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Kidney Transplant Access in the Southeast: View From the Bottom

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Abstract

The Southeastern region of the United States has the highest burden of end-stage renal disease (ESRD) but the lowest rates of kidney transplantation in the nation. There are many patient-, dialysis facility-, ESRD Network- and health system-level barriers that contribute to this regional disparity. Compared to the rest of the nation, the Southeast has a larger population of African-Americans and higher poverty, as well as more prevalent ESRD risk factors including hypertension, obesity and diabetes. Dialysis facilities—where ESRD patients receive the majority of their healthcare—play an important role in transplant access. Identifying characteristics of individual dialysis units with low rates of kidney transplantation, such as understaffing or for-profit status, can help identify targets for quality improvement initiatives. Geographic differences across the country can identify opportunities to increase funding for healthcare resources in proportion to patient and disease burden. Focusing interventions among dialysis facilities with the lowest transplant rates within the Southeast, such as provider and patient education, has the potential to increase referrals for kidney transplantation, leading to higher rates of kidney transplants in this region. Referral for transplantation should be measured on a national level to monitor disparities in early access to transplantation. Transplant centers have an obligation to assist under-served populations in ensuring equity in access to services. Policies that improve access to care for patients, such as the Affordable Care Act and Medicaid expansion, are particularly important for Southern states and may alleviate geographic disparities.

Keywords

Disparities; kidney transplantation; quality; Southeast

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Introduction

The Southeastern region of the United States has the lowest rates of kidney transplantation in the nation, as well as one of the highest kidney disease burdens. In addition to low kidney transplant rates, Southern states are consistently ranked among the bottom for other indicators of access to healthcare and health outcomes. Examples include higher rates of chronic diseases such as stroke (1), hypertension, diabetes, obesity (2), high rates of low birth weight and infant mortality (3), low life expectancy, high hospitalization rates for chronic conditions (4), and high premature mortality rates (5).

There are many potential reasons for the geographic clustering of poor health outcomes and access to care in the Southeast, including differences in patient demographics, risk factors, characteristics of neighborhoods and the availability of high-quality care in the South compared with other areas of the country. Minority race/ethnicity is associated with poor health outcomes in the United States (6), and the South has the highest proportion of African-Americans (7). However, geographic differences in health outcomes exist above and beyond differences in racial composition of geographic regions.

Health outcomes are inextricably linked with poverty. People with low income receive worse care than those with middle or high income on 60% of more than 100 quality-care measures (8). The South, and particularly the Southeast or “Deep South,” has a higher concentration of poverty compared with other regions of the nation. This demarcation of poverty between the North and South is known as the “continental poverty divide” (9) (Figure 1A). Southern states are among the lowest states for high school graduation rates, highest proportion of uninsured patients and lowest household income (7). For example, in Georgia, 91% of counties have a lower life expectancy than the United States median of 76.5 years (7). The divide between poor and rich is the highest it has been since the 1920s, and the gap is only getting wider (7). A difference of only a few miles can mean a difference in up to 25 years of life expectancy for infants born in New Orleans (10).

Many studies have supported the link between neighborhood location and health outcomes. An Institute for Health Metrics and Evaluation report “State of US Health” found that people who live in Appalachia or the rural South are as unhealthy as people living in Algeria or Bangladesh (2). Even after controlling for individual-level socioeconomic status (SES) measures such as insurance and education level, the poverty level of neighborhood residence is an independent risk factor for all-cause mortality (11). Data suggest that for blacks, but not whites, the risk of end-stage renal disease (ESRD) increases with increasing time of residence in the Southeast (12). The influence of SES on the development of risk factors for kidney disease begins early in life (13). Among ESRD patients, barriers in access to kidney transplantation start much earlier than the time of ESRD diagnosis; neighborhood characteristics such as poverty (14), residential segregation (15) and urban/rural location (15) are associated with access to kidney transplantation. As expected, the concentration of high-poverty neighborhoods in the Southern United States (9) results in geographic differences in access to optimal care for ESRD patients compared with other regions of the country (16) including lower rates of arteriovenous fistula use (17) and decreased access to the deceased donor waiting list (18) and to kidney transplantation (19,20).

Can we blame our poor health outcomes on where we live? Although the burden of many chronic diseases is higher, access to optimal healthcare is lower and rates of poverty are among the highest in the South compared with the rest of the United States, we present several opportunities for overcoming these geographic disparities in this viewpoint article. The purpose of this paper is to summarize several potential individual-, dialysis facility-, ESRD Network- and health system-level reasons why the Southeastern United States is at the bottom of the list with respect to access to kidney transplantation. In addition, we offer our viewpoint—as members of the kidney transplant community in Georgia and key stakeholders into the health of this community—of several proposed strategies for overcoming these differences and striving for geographic equity in healthcare access and outcomes.

Access to Kidney Transplantation in the Southeastern United States

The ESRD Networks are contracted by the Centers for Medicare & Medicaid Services (CMS) to oversee the quality of care provided to dialysis patients within each of 18 geographical regions (21). As we report in this issue of AJT, dialysis facilities in ESRD Network 6 (GA, NC and SC) have the lowest facility-level standardized transplant ratios (STRs) of all ESRD Networks (Figure 2). Within Network 6, the state of Georgia has the lowest STR (0.57), where a total of 87% of facilities in Georgia have an STR < 1. Other Southern ESRD Network regions are also among the lowest ranked ESRD Networks for STRs—Network 13 (AR, LA and OK) with STR 0.72, and Network 8 (AL, MS and TN) with STR 0.75 (16). The Northeast region has the highest STR; Network 1 (CT, ME, MA, NH, RI and VT) has an STR of 1.61. What might explain these geographic differences in access to kidney transplantation?

Patient-Level Factors and Opportunities

The patient population of the South is different than the rest of the nation. The public health burden of ESRD in this region is high—the ESRD incidence rate is 380 patients per million population in Network 6, versus 343 in the United States overall. African-Americans make up 55.4% of the incident ESRD population and 67% of the prevalent ESRD population in Network 6, compared to 28% and 37% of the national ESRD population, respectively (22). The racial composition of the region explains in part the higher incidence rate of ESRD, which is about four times higher among African-Americans versus whites (22). Research has consistently documented racial disparities in access to kidney transplantation (23), particularly in the Southeast (14,24), likely explaining some of the geographic differences in transplant access.

In addition, individuals residing in the Southern region of the country are more likely poor compared with other areas of the country. Residents of Georgia, North Carolina and South Carolina are among the most likely to be uninsured (7) and have the lowest 4-year high school graduation rates (25). The influence of individual-level poverty on access to kidney transplantation in the Southeast has also been well established; patients who have lower education levels, live in higher poverty neighborhoods and have public (vs. private) health insurance experience reduced access to kidney transplantation (14,24).

Risk factors for kidney disease, including diabetes, hypertension and obesity, are more prevalent in the Southeastern United States compared with other regions of the country (2). Hypertension and diabetes that account for more than 60% of incident ESRD (26) are more common among minorities and individuals with lower SES (27,28). Obesity and physical inactivity are also risk factors for chronic kidney disease (CKD) (29). A recent study examining county-level differences in physical activity and obesity found wide variation across the nation, and counties in the Deep South were among the worst regions (30). The reasons for the differences in these risk factors for CKD and ESRD in the South, versus other regions of the country, may begin as early as *in utero* (31), may influence individuals throughout the course of their life (32), and may include genetic predisposition (33), individual-level poverty and environmental factors such as a high-salt diet (34).

The proportion of ESRD patients who are medically eligible for kidney transplantation is unknown; and the definition of medical eligibility may vary by transplant center. It is also unclear whether regional differences in medical eligibility contribute to geographic differences in transplant rates. Estimates of ineligibility due to medical contraindications range from 8% to 20% (35–37) depending on the population, although these estimates are based on single-center data for referred patients; no regional comparisons are available, so it is unknown whether a greater proportion of patients from the South are medically ineligible for transplant. A higher prevalence of hypertension, diabetes and obesity in the region implies that there remains significant opportunity for improving primary prevention of renal disease in the South, as well as for earlier referral of late-stage CKD patients for kidney transplantation.

Dialysis Facility–Level Factors and Opportunities

Dialysis facilities play a key role in patient access to kidney transplantation. The variability in STRs observed across dialysis facilities in the United States, and even within states with low STRs—such as Georgia (Figure 3)—suggests that there may be differences at the dialysis facility level that could contribute to some of the observed differences in STR. In this issue of AJT, we report that the lowest rates of transplantation are among patients in dialysis facilities located in the South and Southeast. Surprisingly, no patients from 36 facilities in ESRD Network 6 received a kidney transplant over the recent 4-year period studied (8% of all facilities in the Network) (38). This included 24 facilities in Georgia (10% of all facilities in Georgia) and 10 in Atlanta alone without a single transplant. There are many potential reasons for the variability seen in transplant rates between different dialysis facilities, including that eligible patients are not being referred for transplant, and that referred patients do not follow through with their evaluation. At Emory, the largest transplant center in Georgia, nearly half of patients who are referred do not show up to start the transplant evaluation process (24). Referral and evaluation data are not available on a national level, so it is unclear whether these differences are unique to the Southeast.

We reported national data on dialysis facility–level factors associated with STR and transplant access. We found that as the number of staff per facility increased, so did access to kidney transplantation. The mean number of staff within facilities located in ESRD Network 6 is among the lowest in the nation, at 13.6 ± 6.2 . In addition, we found

significantly fewer staff among for-profit versus nonprofit facilities. Lower staffing may be a result of less funding for dialysis facilities; increasing administrative requirements may also make staff increasingly busy. For instance after the institution of the revised 2008 CMS conditions for coverage, surveys report that nephrology social worker patient caseloads increased 8% from 2007 to 2010 (39); the number of job tasks performed by social workers also increased (40). Financial pressures may be particularly felt by for-profit centers. These pressures have further increased in recent years with the 2011 institution of a bundled payment system for dialysis services which includes medication costs, as well as the recently proposed 9% cut in dialysis reimbursement; administrators may continue to focus on cutting costs, resulting in further reductions in staffing. A decrease in staffing may lead to disparities in the quality of education offered to patients regarding transplantation in the Southeast, as well as at for-profit versus nonprofit facilities, and may explain some of the observed disparities (41). However, profit status was still a significant predictor of STR after controlling for staffing levels within facilities. The fact that the association of for-profit status and lower transplant rates has been documented since 1999 (42) continues to raise the question of whether there is an inherent conflict of interest which prevents some for-profit centers from pursuing renal transplantation for some eligible ESRD patients. It is currently unknown whether the impact of either for-profit facilities or staffing within a facility on transplant access varies across geographic regions.

There are a number of opportunities to improve access to transplant at the dialysis facility level to ensure that all medically eligible patients are referred for kidney transplantation, and complete the evaluation process. Although dialysis units report that education occurs, patient surveys reveal many do not receive transplant education (43). There is no standardized curriculum or educational program that can ensure patients receive basic information on kidney transplantation. Unfortunately, lack of reimbursement is often cited as a reason for less education of patients within for-profit dialysis facilities (41). A national policy standardizing patient education could help ensure that decisions regarding transplantation are patient-centered, and that patients are engaged, medically appropriate and financially eligible (41). As the patient's de facto "medical home," dialysis centers should actively partner with transplant centers to help patients complete the required medical evaluation, coordinate testing with the outpatient dialysis schedule, and help patients to schedule and complete tests and procedures which can be performed locally, such as colonoscopies, pap smears, mammograms and cardiac testing. Indeed dialysis centers play a central role in maintaining patient health during the years spent on the waitlist, managing cardiovascular risk, nutrition, diabetes, and bone disease, and providing preventive services such as immunization. Although these dialysis facility-based opportunities are not specific to the South, a regional focus on these best practices will help move Southern ESRD patients away from the bottom in terms of ensuring all eligible patients have the opportunity to receive a kidney transplant. There is a clear need to monitor referral for kidney transplantation in national surveillance data in order to evaluate regional differences in referrals and measure how such interventions or policy changes may influence referral over time.

ESRD Network–Level Factors and Opportunities

ESRD Network 6 is the largest ESRD Network in the nation, with more than 550 facilities treating nearly 40 000 patients (44). Southern ESRD Networks consistently score lower on national quality measures such as arteriovenous fistula placement rates and hemoglobin levels (45). This suggests there may be an association between the ESRD Network, dialysis facility characteristics and quality of care within facilities. However, the only ESRD Network–level factor we found to be associated with dialysis facility STR was the number of transplant centers per 10 000 ESRD patients. Network 6 has the fewest of all ESRD Network regions, with 2.2 transplant centers per 10 000 ESRD patients. The concept that fewer transplant centers contribute to lower transplant rates in the Southeast, an area of higher ESRD incidence, complements prior research showing that transplant rates are lower in areas of higher ESRD incidence (20). The inequitable distribution of transplant centers in regions of the country with a greater burden of disease may itself be an additional barrier to equitable patient access to kidney transplantation.

In addition to the relative lack of transplant centers, Georgia and the Southeast rank near the bottom in other measures of healthcare infrastructure, such as numbers of physicians and number of graduate medical education training programs (46). Paradoxically, transplant waiting times are relatively short in the Southeast, but centers may be working close to their capacity to evaluate and list patients, and in particular to evaluate patient and donor pairs for living donor transplantation. Although the association of fewer transplant centers per 10 000 ESRD patients does not prove causality, investigating whether increasing the number of transplant centers in certain areas could improve transplant rates should be an active area of social policy research. However, we believe transplant centers should be equitably distributed—the location of transplant centers should mirror the location of areas of high disease burden.

In September 2010, the Southeastern Kidney Council, the organization that holds the CMS contract for ESRD Network 6, initiated the development of a community-based Southeastern Kidney Transplant Coalition to identify and reduce barriers to transplantation in our region. The Coalition is comprised of a multidisciplinary group of more than 40 voluntary stakeholders in the ESRD community, including patients, dialysis facilities, transplant centers, administrators, social workers, organ procurement organizations, providers and patient advocacy groups within Georgia, North Carolina and South Carolina. Members of the coalition have come together to address the barriers to kidney transplantation, and to work with ESRD Network 6 to conduct quality improvement (QI) interventions to improve access to kidney transplantation, in particular for patients in dialysis facilities with the lowest transplant rates. This work is now being completed as part of the CMS Innovation Pilot Projects (47). The CMS ESRD Network 2013 Statement of Work includes a requirement to measure and reduce health disparities in all ESRD Network activities and to conduct a pilot innovation project to reduce disparity specifically in transplant referral, a key step in access to transplantation. Seven ESRD Networks (1, 2, 6, 8, 9/10 and 15) have chosen QI projects on reducing disparity in transplant referral. The Southeastern Transplant Coalition can serve as a model for the transplant community coming together to address issues of importance and to improve transplant care. Outcomes,

such as a better understanding of transplant referral among all ESRD Networks, may help focus interventions, funding and regional policy initiatives to reduce geographic differences and increase transplant rates, as well as reducing racial disparity in access to transplantation.

Health System–Level Differences and Opportunities

There are many other health system– and policy-level factors that influence geographic differences in kidney transplant access. The overall availability of organs varies by organ procurement organization donation service area due to differences in organ demand, organ utilization, discard rates, donor recruitment and expanded criteria donor (ECD) utilization (19). An individual transplant center's practices in accepting organs may be more or less conservative due to increased scrutiny of transplant center performance by regulatory bodies (48). It is unknown whether the behavioral economics of transplant programs varies by region, but there is some evidence that this may play a role in the geographic differences in transplant access. It is notable that Southern states, including Georgia, have medium to high deceased donation rates and organ supply in comparison to other regions of the country (20). In addition, the acceptance of ECD organs may not offer as great a survival benefit to young ESRD patients, yet are more likely to be accepted by young African-Americans with low income or education, compared with whites and those with higher SES (49). Transplant centers also have a responsibility to ensure that underprivileged and/or minority patient populations have adequate support and resources to pursue transplantation, including transportation resources, financial assistance and/or patient navigators to help guide patients through potential barriers to waitlisting.

Differences in federal or state policies that influence access to care may play a role in geographic differences in access to transplantation. Most recently many Southern states have decided to forgo Medicaid expansion, including every state in the Deep South except Arkansas, but including North Carolina, South Carolina and Georgia; the map of states not expanding Medicaid mirrors the continental poverty divide (see Figure 1B). It is disappointing that the residents of the 26 states failing to expand Medicaid are disproportionately poor, uninsured and African-American (50). This policy will reduce access to CKD screening, as well as to treatment of risk factors such as hypertension and diabetes that can slow the progression of CKD, thereby reducing the demand for kidney transplants. We urge state governments to expand Medicaid as called for in the Affordable Care Act, particularly in Southern communities; we must not limit affordable healthcare among the US citizens most affected by, or most at risk for, kidney disease.

Conclusion

Despite a high incidence of kidney disease, a high demand for kidney organs and a relatively large supply of deceased kidney donors, Southern states have the lowest rates of kidney transplantation in the nation. Our observation that the dialysis facility–level kidney transplant rates vary substantially within the Southeast suggests that there may be a significant opportunity to focus efforts to improve access to kidney transplantation on a dialysis facility level. A targeted intervention among poorly performing dialysis facilities within ESRD Network regions with low transplant rates has the potential to increase

referrals for kidney transplantation, leading to higher rates of living and deceased donor kidney transplants, and a reduction in disparities in access to kidney transplantation. Furthermore, regionally coordinated policy changes—such as initiatives to increase staffing, standardize patient education and expand Medicaid eligibility—are needed. Additional transplant centers in areas of high ESRD burden may be required. These are first steps to eliminate health disparities that exist on a structural level (51,52).

In *Crossing the Quality Chasm*, the Institute of Medicine cites equitable healthcare as one of the six aims for improvement concluding, “the quality of care should not differ because of such characteristics as gender, race, age, ethnicity, income, education, disability, sexual orientation or location of residence” (53), p. 53). In our location of residence, in the Southeastern United States, we have outlined major inequities that lead to diminish access to healthcare in general, and to kidney transplantation specifically. We believe that large-scale neighborhood or regional interventions that address improvement in social opportunity, and changes in healthcare policies to improve access to healthcare services, are warranted in many Southern states.

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Abbreviations

CKD	chronic kidney disease
CMS	Centers for Medicare & Medicaid Services
ECD	expanded criteria donor
ESRD	end-stage renal disease
QI	quality improvement
SES	socioeconomic status
STR	standardized transplant ratio

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Figure 1.

(A) The continental poverty divide. This map shows county-level concentrated poverty areas and spatial outliers of poverty. Southern US states are characterized by high levels of poverty, with pockets of low-poverty outliers. In contrast, Northern states are characterized by areas of concentrated low-poverty areas, with high poverty spatial outliers. (B) US states are not expanding Medicaid under the Affordable Care Act.

Figure 2. Standardized transplant ratio (STR) rank by state, US dialysis facilities 2007–2010. An STR is defined as the observed number of transplants within a dialysis facility divided by the expected number of transplants within that facility. An STR value of 1.0 is the national average. Dialysis facilities with STR < 1 indicate that the number of observed transplants is less than expected. Dialysis facilities with STR > 1 indicate that the number of observed transplants is more than expected. Southern states are ranked among the lowest states for STR.

Figure 3. Dialysis facility-level standardized transplant ratios (STRs) in Georgia, 2007–2010

The state of Georgia has the lowest dialysis facility-level STR. There is much variability in STR within the state of Georgia, where 14% of facilities had more transplants than expected ($STR > 1$) and 86% had fewer transplants than expected ($STR < 1$). A total of 24 dialysis facilities had no transplants over a 4-year time period.