Cost: Optimizing Care for Undocumented Immigrants with End-Stage Kidney Disease Through Intelligent Health Policy

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Abstract

End-stage kidney disease (ESKD) is a lethal condition requiring ongoing treatment in order to prevent one of several potential life-threatening complications. Federal policy mandates hospitals provide emergent treatment to undocumented immigrants suffering one of these complications (such as hemodialysis) and provides partial funding for this treatment through Emergency Medicaid. It does not however, provide explicit funding for the ongoing, scheduled treatments necessary to prevent these lethal complications. Indirect epidemiologic evidence suggests undocumented immigrants present a significant ESKD burden to the U.S. health care system, and limited patient level data suggests that the absence of funding for routine treatment has led to the delivery of substandard care at increased cost. Given the lethality of ESKD, and both the availability and significant cost of effective treatment, *timely* investigation is required to identify health care policy that will optimize treatment of ESKD in the undocumented immigrant population. Meanwhile, *immediate* intervention is needed to improve access to, as well as the quality and cost of treatment currently received by members of this population. Such intervention could include nationwide expansion of Emergency Medicaid to all undocumented immigrants with ESKD.

Preface

"In what must be the most tragic irony of the twentieth century, people are dying because they cannot get access to proper medical care. More than 8,000 Americans will die this year from kidney disease who could have been saved if they had been able to afford an artificial kidney machine or transplantation. These will be needless deaths —deaths which should shock our conscience and shame our sensibility"

 Vance Hartke (D-Senator, Indiana), comments to members of Congress regarding Americans' limited access to treatment for endstage kidney disease prior to the creation of Medicare's ESKD program in 1973 (U.S. Congress, Senate Committee on Finance, 1972)¹

I remember the faces, though not the names, of the undocumented immigrants I have had the pleasure to care for over the past seven years. It is difficult not to be moved by their stories of sacrifice and the predicament they face, receiving a new diagnosis of end-stage kidney disease with limited financial resources and family support with which to confront it. As a physician, I find it remarkable to think that our system could treat these individuals with anything less than the standard of care, yet that is what undocumented immigrants may face: in medical centers throughout the country, these patients experience care as if the thirty years since legislation extending Emergency Medicaid to people with ESKD had never happened. At the heart of this issue are federal policies that do not address medical reality, blindly blocking the participation of undocumented immigrants in Medicare and Medicaid without so much as an intelligent data collection system to assess the down stream effect. It is my hope that the medical community will be proactive in studying this issue and ultimately in improving care to this population through thoughtful health care policy and timely action.

Table of Contents

Abstractii
Prefaceiii
Table of Contentsiv
Table of Figuresv
Overview1
Introduction
A Systematic Description of Selected States' Emergency Medicaid Funding 10
Assessing Access, Quality, and Cost of ESKD Treatment for Undocumented
Immigrants Under Current Federal Policy: A Systematic Review
Final Conclusions, Policy Recommendations19
References25

List of Figures

Table 1. Undocumented Immigrant Population 1990 and 2000 in the 25 Most	
Populated States	.28
Table 2. A Summary of States' Emergency Medicaid Coverage for Renal	
Replacement Therapy for Undocumented Immigrants	.29
Table 3. Summary of Findings from Systematic Review of the Literature	
Regarding the Care Received by Undocumented Immigrants with End-Stage	
Kidney Disease	. 32

Overview

End-stage kidney disease (ESKD) is a lethal condition where one's kidneys no longer perform their vital functions and ongoing treatment is mandatory to sustain life. Without it, death can occur within hours to days, most often resulting from one of several inevitable complications of kidney failure, including cardiac arrhythmia from electrolyte abnormalities, or respiratory failure from volume overload. In those known to have ESKD, these lethal complications may be prevented entirely with one of three available treatments: kidney transplantation, daily peritoneal dialysis, or ongoing hemodialysis that is typically performed three days a week (these treatments are often referred to in this paper as renal replacement therapy or RRT). In instances where patients present to medical care with untreated ESKD, emergent hemodialysis therapy can temporarily remedy these life-threatening sequelae, but it must be continued on a routine basis to prevent recurrence.

The growth of the undocumented immigrant population in the United States to more than 11 million² and the high prevalence of ESKD in the Hispanic population³ suggest that a large number of undocumented immigrants suffering from ESKD reside within the U.S. The cost of treating ESKD is estimated at more than 70,000 dollars per year on hemodialysis³. Caring for this population of undocumented immigrants with ESKD likely imparts a substantial cost to the U.S. health care system. Given the lethal nature of ESKD, the availability of effective treatment, as well as the significant cost of this treatment, *rational health care policy is required to optimize access to, as well as to optimize the quality and cost of RRT for this population*.

Almost all American citizens with ESKD are assured coverage for RRT through Medicare or Medicaid. Yet, a complex web of Federal legislation currently determines the funding for, and ultimately the care received by, undocumented immigrants with ESKD. Under current Federal law, hospitals receiving Medicare dollars are required to provide emergent RRT to undocumented immigrants suffering life-threatening sequelae of kidney failure⁴.

For those undocumented immigrants who are otherwise in a Medicaid eligible category (e.g. disabled, pregnant, children) and who meet the state income and state residency requirements, the cost of this care is shared between States and the Federal Government via 'emergency Medicaid'. However, no Federal policies currently mandate funding for ongoing RRT. And, as undocumented immigrants are specifically barred from participation in Medicare, and from receiving full scope Medicaid benefits (which together fund the vast majority of RRT for Americans) no Federal dollars are explicitly allocated to fund non-emergent care, including ongoing RRT. Thus, the current Federal funding climate supports the provision of acute, but not ongoing chronic, care for undocumented immigrants with ESKD.

In the absence of explicit Federal funding, States must decide if, and how, they will fund ongoing RRT for undocumented immigrants. Recognizing this fact, but also understanding that partial Federal funding is available for the emergent dialysis hospitals are obligated to provide, States have three options: provide *no* funding for ongoing RRT (leaving providers of scheduled RRT to seek funding through other means – e.g. local government or charity, or to deny non-emergent care); fund ongoing RRT with no Federal assistance; or attempt to obtain some monies from the Federal Government for ongoing RRT under existing policies. State policies appear to vary widely, though to date, no systematic description of State funding for RRT exists.

In this paper, I begin by grounding a claim for effective health care policy about RRT for undocumented immigrants with ESKD in terms of the system's stated commitments to extending access, reducing cost, and raising quality. I examine current policy in more detail. Next, I present a review of selected states' Medicaid policies to understand the variability of funding policies between states, and a systematic review of relevant medical literature to understand the *access* undocumented immigrants currently have to RRT, the *quality* of the care they receive, as well as the *cost* of this care. Finally, I summarize existing barriers to studying this population, make recommendations for investigations to better understand the down stream effect of current funding models on access, cost,

and quality, and suggest immediate improvements to current policy that would likely improve all three.

Introduction

End-stage Kidney Disease: Medical Context

Kidneys perform numerous vital functions in the body. Each is composed of nearly a million individual filtering units (nephrons) that work in parallel to maintain electrolyte balance, regulating blood volume, and remove numerous waste products from the blood. Kidney function can be quantified by determining the rate at which kidneys filter and remove substances from the blood, a measure called glomerular filtration rate (GFR). As a person's kidneys lose function, by definition, his or her GFR falls.

Because of the abundance of nephrons in the kidney, and the capacity of each to increase its production when other nephrons fail, one can suffer significant kidney damage without a noticeable effect on the functions the kidney performs. However, as loss of functioning nephrons begins to exceed the reserve capacity of those remaining, and GFR begins to fall, one may experience numerous sequelae including retention of salt and water identifiable as a rise in blood pressure or generalized swelling.

In most cases, one can lose more than 90% of kidney function before suffering life-threatening complications of kidney failure. The most common life threatening complications include severely elevated serum potassium levels (which can cause cardiac arrest), volume overload (which can cause heart and respiratory failure), and uremia (a build up of metabolic waste products in the blood that cause irritation of the lining of the heart or a fatal acidosis).

Three therapies exist to *prevent* the life threatening complications of kidney failure: kidney transplantation, peritoneal dialysis, and hemodialysis. Kidney transplantation is considered the best treatment for ESKD, as the 10-year graft survival rate for a kidney transplanted from a deceased donor is approximately 40%³. Transplantation offers many recipients nearly twice the life

expectancy of either form of dialysis⁵, and within one year of a successful kidney transplant it is the cheapest form of RRT. The first year of a kidney transplant costs approximately \$105,000, but the annual cost of maintaining it drops to approximately \$17,000 thereafter³. By comparison, peritoneal dialysis is a daily therapy performed by the affected individual at home. Peritoneal dialysis requires a baseline level of physical and cognitive function, as well as a commitment to self-care. At approximately \$53,000 dollars per year it is considerably more expensive than kidney transplantation after the first year, but cheaper than hemodialysis, which costs approximately \$72,000 annually ³. Hemodialysis is the one therapy of the three available emergently to *treat* complications of ESKD (e.g. in instances where one's kidney disease has previously gone untreated). However, like peritoneal dialysis, it must be performed on a scheduled basis, usually three days a week, in order to prevent the lethal sequelae of ESKD.

Although ESKD may have a slightly different medical definition, for the purposes of this paper, *ESKD* will be considered a condition where ongoing RRT is required to prevent immediately life threatening sequelae of kidney failure.

End-Stage Kidney Disease: Relevant Epidemiology

ESKD can result from numerous disease processes and appears to be growing in incidence and prevalence throughout the world, though this is perhaps best illustrated with U.S. data. In 1980 approximately 20,000 new cases of ESKD were identified in the U.S. Medicare population; this number grew to 100,000 in 2006^3 . This rise is attributed in part to the increased incidence of diabetes and hypertension in the population. The top attributed causes of ESKD in 2006 and 1980 were diabetes (44% v. 15%, respectively), hypertension (27% v. 18%), glomerulonephritis (7% v. 16%), cystic kidney diseases (2% v. 4%), and urologic conditions (2% v. 3%).³

The prevalent ESKD population is growing as well, rising from almost 60,000 in 1980 to more than 500,000 in 2006³. This is due in part to the increased incidence described above, but also to the increased survival of individuals with ESKD. The 5-year adjusted survival of all ESKD patients in

1980 was approximately 30%, climbing to nearly 40% in 2001³, despite the increased prevalence of diabetes, a predictor of worse outcomes.

U.S. Medicare data also illustrate a significant difference in incidence and prevalence rates of ESKD by race/ethnicity. Relevant to this paper is the disparity in rates between Hispanics and Non-Hispanics, as Hispanics compromise the majority of undocumented immigrants in the U.S.⁶ Hispanics compared to non-Hispanics are reported to have an approximately 33% higher rate of progression from intermediate stages of chronic kidney disease to ESKD⁷, and an adjusted incident rate in 2006 of approximately 520 per million v. 347 per million³. The adjusted point prevalence rate of ESKD in the Hispanic v. Non-Hispanic populations was 2,326 per million v. 1,576 per million³. The increased incidence of ESKD in the Hispanic population is poorly understood, though the increased prevalence may be due in part to an increased survival rate among Hispanic's with ESKD³.

Undocumented Immigrants and ESKD: Prevalence, Cost, and Distribution

To understand the importance of effective policymaking for treatment of undocumented immigrants with ESKD, it is critical to estimate the size and distribution of the affected population, and the cost of providing RRT. This is a difficult challenge, as there are no published estimates of the number of undocumented immigrants residing in the U.S. with ESKD, nor are there systems-level data to estimate the cost caring for them. However, rough estimates may be constructed using indirect methods.

To estimate the number of undocumented immigrants suffering from ESKD, we can begin with an estimate of the total population, which over the last 20 years has doubled, from 3.5 million in 1990, to 7 million in 2000⁸, and nearly tripling to approximately 11.8 million in 2007⁹. This represents an average annual rate of growth of 4.5%. Most undocumented immigrants appear to be Hispanic, as approximately 78% are born in Mexico or Latin America². By applying the prevalence rate cited above for Hispanics and Non-Hispanics, we can estimate that perhaps as many as 24,000 undocumented immigrants may be

living in the U.S. with ESKD.

One way to estimate the potential cost of caring for this population is to assume that the care they receive mirrors that received by American citizens, understanding that current care practices for undocumented immigrants may be more or less expensive, as their access to therapy is quite different than that of American citizens. For the purposes of this estimate, we will also assume the population has no access to kidney transplantation, as Federal funds are explicitly barred for this purpose¹⁰, and rely upon the estimate that 24,000 undocumented immigrants are living in the U.S. with ESKD. If 93.6% of undocumented immigrant ESKD patients receive scheduled hemodialysis, and 6.2% peritoneal dialysis (as is the case with the U.S. Medicare population in 2006) ³, at the annual costs cited above, as much as \$1.7 billion may be spent to provide RRT to undocumented immigrants.

To put this into context, at the start of Medicare's ESKD program in 1973, members of Congress estimated 20,000 to 25,000 Americans would be candidates for dialysis and that the first year cost of Medicare's ESKD program would range between \$100 and \$500 million dollars ¹. Meanwhile, almost 10 years later, in 1980, nearly 60,000 persons were enrolled. In 1995 that number grew to approximately 287,000 persons, and in 2006 more than 500,000 persons participated in Medicare's ESKD program. The total Medicare costs of reported ESKD in 1995 were almost \$9 billion and in 2006 were more than \$20 billion³.

Historically, undocumented immigrants have concentrated in a limited number of states (*Table 1.*), focusing the burden of suffering and cost of caring for this population on a limited section of the health care system. However, the distribution of the undocumented immigrant population has shifted in recent years, diffusing both burden and cost. In 1990, 88% of undocumented immigrants resided in 6 States ("the Big Six"): California (45%), New York (15%), Texas (11%), Florida (9%), Illinois (4%), and New Jersey (4%). Only 12% of the entire population was thought to live in the other 44 states. By 2002 to 2004, 44% of undocumented immigrants lived outside The Big Six⁶. North Carolina experienced a nearly 700% increase in its undocumented population between

1990 and 2000, the greatest relative growth of any state ⁸. A recent survey of ASN member nephrologists reported 65% of responding nephrologists in 44 states had provided care for illegal undocumented patients with ESRD, and 60% reported an increasing prevalence of undocumented immigrants with ESKD in their practice, a finding associated with working in a state with a high undocumented immigrant activity¹¹.

TABLE 1. ---- INSERT HERE ----

Relevant Legislation, Available Funding

Several pieces of legislation define current RRT funding for both Americans and undocumented immigrants with ESKD. The history of ESKD funding begins with enactment of Titles XVIII and XIX of the Social Security Act in1965 that created Medicare and Medicaid. Medicare, funded exclusively with federal dollars, was created as an insurance program to guarantee health coverage to those over 65. Meanwhile, Medicaid, funded jointly with state and federal dollars, is a social protection program to help some of those who are too poor to afford health care. Under Medicaid, states have some flexibility to determine eligibility criteria and available services (with minimum requirements). Undocumented Immigrants were barred from Medicare at its inception. However, the original Medicaid Act did not address the availability of Medicaid to non-citizens ¹².

Hemodialysis was first used to treat ESKD during World War II. It was available for routine use by the 1960's, but due to its exorbitant cost, was accessible by a limited few¹³. In 1972, Vance Hartke, a Democratic senator from Indiana, and his colleagues in Congress, recognized that many Americans with ESKD were dying despite the availability of effective treatments¹. In response, Hartke and colleagues amended the Social Security Act of 1972 with section 299I, extending Medicare coverage to most American's with ESKD and essentially guaranteeing them access to this life saving RRT. For those remaining Americans suffering from ESKD who were ineligible for Medicare (e.g. those with insufficient work credits to qualify), so called "non-eligibles", States'

Medicaid programs, kidney disease programs, the Indian Health Service, and the Department of Veterans Affairs offered public funding for RRT¹³.

In 1986, Congress passed The Omnibus Budget Reconciliation Act (OBRA86), dramatically reducing available funding for undocumented immigrant medical care, while at the same time mandating the provision on of emergent care, putting hospitals and providers of RRT in a difficult position¹⁴. Further, OBRA86 contained the Emergency Medical Treatment and Active Labor Act (EMTALA), which mandates that hospitals receiving Medicare funds (as per U.S.C. 42 § 1395dd):

"provide for an appropriate medical screening examination within the capability of the hospital's emergency department...to determine whether or not an emergency medical condition exists".

And, if such a condition is identified,

"...the hospital must provide either (A) within the staff and facilities available at the hospital, for such further medical examination and such treatment as may be required to stabilize the medical condition, or (B) for transfer of the individual to another medical facility".

OBRA86 is an important piece of legislation for undocumented immigrants with ESKD, as it requires treatment be provided for any life-threatening complication of advanced renal failure (through EMTALA) and provides Federal dollars for this treatment, while at the same time bars Federal Medicaid funds for the treatment of non-emergent conditions. Further, it defines Emergency Medical Condition as the following (as per U.S.C. 42 § 1396b(v)(3)(A)-(C)):

"(A) a medical condition manifesting itself by acute symptoms of sufficient severity (including severe pain) such that the absence of immediate medical attention could reasonably be expected to result in—

(i) placing the health of the individual (or, with respect to a pregnant woman, the health of the woman or her unborn child) in serious jeopardy,

(ii) serious impairment to bodily functions, or

(iii) serious dysfunction of any bodily organ or part;"

This somewhat vague definition has left open to interpretation what constitutes an emergency medical condition, and in some instances patients and providers have sought Medicaid dollars for what the court has ultimately deemed to be non-emergent care. In the case of Quiceno vs. Department of Social Services (DSS), the family of a deceased patient in Connecticut filed suit when the Connecticut DSS declined Medicaid coverage for ongoing hemodialysis citing that hemodialysis did not constitute an "emergency medical condition"¹⁵. The court ultimately ruled in favor of the Connecticut DSS. In few, but notable instances, States like North Carolina and California have taken advantage of this ambiguous definition authorizing Medicaid, and ultimately federal dollars, to provide ongoing hemodialysis outside of an emergency setting^{16, 17}. The frequency of this practice is explored later in this paper.

Additional pieces of legislation regulating funding for the care of undocumented immigrants with ESKD include the Omnibus and Reconciliation Act of 1993 (OBRA93), the Balanced Budget Act of 1997 (BBA97), and the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA03). OBRA93 specifically prohibits Medicaid dollars from funding an organ transplant procedure for an undocumented immigrant¹⁰. As a result, no federal funds are available to provide undocumented immigrants with the medical treatment of choice for ESKD. BBA97 provided \$25 million annually from 1998 to 2001 to the 12 states with the greatest number of undocumented aliens to cover the provision of emergency services¹⁸, and MMA03 provided \$250 million per year from 2005 to 2008 to hospitals and eligible providers for emergency care delivered to undocumented aliens¹⁹.

Research questions

ESKD is a lethal, but treatable condition for those who can afford one of several life saving therapies. These therapies are available to essentially all Americans through Medicare and Medicaid. Current federal policy mandates and allocates partial funding for *treatment* of the life threatening sequelae experienced by

undocumented immigrants with ESKD, but provides no 'dedicated' funding for the ongoing therapy required to *prevent* these inevitable life threatening sequelae. The sole opportunity for states to obtain some federal funding for the provision of ongoing therapy is by taking advantage of the 'lose' definition of 'emergency medical condition' under current Federal policy, and offering providers of ongoing RRT payment with emergency Medicaid which is jointly funded with State and Federal dollars. The remainder of the paper investigates two questions:

1. How many of the states with the largest undocumented immigrant populations provide funding for ongoing RRT through Emergency Medicaid?

2. What access do undocumented immigrants with ESKD have to ongoing RRT, and what is the cost and quality of the care they receive?

A Systematic Description of Selected States' Emergency Medicaid Funding

Methods

Our understanding of the variability and mechanisms by which States fund ongoing RRT for undocumented immigrants requires a systematic search of Emergency Medicaid policies. A search of these policies was conducted for the 10 states with the largest estimated undocumented immigrant populations: California, Texas, New York, Illinois, Florida, Arizona, Georgia, New Jersey, North Carolina, and Colorado. Specifically, I reviewed Medicaid policies for statements authorizing explicit coverage for ongoing dialysis (or some other descriptor, e.g. RRT, hemodialysis, peritoneal dialysis, etc.).

The search had two phases. The first was an exploratory search of 30 states' Medicaid websites looking for any statement regarding medical coverage for undocumented immigrants. As would be anticipated based on the federal policy outlined, I found references only to emergency medical coverage. Because the only statements about coverage of dialysis for this population were located in state's Medicaid policy manuals, I decided, in consultation with faculty

advisors, to make the second phase of the exploration a systematic review of all relevant Medicaid policy manuals for the 10 states with the largest undocumented immigrant populations. Since many states have several Medicaid manuals, I searched those specifically directed toward physicians, hospitals, dialysis providers, and consumers by using the following terms, "dialysis", "kidney", "renal", "immigrant", "alien", and "emergency".

Systematic State Policy Review Findings

Of the 10 states I investigated, 5 -- California, Illinois, Florida, Arizona, and North Carolina -- explicitly provide Medicaid coverage for ongoing dialysis in the undocumented immigrant population. None of the remaining five explicitly denies coverage for ongoing RRT, but all cite the federal definition of "emergency medical condition" in defining covered treatments (*Table 2*). For the purposes of this review I presumed that the absence of stated Medicaid coverage meant no coverage was available, though this may be a flawed presumption. For example, New York has been cited in the media as providing funding ²⁰ but had no statement of coverage in its on-line manuals. The discrepancy between reports of coverage and what is in the manual may have several possible explanations: New York offers coverage *outside* its Medicaid program; its coverage is offered through Medicaid, but not explicitly stated in the available manuals; or the journalist reporting this was simply incorrect.

I found Colorado's manual on the Code of Colorado Regulations website, which posts administrative rules of the executive agencies. This suggests that Medicaid coverage for some states may be determined through a 'rules' process rather than a legislative process.

I saw no obvious association between geography or the size of states' undocumented immigrant population, and Medicaid coverage, but this lack of apparent association is not testable within the scope of the present project.

TABLE 2. ---- INSERT HERE ----

Summary

Of the 10 states with the greatest undocumented immigrant population, half of them offered coverage for ongoing RRT for undocumented immigrants. It is possible that this underestimates coverage, but not in terms of the explicit provisions published in their Medicaid manuals – to the extent that states offer more, or other, coverage, they do it outside of the policy procedures governed explicitly by their Medicaid manuals . Clearly, a number of states with the greatest potential burden of undocumented immigrants have used the vague definition of 'emergency medical condition' in federal Medicaid legislation for the purposes of obtaining federal funds for the care of undocumented immigrants. State Medicaid coverage may be determined in some states by executive rather than legislative processes, as suggested by the Colorado case, suggesting that future Medicaid expansion could occur in states who define the expansion in terms of their own Medicaid purview, outside the national political process.

Assessing Access, Quality, and Cost of ESKD Treatment for Undocumented Immigrants under Current Federal Policy: A Systematic Review

Methods

In order to assess undocumented immigrants' *access* to RRT, and the *quality* and the *cost* of the care they receive, I conducted a systematic review of the medical literature. I entered these terms into PubMed: "immigrant and kidney", "immigrant and renal", "immigrant and dialysis", "immigrant and Medicaid", "alien and kidney", alien and renal", "alien and dialysis", and "alien and Medicaid".

At the outset, I did not use PubMed limits to restrict the search, for example, to English only, human only, or other restrictions. Instead, I allowed the search terms to turn up all possible literature. This open search identified a total of one hundred thirty-two articles. I then eliminated 107 articles because they were not in English, or were animal, cellular, or other basic science studies, or

were not principally about the management of ESKD (that is, articles in which ESKD was a sequel or a secondary concern), or did not report patient data. I excluded studies that included immigrants as a single population, not specifically distinguishing "undocumented" immigrants, but articles that used a clearly equivalent term with a similar definition were acceptable. I excluded studies of children only (because children may have access to treatment through other state programs²¹) or with a sole focus on obstetric or oncologic issues.

This left me with 26 articles or abstracts for further review. I found that three of the remaining 26 sufficiently met the inclusion criteria for systematic review. I added a fourth that, although it did not meet the pre-specified inclusion criteria because it was a national survey of nephrologists rather than a study of patients, nonetheless offered additional important insights with sufficiently high quality data. Because the intent of this review was to assess access, quality, and cost of ESKD care in the context of the Federal policies outlined above, I considered case reports and case series for inclusion. I performed a "hand search" of the reference lists of review articles, narratives and editorials to capture references not captured by my PubMed search, but I did not include such literature in the review. The articles are discussed individually, followed by a summary of the evidence.

Search results

These studies methods and conclusions are summarized in *Table 3*, and discussed below.

TABLE 3. ---- INSERT HERE ----

The first study, by Sheikh-Hamad et al.,²² was performed in Houston, TX, a state that does not provide Emergency Medicaid funding for routine RRT. However, some *hospital districts* in the state have opted to finance care (without federal dollars). In this study, the authors take advantage of a 1997 change in their hospital district's funding policy in order to examine the costs and outcomes of

caring for undocumented immigrants under two different RRT provision strategies. Prior to 1997, the district funded standard maintenance dialysis (e.g. 3 times per week) for undocumented immigrants with ESKD, a policy that changed after 1997. Those undocumented immigrants with ESKD presenting after 1997 were provided 'emergent' dialysis only (provided during unscheduled visits to the Emergency Department). However, despite this change in policy, those receiving standard care prior to 1997 continued to receive this care after 1997. Patients receiving a minimum of 4 consecutive months of follow-up and care between July 1, 2000 and February 28, 2002 were considered eligible for the study. The cost and quality of the care received by these patients were compared by the authors retrospectively.

Thirty-five patients were included in the Texas study, 22 in the standard dialysis cohort (standard dialysis patients, SDP) and 13 in the 'emergent care' cohort (emergent care patients, ECP). By definition, the ECP group received dialysis less often than did the SCP group; the former received dialysis two to three times during each in-patient stay, which occurred only after presenting to the emergency department. Meanwhile, the SDP group received dialysis three times per week. As a result, the ECP group received fewer dialysis treatments annually (98 v. 154, p<0.0001).

Regarding quality of care, most dialysis in the ECP group was provided via temporary central venous catheters (removed upon discharge). The SDP group received dialysis through AV fistulae or grafts. This presents two important issues. First, it is well described in the nephrology literature that use of central venous catheters (CVCs) for ongoing hemodialysis is associated with significant increased risk of infection and death compared to AV fistulae²³⁻²⁵, and we have no reason to assume this risk would not be borne by the undocumented immigrant population as well. The frequent placement and removal of temporary CVCs creates additional risk. CVCs used for outpatient dialysis are most often 'tunneled', running under the surface of the skin for a short distance before penetrating the wall of a great vein. Tunneling allows CVCs to remain in place for weeks to months with a relatively lower risk of infection than is true when

temporary CVCs are used. The practice described in this article, use of temporary CVCs, requires placement of a CVC each time the patient presents for care. Each placement requires puncturing a large vein (internal jugular vein, subclavian vein, or femoral vein) with a large needle and dilating this hole to accommodate a large diameter catheter, an uncomfortable and often painful procedure associated with a list of well described potential complications (e.g. puncture of the carotid artery, pneumothorax, pseudoaneurysms, bleeding, and infection), the probability of which must be multiplied by the number of procedures performed.

Dialysis adequacy is another quality measure, and the ECP group had lower measures of dialysis adequacy (KT/V 0.9 v. 1.64), and reported greater physical pain and lower levels of physical function. KT/V is a measure that describes the degree to which a person's blood has been 'cleaned' on dialysis, with the national standard for hemodialysis suggesting a minimum KT/V of 1.2, and a target of 1.4 ²⁶. It is important to note that inadequate dialysis dosing, as measured by KT/V is associated with a higher mortality rate.²⁷

Regarding cost, the ECP group spent more days as inpatients (162 v. 10.1, p<0.0001), had more emergency department visits (26.3 v. 1.4, p<0.0001), received more blood transfusions (24.9 v. 2.2, p<0.0001), and had a higher mean annualized cost of care (\$284,655 v \$76,906).

This study is unique for its comparison of two practice strategies devised in direct response to a shift in local funding policy for RRT to undocumented immigrants. It demonstrates that the absence of funding for ongoing RRT is associated with less access to care, worse quality of care, and costs that are significantly greater than those for standard care. Further, the specific substandard quality measures identified (use of CVCs and inadequate dialysis) are both associated with higher morbidity and mortality in dialysis populations.

Although the article did not address this, it would be helpful to understand the actual cost of care for each group, as well as the total reimbursement and source and targets of payment. This would allow for a more detailed policy assessment and bring to light motivations in altering the finance strategy, an

important part of anticipating the political process of policy change. Important weaknesses in this study are its small sample size, retrospective design, and the paucity of information provided regarding inclusion criteria (e.g. were all patients meeting the inclusion criteria included?) and patient characteristics (e.g. comorbidities, access to medical care other than RRT, etc.) despite the availability of patient level data. These limit any assessment of selection bias and conclusions that can be drawn regarding cause and effect.

The second article, by Coritsidis et al,.²⁸ comes from New York, a state that is reported to provide Medicaid funding for routine dialysis in the undocumented immigrant population²⁰, though I did not uncover this coverage in the earlier systematic review of states' Emergency Medicaid policies. In this study, the authors characterize a cohort of undocumented immigrants receiving maintenance dialysis at two teaching hospitals prior to 2001 (n=55), and compare their pre-dialysis care and health care utilization to a cohort of American citizens with ESRD (n=223). With variable statistical significance, undocumented immigrants reportedly received less pre-ESRD care (27% v. 61%, p=0.01), started dialysis with significantly lower glomerular filtration rates (GFR) (5.53 v. 6.29, p=0.03), had higher blood pressure (mean arterial pressures 119.9 v. 108.9, p=0.001), had longer length of stays when starting dialysis (10.0 v. 7.7 days, p<0.06) with greater costs incurred during the admission (\$16,076 v. \$11,396, p<0.003).

This paper focuses on pre-dialysis care, and because it describes only those patients receiving scheduled dialysis, it offers little insight into the access, quality, and cost of RRT provided to undocumented immigrants without available state funding. The study does raise several points of relevance to future funding policy. First, it suggests that disparities in access to *pre*-dialysis care between undocumented immigrants and American citizens may lead to more advanced kidney failure at the time of presentation, as well as greater costs associated with the start of dialysis. This raises the possibility that improving access to health care for undocumented immigrants prior to the initiation of RRT could offer

financial savings. My own clinical experience suggests that, it is also possible that despite New York's funding policy, some of the increase in cost and length of stay at the initiation of dialysis may arise from administrative difficulties obtaining Medicaid funding for non-emergent RRT. Or, if reimbursement is at less than Medicare rates, it may take more time to place patients, as centers may be less likely to take a patient for less payment. Nonetheless, this study demonstrates that funding for standard RRT does not eliminate disparities in pre-dialysis care; nor does it lower the cost of care at the initiation of dialysis. Finally, to address the potential moral hazard problem of immigrants rushing to the U.S. for care, the qualitative impression from the study is that this is not a significant concern: all study participants denied coming to the U.S. for medical care, and only 1 of 26 patients knew that he or she had kidney disease before emigrating.

The third study, by Dubard and Massing, focuses solely on the issue of cost, and can be summarized briefly.²⁹ The authors conduct a descriptive analysis of North Carolina Medicaid administrative data for all claims reimbursed under Emergency Medicaid between 2001 and 2004. They find that 99.2% of Emergency Medicaid claims were for care provided to undocumented immigrants. Although claims for RRT were not itemized, they reported a spending category for chronic renal failure, which likely contains the RRT costs for the undocumented immigrant population. Depending on the reimbursement rate, it is unlikely this represents the total cost of providing RRT. Based on 2004 data, and a total emergency Medicaid expenditure of approximately \$53 million, roughly \$750,000 was spent on 'chronic renal failure', of which likely a sizeable portion is related to the provision of ongoing dialysis.

Interpreting this number requires more detailed itemization, as well as an estimate of the number of undocumented immigrants receiving routine dialysis in NC, which the authors did not provide. The numbers in the article are considerably smaller than one would anticipate given the size of the undocumented immigrant population in NC.

The fourth study, by Hurley et al.,¹¹ contained no population or patient data, but I included it because it provides additional insight into access, quality, cost, and funding policy. Hurley et al., surveyed 1,723 American Society of Nephrology member nephrologists about their perceptions of the care delivered to, and funding provided for, undocumented immigrants with ESKD. The authors had a 57% response rate, without evidence of reporting bias.

In the survey, only 41% of nephrologists thought access to care for the undocumented was adequate, and 24% reported having advised a patient to move to another state within the past year. However, 51% agreed or somewhat agreed that the undocumented have access to maintenance dialysis; this response was positively associated with being from a state with a large undocumented population, and negatively associated with being from the south. The authors did not find a clustering of responses within states, perhaps suggesting individual state policies alone do not explain access to long-term dialysis therapy. This may be due to the availability of additional sources of funding in states without emergency Medicaid funding. Ninety -one percent agreed or somewhat agreed that undocumented immigrants had access to emergent dialysis, for which service is mandated and payment provided, suggesting that funding policy is only one barrier to accessing RRT in this population.

The survey did not include other measures of cost or quality were presented, but participants were asked about their perceptions of reimbursement. Only 4% said that inpatient reimbursement was adequate, while 5% reported adequate reimbursement for outpatient care. Given the overwhelming perception that reimbursement is inadequate, it is likely this perception is shared by providers in states with Medicaid funding. This suggests that providers may disproportionately shoulder the cost of caring for undocumented immigrants in States with Emergency Medicaid payment. Further, it suggests that there may be financial disincentives to caring for this population, and that access and quality of care may not be entirely addressed by universal Emergency Medicaid funding for RRT in this population.

Summary

Few published studies assess the *access* undocumented immigrants have to RRT, or the *quality* of the care they receive in a comprehensive, systematic fashion. As discussed below, this population is exceptionally difficult to identify. Only one study explicitly examined the relationship off access, cost, and quality to funding policy, and it was limited in size and design. In spite of these limitations, the data strongly suggest that both access and quality vary tremendously with funding policy, and that the absence of available funding is associated with limited access and substandard care, both before and after the onset of ESKD.

The total cost of caring for this population may be less than we have anticipated, if, systems level data from NC, a state with Emergency Medicaid funding for RRT, are generalizable. On the other hand , nephrologists' negative perceptions of reimbursement for RRT in this population suggest that Medicaid payment may not be comprehensive, and therefore may understate the actual cost of care. The studies from Texas and New York suggest that cost varies directly with available funding and the resulting down stream service delivery model. Though there are significant weaknesses in these studies , routine dialysis appears considerably less expensive than intermittent emergent dialysis, though the cost of emergency care is shared between States and the Federal government, rather than individual states, hospitals, or providers.

Final Conclusions, Policy Recommendations

Barriers to Understanding

A recurrent theme in the present project is the absence of available information about the health status of the undocumented immigrant population, a diverse population with unique socioeconomic circumstances. The scarcity of data may arise from the difficulty of identifying this population, for many reasons, including legal protections prohibiting prospective identification. These difficulties are well

illustrated in a 2004 report from the General Accounting Office (GAO), "Undocumented Aliens" in which 503 hospitals in 10 states (nine states with the highest number of undocumented immigrants, plus New Mexico) were surveyed in an attempt to quantify the impact of the undocumented population on hospitals' uncompensated care costs³⁰. Despite bringing federal government resources to the task, only 39% of hospitals provided enough information to make a valid assessment, and less than 5% used a means other than lack of a social security to identify undocumented immigrants.

Several groups have examined the health care resources utilized by the 'immigrant' population, but few have delineated those specifically used by undocumented immigrants. Recent work appears to have been stimulated by the Personal Work and Responsibility Reconciliation Act of 1996³¹, a piece of legislation that made most legal immigrants entering the U.S. after 1996 ineligible for Medicaid for 5 years after entry. Mohanty, Woolhandler, Himmelstein, et al. merged two national databases, the Medical Expenditure Panel Survey (MEPS, a survey designed to provide an estimate of expenditures and health services for the US civilian population) and the National Health Interview Survey (NHIS, which contains demographic information including birth place) estimating that \$39.5 billion was spent on immigrant health care in 1998 (7.9% U.S. total), but made no distinction regarding legal status.³² Meanwhile, Goldman, Smith, and Sood demonstrated that such a distinction is important by merging data from the Los Angeles Family and Neighborhood Survey (LFANS) and MEPS³³. In their analysis, 94% of undocumented immigrants were Hispanic, while half immigrant citizens were White or Asian; 5% of the undocumented had college degrees versus 32% of immigrant citizens; household incomes of immigrant citizens were three times that of undocumented immigrants; and 68% of undocumented immigrants were uninsured compared to 23% of naturalized immigrants – a replicated finding ³⁴ that appears mostly explained by the differences in employer based coverage (23% v. 59%)³³.

Goldman also found that undocumented immigrants were less likely to report having a chronic medical condition, 19% vs. 27% of foreign-born U.S.

citizens, including diabetes (8% v. 5%) and hypertension (13% v. 11%) which as the authors point out, may be due to lower rates of diagnosis related to less contact with the health care system rather than a generally healthier population³³. This is supported by data from Amato, et al. who demonstrated a significant discrepancy between rates of self reporting diabetes and diabetes determined by serum testing in a population screening performed in Morelia, Mexico³⁵.

Identifying members of the undocumented immigrant population in the health care system would help efforts to describe disease incidence and prevalence, and is absolutely critical to understanding *access*, *quality*, *cost*, and the policies that influence each of these. One way to do this would be to use existing infrastructure to register and track those undocumented immigrants currently receiving routine dialysis across the country through Emergency Medicaid funding. Ongoing applications required to maintain Emergency Medicaid funding could be amended to include the same quality measures reported for patients in Medicare's ESKD program. Since applications are often submitted on a regular basis on the applicant's behalf (e.g. as in North Carolina Emergency Medicaid), concerns about reporting of the patient's immigration status can be addressed.

An important weakness of studying those receiving RRT through Emergency Medicaid exclusively is the inability to investigate outcomes associated with different funding strategies (though it would provide the ability to investigate outcomes associated with different means of administering the same program – that is, how do different administrative procedures affect access to care?). One solution would be for those undocumented immigrants receiving dialysis with charity care funds, or other funding mechanisms, to have the dialysis unit in which they dialyze report quality measures to a central location. Again, as such reporting is standard for Medicare patients; this should not require a significant investment in infrastructure. These outcomes, for example, could be reported to the ESRD Network. The ESRD Network is a non-profit organization with a large membership of ESRD providers, organized by region, who provide routine detailed patient level reports concerning the quality of RRT care in an

effort to monitor and improve care delivery in their region. By simply adding a code for immigration status to these routine reports, a good deal of information could be collected regarding the quality of care received by undocumented immigrants in states without Medicaid funding for RRT. This would not however capture the care delivered exclusively in Emergency Departments.

Expanding Current Research

Given the lethality of ESKD, and the availability of effective therapies, there is real urgency to describe the prevalence of ESKD in the undocumented population, as well as the cost and quality of the care they receive. An immediate first step would be to describe the Emergency Medicaid policies for all 50 states followed by a cross sectional survey of receipts and patient level data collected by programs funding RRT for undocumented immigrants. The objective would be to devise a rough estimate of care costs and to pool reported patient level data for a cross sectional description of the population's health characteristics and health care needs. This data could also be examined in the context of state's undocumented immigrant populations to devise an estimate of ESKD prevalence.

National surveys like the National Health and Nutrition Examination Survey (NHANES) could be amended to include immigration status. This would provide a wealth of information about the prevalence, and ultimately incidence, of kidney disease in this population, as well as that of risk factors for kidney disease.

We can only understand the effect of funding policy on access, outcomes, and cost via analysis of, patient level data collected in states and communities with a range of different funding strategies. For example, in ESRD Network area 6, which includes North Carolina (who provides Emergency Medicaid funding for RRT) and Georgia (who does not), an electronic database could be constructed to prospectively record quality and cost measures. Doing so in an established network would make use of an existing organizational infrastructure, and hopefully reduce regional selection bias somewhat by choosing areas for study

that are in close proximity. Additionally, similar to the Texas study, but with a prospective design, one could consider examining two different care models in a single center, or region, with a randomized design trial.

Another important question, but one beyond the scope of this paper, is the distribution of care burden (i.e. costs) within the health care system. What is the cost of care for those states with Emergency Medicaid programs that fund ongoing RRT? What is the level of reimbursement? Who gets paid? How much? Are physicians bearing a greater burden of the cost of care than hospitals and taxpayers? These are critical questions to understanding those forces interested in changing (or not changing) current policy and in shaping future policy.

Recommendations for Policy Change

The data from Houston, though limited in several ways, make a compelling and, perhaps most important, a logical argument, that funding scheduled RRT in the undocumented immigrant population is far less expensive than is funding care provided on an emergent basis, and it is associated with improved quality of care. An additional fact to consider is the increased productivity that may be expected from a patient receiving scheduled therapy compared to one who is chronically ill. For example, providing universal funding for peritoneal dialysis would allow many undocumented immigrants with ESKD the freedom to work while receiving standard treatment.

An additional policy to consider changing is that regarding the ban on using federal dollars to fund kidney transplants for the undocumented population, particularly as transplantation is the most medically effective and cost effective treatment available for ESKD. Why eliminate this as a potential therapy? Strong arguments have been made for and against this practice ³⁶; ³⁷. A large part of the con argument can be effectively negated by mandating that living donors be used. This would prevent an exacerbation of the already significant mismatch between supply and demand of transplant organs for citizens; it would

of course mandate careful screening of appropriate donor motivation, but this practice is already in place.

Conclusion

Undocumented immigrants with ESKD are a vulnerable population, affected by a lethal disease treatable only by costly therapies. Since the system is already obliged by law, as well as by ethics, to provide emergency care to this population, a timely investigation into current care practices and policies is in order to create solutions that achieve better quality with a more efficient use of resources. In the meantime, available evidence, while limited, is sufficiently compelling to support immediate expansion of Emergency Medicaid to cover RRT nationwide; and the prospective collection of data to describe the cost and quality of care received by this population as policy changes are made.

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2000 Population Rank	1990 Population Rank	State	2000 Population	1990 Population	% Growth 1990 to 2000
1	1	California	2209	1476	50%
2	2	Texas	1041	438	138%
3	3	New York	489	357	37%
4	5	Illinois	432	194	123%
5	4	Florida	337	239	41%
6	7	Arizona	283	88	222%
7	11	Georgia	228	34	571%
8	6	New Jersey	221	95	133%
9	15	North Carolina	206	26	692%
10	13	Colorado	144	31	365%
11	10	Washington	136	39	249%
12	9	Virginia	103	48	115%
13	14	Nevada	101	27	274%
14	16	Oregon	90	26	246%
15	8	Massachusetts	87	53	64%
16	18	Michigan	70	23	204%
17	23	Utah	65	15	333%
18	25	Minnesota	60	13	362%
19	12	Maryland	56	34	65%
20	17	Pennsylvania	49	25	96%
21	26	Kansas	47	13	262%
23	21	Oklahoma	46	16	188%
22	31	Tennessee	46	9	411%
24	28	Indiana	45	11	309%
25	30	Wisconsin	41	10	310%

Table 1. Undocumented Immigration Population 1990 and 2000 in the 25 Most Populated States (population figures in thousands)*

Data from Estimates of the Unauthorized Immigrant Population Residing in the United States: 1990 to 2000 Office of Policy and Planning U.S. Immigration and Naturalization Service⁸

Table 2 page 1/3 (FINAL TABLE2.DOC)

Table 2 page 2/3 (FINAL TABLE2.DOC)

Table 2 page 3/3 (FINAL TABLE2.DOC)

Table 3. Summary of Findings from Systematic Review of the LiteratureRegarding the Care Received by Undocumented Immigrants with End-
Stage Kidney Disease

Citation	Methods Summary	Results, Conclusions
Care for Immigrants with	Retrospective cohort	Standard dialysis patients (SDP, n=22) v. 'emergent care'
End-Stage Renal	study examining cost	patients: (ECP, n=13):
Disease in Houston: a	and quality of care	ACCESS:
comparison of two	received by	* ECP received fewer dialysis treatments annually (98 v. 154,
practices.	undocumented	p<0.0001)
Sheik-Hamad D, Paiuk E,	immigrants under two	* ECP patients received an average of two to three dialysis
Wright A, et al. Care for	care strategies:	treatments as in-patients prior to discharge
immigrants with end-stage		QUALITY:
renal disease in Houston:	1) Standard ongoing	* SDP more often received dialysis using AV fistulae or grafts vs.
a comparison of two	dialysis (i.e., 3	ECP who received treatment via temporary venous catheters
Madiaina 102:52 59	times per week),	(removed upon discharge)
Medicine. 103:53-58,	VS.	
2007.	2) Ongoing	1.04) *ECD reported greater physical pain and a lower level of physical
	(provided during	ECP reported greater physical pain and a lower level of physical function
	to the Emergency	$\frac{0007}{1000}$.
	Department)	*ECP had more emergency department visits (26.3×1.4
	Department).	p < 0.0001
		* ECP received more blood transfusions (24.9 v 2.2 p<0.0001)
		*SDP had lower mean annualized cost (\$76,906 v. \$284,655)
The Initiation of Dialysis	Retrospective cohort	Undocumented immigrants (UI), n=55 v, American citizens (AC).
in Undocumented	study examining	n=223:
Aliens: The Impact on a	patient characteristics.	* Demonstrates that emergency Medicaid funding for ongoing
Public Health System.	pre-dialysis care, cost	RRT does not eliminate disparities between UI and AC in pre-
²⁸ Coritsidis GN, Khamash	of care at the start of	dialysis care, or the cost of care at the initiation of dialysis
H, Ahmed SI, et al. The	dialysis, and attitudes	* UI received less pre-ESRD care (27% v. 61%, p=0.01); started
initiation of dialysis in	of undocumented	dialysis with lower glomerular filtrations rates (GFR (5.53 v. 6.29,
undocumented aliens: the	immigrants v.	p=0.03); had higher blood pressure at start of HD (mean arterial
impact on a public hospital	American citizen	pressures 119.9 v. 108.9, p=0.001); had longer length of stays
system. Am J Kidney	receiving maintenance	when starting dialysis (10.0 v. 7.7 days, p<0.06) and had greater
Dis.43:424-432, 2004	dialysis at two	costs for this admission (\$16,076 v. \$11,396, p<0.003).
	teaching hospitals in	* Few UI (4%) reported knowledge of kidney disease prior to
	NY prior to '01.	immigrating.
Care of Undocumented	Cross sectional mail	990 of 1723 (57%) nephrologists responded:
Individuals with ESKD:	and internet survey of	100500
A National Survey of	American Society of	AUCESS:
U.S. Nephrologists.	nephrologists	41% of hephrologists thought of had adequate access to care
Pratto S Lings Caro of	nephrologists	(44% uisagieeu wiiii iiiis) * 51% of pophrologiets agrood or somewhat agrood that III have
undocumented individuals	October 2006 and	access to maintenance dialysis (this response was positively
with ESRD: A national	February 2007	associated with being from state with high LII population
survey of US	regarding their	negatively associated from being from the south)
nephrologists, Am J	perceptions of the care	*91% agreed or somewhat agreed that UI had access to
Kidney Dis, epub DOI:	delivered to and	emergent dialysis
0.1053/j.ajkd.2008.12.029.	funding provided for	* 59% of nephrologists reported providing emergent dialvsis care
	undocumented	to UI, 28% of whom reported UI receive only emergent care.
	immigrants (UI) with	* Providing dialysis to UI with ESKD was positively associated
	ESKD.	with practice in high undocumented population state
		* No significant clustering of responses within states was found
		suggesting individual state policies alone do not explain

		 perceptions of access * 24% of nephrologists had advised a patient to move to another state within the past year <u>COST</u>: * 4% reported inpatient, 5% reported outpatient dialysis reimbursement was adequate. * 35% reported their outpatient dialysis unit provided uncompensated care <u>QUALITY:</u> * Of nephrologists caring for UI, 67% reported thrice-weekly outpatient dialysis therapy at a dialysis center v. 3% reporting less than 3 times per week. *14% of nephrologists reported providing PD
Trends in Emergency Medicaid Expenditures for Recent and Undocumented Immigrants. DuBard CA, Massing MW. Trends in emergency Medicaid expenditures for recent and undocumented immigrants. JAMA 297:1085-1092, 2007	Descriptive analysis of NC Medicaid claims reimbursed under Emergency Medicaid between 2001 and 2004.	 *48,391 individuals received services during the 4 years of study. *99% of persons served were undocumented immigrant, 93% were Hispanic * Total emergency Medicaid expenditures increased annually 2001 to 2004. * In 2004 \$52,945,304 were reimbursed, 82% was spent for childbirth/complications of pregnancy, and approximately \$750,000 were spent on "chronic renal failure"