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Article

Health Disparities in Autosomal Dominant Polycystic Kidney Disease (ADPKD) in the United States

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Abstract

Background and objectives Autosomal dominant polycystic kidney disease (ADPKD) occurs at conception and is often diagnosed decades prior to kidney failure. Nephrology care and transplantation access should be independent of race and ethnicity. However, institutional racism and barriers to health care may affect patient outcomes in ADPKD. We sought to ascertain the effect of health disparities on outcomes in ADPKD by examining age at onset of kidney failure and access to preemptive transplantation and transplantation after dialysis initiation.

Design, setting, participants, & measurements Retrospective cohort analyses of adults with ADPKD in the United States Renal Data System from January 2000 to June 2018 were merged to US Census income data and evaluated by self-reported race and ethnicity. Age at kidney failure was analyzed in a linear model, and transplant rates before and after dialysis initiation were analyzed in logistic and proportional hazards models in Black and Hispanic patients with ADPKD compared with White patients with ADPKD.

Results A total of 41,485 patients with ADPKD were followed for a median of 25 (interquartile range, 5–54) months. Mean age was 56±12 years; 46% were women, 13% were Black, and 10% were Hispanic. Mean ages at kidney failure were 55±13, 53±12, and 57±12 years for Black patients, Hispanic patients, and White patients, respectively. Odds ratios for preemptive transplant were 0.33 (95% confidence interval, 0.29 to 0.38) for Black patients and 0.50 (95% confidence interval, 0.44 to 0.56) for Hispanic patients compared with White patients. Transplant after dialysis initiation was 0.61 (95% confidence interval, 0.58 to 0.64) for Black patients and 0.78 (95% confidence interval, 0.74 to 0.83) for Hispanic patients.

Conclusions Black and Hispanic patients with ADPKD reach kidney failure earlier and are less likely to receive a kidney transplant preemptively and after initiating dialysis compared with White patients with ADPKD.

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Introduction

Autosomal dominant polycystic kidney disease (ADPKD) is the most common hereditary kidney disorder and the fourth most common cause of kidney failure (1). ADPKD is caused by mutations in *PKD1* or *PKD2* genes in 93% (2), resulting in cyst formation and gradual kidney enlargement over decades prior to loss of kidney function. Patients with ADPKD typically progress to kidney failure in the sixth decade of life (1,3–5).

At-risk individuals are often diagnosed decades prior to starting kidney treatments, with 40% undergoing asymptomatic diagnostic screening (6). Hypertension is a common manifestation, and about half of patients with ADPKD become hypertensive during their late twenties, leading to early diagnosis (7). Others are diagnosed due to gross hematuria, pyelonephritis, or nephrolithiasis. Most individuals with ADPKD are diagnosed more than two decades before kidney failure (8). Diagnosing an individual at risk for progression to kidney failure improves predialysis care through better BP control with appropriate antihypertensives (9), increased fluid intake, medications that slow progression of disease (10), dietary modifications, preemptive transplantation, and appropriate vascular access. In ADPKD families, unaffected relatives are motivated to donate kidneys, promoting a high frequency of transplant evaluation and preemptive transplantation in ADPKD compared with other kidney disorders (11).

Epidemiologic studies show no differences in incidence rates of ADPKD on the basis of racial or ethnic identity (12–14). Small retrospective studies have examined whether disease severity differs on the basis of racial identity with conflicting results (15,16). Concomitant risk factors for kidney damage due to sickle cell disease and *APOL1* may exist in Black patients (17,18); however, there are few data available demonstrating that race is associated with higher risk for progression to kidney failure in ADPKD. Little or no information is currently available regarding associations between age at kidney failure or transplantation

access in individuals who self-identify as Hispanic ADPKD patients.

Institutional racism affects the delivery of medical care, resulting in health disparities and poorer outcomes in Black and Hispanic patients (19–21). Early recognition of kidney disease, access to nephrology care before kidney failure, use of antihypertensive agents, BP control, access to kidney transplantation, preemptive transplantation, and home dialysis are reduced in Black and Hispanic patients compared with White patients (22–26). These health care delivery disparities suggest that patient outcomes in ADPKD may also differ by racial or ethnic identity. The magnitude of health disparity varies throughout the United States, where significant differences in care and outcomes in Black patients and Hispanic patients with kidney failure vary by geographic region (27–29). We therefore sought to evaluate medical care access and kidney outcomes in patients with ADPKD in the United States on the basis of self-reported racial and ethnic identity in the setting of socioeconomic and geographic factors.

Materials and Methods

Study Design

We performed a retrospective cohort analysis of patients with ADPKD using United States Renal Data System (USRDS) and US Census Bureau data. The study population consisted of patients 30 years or older with ADPKD defined by diagnosis codes 753.13, 753.13A, 753.13Y, or Q61.2 and a first transplant or dialysis service date between January 2000 and June 2018. Age ≥30 years was chosen to avoid diagnostic inaccuracies with other hereditary kidney disorders, such as autosomal recessive polycystic kidney disease. We restricted our analyses to three mutually exclusive groups: non-Hispanic White, non-Hispanic Black, and Hispanic patients, which represented >95% of individuals with ADPKD in our USRDS sample. Identification of race and ethnicity was obtained from Medical Evidence Forms; ascertainment of race is made by self-report. The research protocol was approved by the institutional review board of the University of Chicago.

Clinical and health care covariates selected from USRDS Medical Evidence Forms (Centers for Medicare & Medicaid Services Form 2728) and the patients' files included age at first dialysis or transplant, serum albumin, hemoglobin, body mass index, and eGFR using the USRDS variable GFR_EPI, which provides the 2009 Chronic Kidney Disease Epidemiology Collaboration equation without using a race coefficient. Binary variables included sex, nephrology care prior to kidney failure, insurance coverage (private insurance versus all others), and use of erythropoietin-stimulating agents (ESA) prior to kidney failure. USRDS files were used to determine dates of first service and whether this was hemodialysis, peritoneal dialysis, or kidney transplant. Vascular access data, included on the Medical Evidence Form after mid-2005, were analyzed among individuals initiating hemodialysis for whom data were available. Dates of first appearance on the transplant waiting list, first transplant, and death were collected. Patients were followed until first transplantation, death, or June 30, 2018, whichever came first. Median income for each US zip code area in the year of incident kidney failure was obtained from US Census Bureau American Community Survey files.

Statistical Analyses

Mean and median values were used to summarize normally and non-normally distributed continuous covariates, and categorical variables were expressed as percentages. A linear model was constructed to calculate age at the onset of kidney failure adjusted for race and ethnicity, sex, nephrology care and ESA use prior to kidney failure, median income for zip code, insurance status, eGFR, body mass index, hemoglobin level, serum albumin concentration, and whether the initial event was dialysis or transplantation.

A logistic model was constructed to obtain odds ratios for preemptive transplantation by race and ethnicity adjusted for age, sex, serum albumin, body mass index, median income, nephrology care prior to kidney failure, private insurance, and employment status. A Kaplan–Meier plot was constructed to visualize the unadjusted probability of transplantation among patients who initiated dialysis. A cause-specific Cox proportional hazards model was used to obtain hazard ratios for time to transplantation among patients who started dialysis and were not transplanted preemptively. We also performed a subdistribution hazards model according to the method of Fine and Gray (30), treating death as a competing outcome, to account for reported differences in survival of patients receiving dialysis on the basis of race and ethnicity. We performed exploratory subgroup analyses stratified for each of the ESRD networks specified by the Centers for Medicare & Medicaid Services to determine whether transplantation outcomes were influenced by geographical factors, and examined wait times and transplantation outcomes before and after the Kidney Allocation System that occurred on December 4, 2014.

In all models, White patients with ADPKD were the reference group, allowing for calculation of odds ratios and hazard ratios for Black and Hispanic patients. Missing data were handled using multiple imputation using the Markov chain Monte Carlo method, with generation of 25 imputation datasets for each model. Two-way interactions were evaluated and included in the adjusted model when significant. P values of 0.05 were considered statistically significant. All analyses were conducted using SAS, version 9.4 (SAS Institute Inc, Cary, NC).

Results

Between 2000 and 2018, 41,485 patients with ADPKD and age of ≥30 years were enrolled in USRDS. Median follow-up was 25 months (interquartile range, 5–54 months). Mean age at dialysis initiation or transplant was 56±12 years, 46% were women, 77% were White patients, 13% were Black patients, and 10% were Hispanic patients. Patient characteristics are shown in Table 1. Compared with White patients, Black patients and Hispanic patients were more likely to be women; were less likely to have private insurance, employment, or prior nephrology care; and had lower eGFR and hemoglobin levels. Black patients had the lowest serum albumin levels and the most frequent use

Table 1. Characteristics of patients with autosomal dominant polycystic kidney disease in the United States Renal Data System survey at the time of a first transplant or dialysis initiation from January 2000 through June 2018

Characteristic	All, n=41,485	White, n=32,065	Black, n=5517	Hispanic, n=3903
Age at kidney failure onset, yr (SD)	56 (12)	57 (12)	55 (13)	53 (12)
BMI, kg/m^2 (SD)	28.0 (6.8)	28.1 (6.8)	27.9 (7.2)	27.7 (6.5)
Median household income for zip code area, ×$1000 (SD)	54 (22)	56 (22)	46 (20)	47 (21)
eGFR, ml/min per 1.73 m^2 (SD)	8.4 (3.9)	8.8 (3.9)	7.0 (3.4)	7.6 (3.7)
Hemoglobin, g/dl	10.5 (1.8)	10.7 (1.8)	9.7 (1.9)	10.1 (1.8)
Albumin, mg/dl	3.8 (0.6)	3.8 (0.6)	3.6 (0.6)	3.8 (0.6)
Women, %	46	46	50	46
Nephrology care before kidney failure, %	90	92	84	81
EPO, %	33	33	34	30
Private insurance, %	68	73	54	52
Employment, %				
6 mo prior to kidney failure	45	47	39	42
At onset of kidney failure	37	39	29	31
First kidney failure treatment, *n* (%)				
Preemptive transplant	6586 (16)	6009 (19)	266 (5)	311 (8)
Hemodialysis	27,787 (67)	20,365 (63)	4445 (80)	2977 (76)
Peritoneal dialysis	7112 (17)	5691 (18)	806 (15)	615 (16)
Comorbid conditions, %				
Diabetes	9	9	13	11
Hypertension	89	89	92	89
Congestive heart failure	8	8	12	5
Stroke	4	4	6	4
Cancer	4	4	5	2

All variables are presented as mean (SD) unless otherwise stated. Missing data are <1% for all variables except hemoglobin (12%), albumin (23%), nephrology care (25%), and EPO (17%). BMI, body mass index; EPO, erythropoietin.

of ESAs. During the study period, 1,836,245 adult patients without ADPKD were enrolled in USRDS. Their clinical and demographic characteristics are provided in Supplemental Table 1.

Kidney Replacement Therapy Modality and Access

Peritoneal dialysis was the initial kidney treatment in 15% overall, representing 18% of White patients, 15% of Black patients, and 16% of Hispanic patients (P<0.001). Hemodialysis was the initial treatment modality for 63% of White patients, 80% of Black patients, and 76% of Hispanic patients (P<0.001). Vascular access data were missing in 25%–30% of patients who initiated hemodialysis. Central venous catheter use occurred in 53% of White patients, 62% of Black patients, and 63% of Hispanic patients for whom data were available (P<0.001).

Preemptive Kidney Transplant

Transplantation was more frequent in White (52%) compared with Black (31%) or Hispanic (42%) patients with ADPKD. The proportions of preemptive kidney transplantation also differed (5% for Black patients and 8% for Hispanic patients versus 19% for White patients), as did living donor transplantation (7% for Black patients and 15% for Hispanic patients versus 27% for White patients; P<0.001 for all). The proportions of patients included on transplantation waiting lists and elapsed time from waitlisting until transplantation differed significantly across groups (Table 2). Black and Hispanic patients with ADPKD were less likely to be waitlisted prior to kidney failure (20% for Black patients and 22% for Hispanic patients versus 38% of White patients; P<0.001). Median time from waitlisting to kidney transplantation was longer (28 months for Black patients and 24 months for Hispanic patients) compared with 15 months for White patients (P<0.001). Transplant outcomes for patients enrolled before and after the change in the Kidney Allocation System are presented in Supplemental Table 2.

In the adjusted analysis, compared with White patients, kidney treatments were initiated 2.6 (95% confidence interval [95% CI], 2.2 to 2.9) and 4.8 (95% CI, 4.4 to 5.2) years earlier in Black and Hispanic patients, respectively. The effect of median income in the residential zip code was modified by race. Each additional $10,000 was associated with age at kidney failure occurring 0.36 (95% CI, 0.33 to 0.39) years later among White patients. This effect of median income was attenuated to 0.14 (95% CI, 0.03 to 0.25) years among Black patients with ADPKD and not statistically significant at 0.06 (95% CI, −0.06 to 0.18) years among Hispanic patients with ADPKD. This interaction between median income and race was included in the adjusted model for age at kidney failure. An interaction between private health insurance and preemptive transplant was also identified, suggesting that private insurance resulted in earlier transplantation, with modest effect on age at dialysis initiation. In the logistic model, the unadjusted odds of preemptive transplantation were 0.22 (95% CI, 0.19 to 0.25) and 0.38 (95% CI, 0.33 to 0.42) lower for Black and Hispanic patients, respectively. After adjustment for age, sex, income, employment, private health insurance, nephrology care, body mass index, hemoglobin, and serum albumin, preemptive transplantation rates were 0.33 (95% CI, 0.29 to 0.38) and 0.50 (95% CI, 0.44 to 0.56) lower for

Table 2. Transplantation outcomes of patients with autosomal dominant polycystic kidney disease by race and ethnicity

Outcome	All (n=41485)	White (n=32065)	Black (n=5517)	Hispanic (n=3903)	P Value
Waitlisted, n (%)	24,768 (60)	19,603 (61)	2783 (50)	2382 (61)	<0.001
Waitlisted prior to kidney failure, n (%)	14,171 (34)	12,229 (38)	1090 (20)	852 (22)	<0.001
Transplant, all, n (%)	19,953 (48)	16,588 (52)	1728 (31)	1637 (42)	<0.001
Preemptive transplant, n (%)	6586 (16)	6009 (19)	266 (5)	311 (8)	<0.001
LD transplant, n (%)	9610 (23)	8620 (27)	407 (7)	583 (15)	<0.001
Preemptive LD transplant, n (%)	4972 (12)	4579 (14)	158 (3)	235 (6)	<0.001
Kidney failure to waiting list, mo, median (IQR)	−2 (−11 to 8)	−3 (−12 to 6)	5 (−7 to 15)	6 (−5 to 15)	<0.001
Waiting list to transplant, mo, median (IQR)	17 (7–34)	15 (6–31)	28 (11–49)	24 (9–48)	<0.001
Kidney failure to transplant, mo, median (IQR)	10 (0–32)	7 (0–27)	31 (10–57)	29 (6–57)	<0.001

LD, living donor; IQR, interquartile range.

Black and Hispanic patients, respectively (P<0.001 for all). A significant interaction between private insurance and median income was included in the model. No other significant interactions were identified. Odds ratios for the adjusted model are shown in Table 3. Network-specific odds ratios are shown in Figure 1, showing regional variations, but odds of preemptive transplantation were lower for Black patients in all networks. Several networks had low numbers of Hispanic patients with ADPKD, resulting in broad 95% CIs. The proportions of White, Black, and Hispanic patients in each network are shown in Supplemental Table 3.

Transplant after Initiation of Dialysis

Among patients who initiated dialysis, disparities in transplantation rate were less yet still significant. The unadjusted rates of transplantation were 0.52 (95% CI, 0.50 to 0.55) and 0.69 (95% CI, 0.65 to 0.73) lower for Black and Hispanic patients, respectively (Figure 2). After adjustment and accounting for death as a competing risk, transplantation was still 0.61 (95% CI, 0.58 to 0.64) and 0.78 (95% CI, 0.74 to 0.83) less likely in Black and Hispanic patients, respectively (Table 4) (P<0.001 for all). Network-specific hazard ratios for transplantation after dialysis initiation are shown in Figure 3, demonstrating significant variability across ESRD networks. The disparity between Black and White patients for preemptive transplantation was greatest in Network 3 (odds ratio, 0.17; 95% CI, 0.06 to 0.43) and for transplantation after dialysis initiation in Network 11 (hazard ratio, 0.45; 95% CI, 0.36 to 0.58). Networks 6, 8, 9, and 13 had <50 Hispanic patients identified, precluding meaningful comparisons. No ESRD networks demonstrated statistically significant advantage for Black or Hispanic patients compared with White patients. Detailed network-specific odds ratios and hazard ratios are presented in Supplemental Table 4.

Discussion

In this study, important patient outcomes such as age of onset of kidney failure and access to kidney transplantation were strongly associated with race and ethnicity. We observed earlier onset of kidney failure in Black and Hispanic patients with ADPKD, confirming another USRDS cohort analysis (18). Economic and geographic factors may account for the racial and ethnic disparities observed (31). The magnitudes of these differences do not equal the effect of genotype. Patients with *PKD1* reach kidney failure approximately 20 years earlier than patients with *PKD2* (32); patients with *PKD1* with truncating mutations develop kidney failure approximately 8 years earlier than those with nontruncating mutations (33).

Our ADPKD study population, consisting of approximately 2% of incident patients in USRDS over 18 years,

Table 3. Preemptive transplantation as the first ESRD service event by race and ethnicity (odds ratios calculated with White patients with autosomal dominant polycystic kidney disease as the reference group)

Variable	Unadjusted	Adjusted
	Odds Ratio (95% Confidence Interval)	Odds Ratio (95% Confidence Interval)
Black	0.22 (0.19 to 0.25)	0.33 (0.29 to 0.38)
Hispanic	0.38 (0.33 to 0.42)	0.50 (0.44 to 0.56)
Women		1.38 (1.30 to 1.47)
Age at kidney failure, per 10 yr		0.80 (0.78 to 0.83)
Employment		1.90 (1.77 to 2.04)
Private insurance		2.67 (2.43 to 2.93)
Nephrology care prior to kidney failure		2.19 (1.91 to 2.52)
Albumin (serum), per 1.0 g/dl		1.05 (1.04 to 1.06)
Hemoglobin, per 1.0 g/dl		1.20 (1.18 to 1.22)
Body mass index, per 1 kg/m^2		0.98 (0.98 to 0.99)
Median income in zip code, per $10,000, with private insurance		1.14 (1.13 to 1.16)
Median income in zip code, per $10,000, all other insurance		1.25 (1.21 to 1.29)

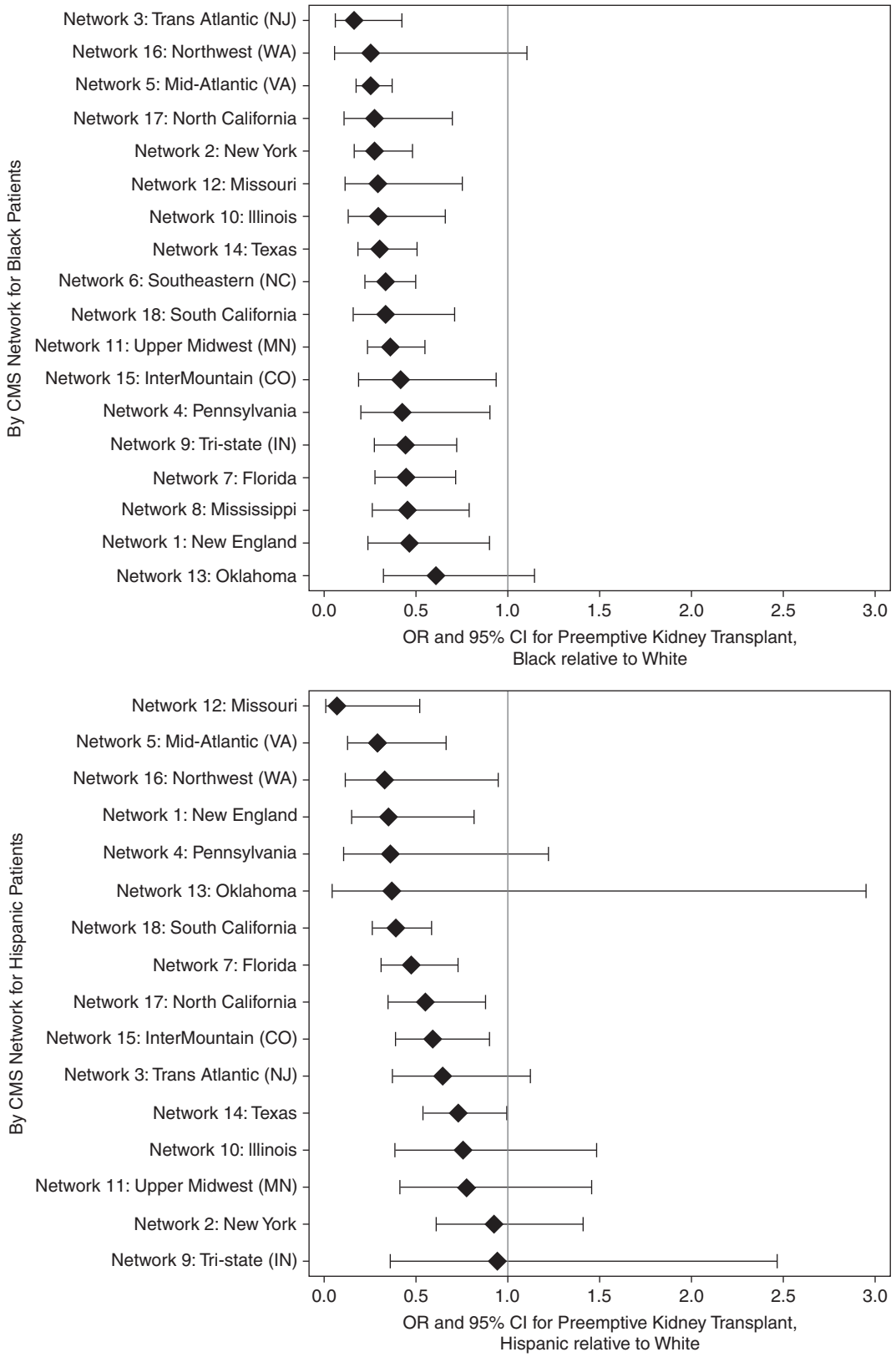

Figure 1. | **Odds ratios (ORs) for preemptive transplantation in Black (upper panel) and Hispanic (lower panel) patients with autosomal dominant polycystic kidney disease (ADPKD) compared with White patients.** Two networks (Network 6 and Network 8) are omitted from the lower panel because no preemptive transplants occurred in Hispanic patients during the study period. 95% CI, 95 confidence interval; CMS, Centers for Medicare & Medicaid Services; CO, Colorado; IN, Indiana; MN, Minnesota; NC, North Carolina; NJ, New Jersey; VA, Virginia; WA, Washington.

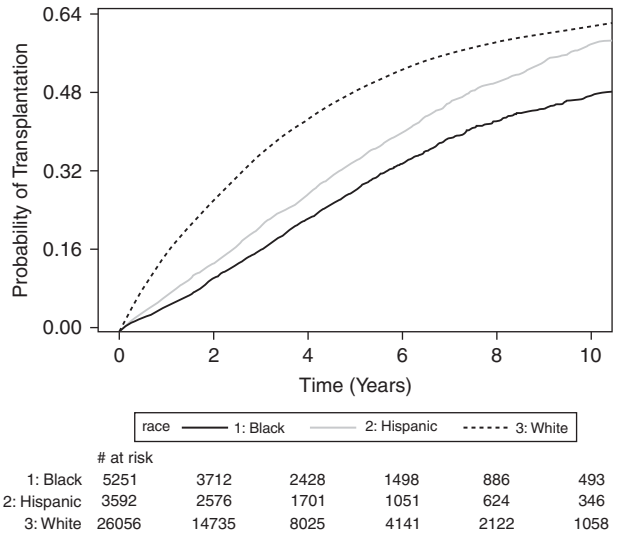

Figure 2. | Kaplan–Meier failure curve representing the unadjusted probability of receiving a kidney transplant by race and ethnicity among patients with ADPKD who initiated dialysis as a first kidney treatment event.

initiated treatment with peritoneal dialysis in 17% of patients compared with 8% for the entire incident USRDS population (34), even though combined liver and kidney volumes are often considered a barrier to peritoneal dialysis. Patients with ADPKD electing hemodialysis were less likely to initiate treatment with a central venous catheter, which is the initial vascular access for >80% of patients on incident hemodialysis (35). Similarly, 16% of patients with ADPKD received preemptive kidney transplants, nearly twice as often as in the full USRDS population (36), but this advantage accrued almost exclusively in White patients with ADPKD. These advantages may reflect earlier predialysis care with appropriate referrals and preparation for dialysis and transplantation. Patients with ADPKD are also supported by national advocacy groups, such as the PKD Foundation, that concentrate on advancing quality of care and influencing public policy to promote better patient outcomes. Our data show that these advantages are significantly greater among White patients. Health equity in ADPKD care is therefore an important goal.

In this cohort, age at onset of kidney failure was significantly earlier among Black and Hispanic patients with ADPKD compared with White patients with ADPKD. Employment often ceases once kidney failure occurs, reducing access to insurance, transportation, medications, and optimal nutrition. Earlier onset of kidney failure in Black and Hispanic patients reduces productive working years. Household income and private insurance were lower among Black and Hispanic patients, which may independently affect patient outcomes and transplantation rates. Early nephrology referral with disease-specific management of ADPKD and management of comorbid conditions can be compromised by financial adversity. Greater efforts to accommodate workplace needs and maintain financial

Table 4. Transplantation after initiation of dialysis by race and ethnicity (odds ratios calculated with White patients with autosomal dominant polycystic kidney disease as the reference group)

Variable	Unadjusted		Adjusted, Cause Specific		Adjusted, Subdistribution Hazards	
	Hazard Ratio (95% Confidence Interval)	*P* Value	Hazard Ratio (95% Confidence Interval)	*P* Value	Hazard Ratio (95% Confidence Interval)	*P* Value
Black	0.52 (0.50 to 0.55)	<0.001	0.57 (0.54 to 0.60)	<0.001	0.61 (0.58 to 0.64)	<0.001
Hispanic	0.69 (0.65 to 0.73)	<0.001	0.71 (0.67 to 0.75)	<0.001	0.78 (0.74 to 0.83)	<0.001
Women			1.01 (0.98 to 1.05)	0.50	1.04 (1.01 to 1.08)	0.02
Age at kidney failure, per 10 yr			0.71 (0.70 to 0.72)	<0.001	0.66 (0.65 to 0.67)	<0.001
Median income in zip code, per $10,000			1.06 (1.06 to 1.07)	<0.001	1.06 (1.06 to 1.07)	<0.001
Employment			1.47 (1.41 to 1.53)	<0.001	1.58 (1.52 to 1.65)	<0.001
Private insurance			2.09 (2.01 to 2.19)	<0.001	2.15 (2.05 to 2.25)	<0.001
Nephrology care prior to kidney failure			1.37 (1.28 to 1.46)	<0.001	1.34 (1.25 to 1.44)	<0.001
Albumin (serum), per 1.0 g/dl			1.01 (1.01 to 1.02)	<0.001	1.02 (1.02 to 1.03)	<0.001
Hemoglobin, per 1.0 g/dl			1.02 (1.00 to 1.03)	0.005	1.02 (1.01 to 1.03)	0.002
Body mass index, per 1 kg/m^2			0.98 (0.98 to 0.98)	<0.001	0.98 (0.98 to 0.98)	<0.001

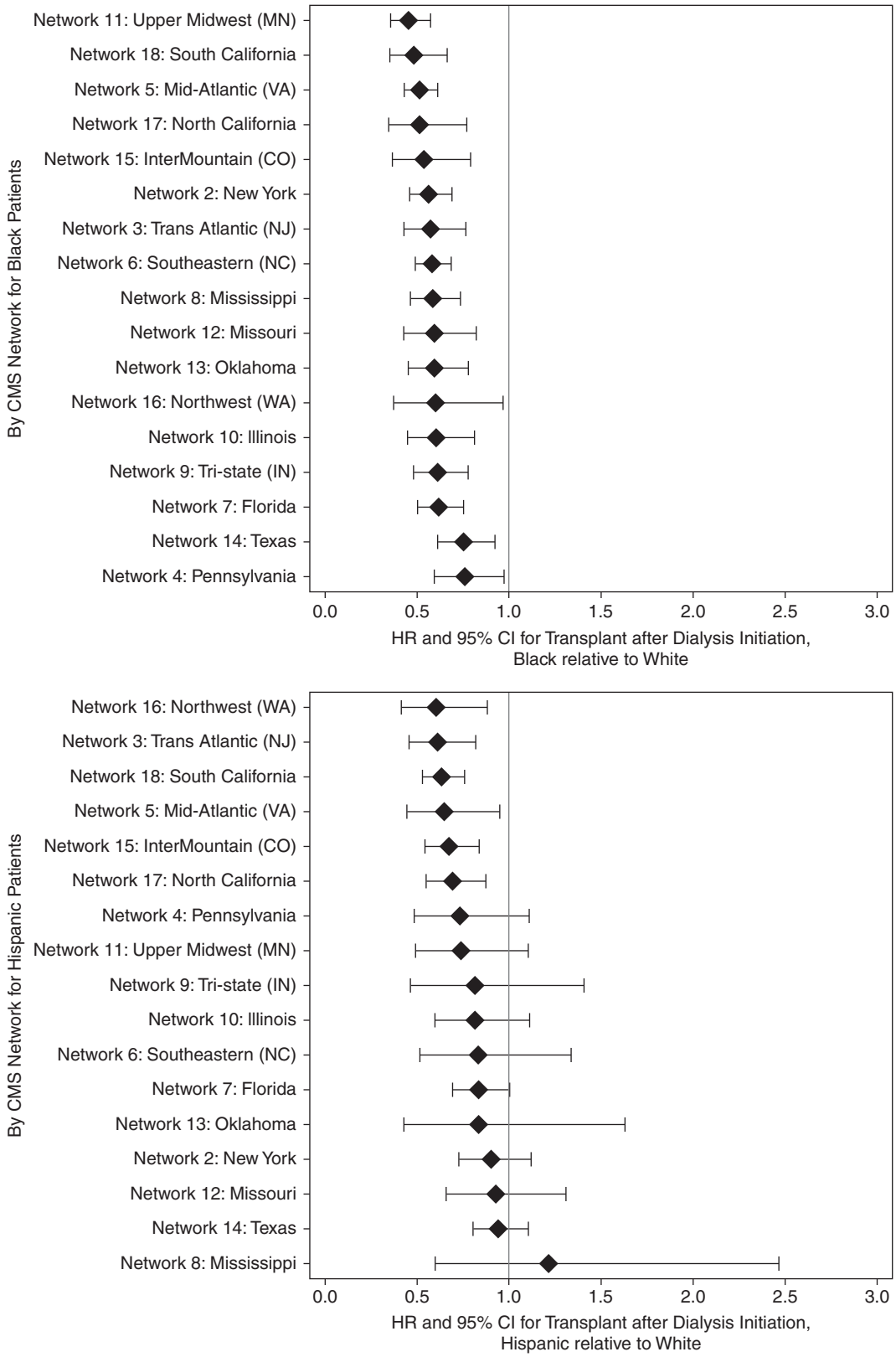

Figure 3. | **Adjusted hazard ratios (HRs) for transplantation among patients initiating dialysis in Black (upper panel) and Hispanic (lower panel) patients with ADPKD compared with White patients.** CO, Colorado; IN, Indiana; MN, Minnesota; NC, North Carolina; NJ, New Jersey; VA, Virginia; WA, Washington.

solvency and insurance coverage before and after kidney failure are an effective way to improve health equity in ADPKD. For example, providing Medicare coverage to uninsured or underinsured patients when eligible for kidney transplant evaluation (when the eGFR is <20 ml/min per 1.73 m^2) rather than upon the onset of kidney failure could enhance access to transplantation.

Access to transplantation is crucial to securing optimal outcomes in all patients with kidney failure. Black and Hispanic patients with ADPKD demonstrated less access to transplantation and a lower rate of preemptive transplantation for many reasons. Late referral to nephrology care is associated with less awareness of care options and reduced access to transplantation (37,38). Preemptive transplantation typically requires a living donor given that a deceased donor transplant typically requires years to obtain. Unaffected family members often donate kidneys to affected relatives with ADPKD, progressively depleting the living donor pools within ADPKD families. Potential explanations for our observation include the known reduced referral rates for Black patients for preemptive transplantation (39–42). To counteract this phenomenon, early educational initiatives directed at increasing awareness of living donation and guidance about living donor risk stratification may help. Incorporation of culturally competent practices and language concordant care can reduce barriers to transplantation among recipients and donors alike (43–45). Social and economic challenges may make donation more of a hardship. On the basis of our study findings, policy initiatives protecting living donors from financial hardships and job loss are just as important in ADPKD as other kidney diseases.

Although there are many correctable structural aspects to improving nephrology care and better access to preemptive transplantation in Black patients and Hispanic patients, other medical comorbidities may play a role in the differences in age of onset of kidney failure and transplantation rates. Black patients had significantly lower hemoglobin and albumin levels and greater use of ESA agents at the time of initiation of KRT. Measuring the potential effect of disorders, such sickle cell trait or thalassemia, was not possible and may negatively affect the rate of progression of kidney disease. APOL1 mutations, specific to Black individuals, occur in recessive fashion in 13% of individuals and modify the risk of kidney disease (46). Finally, comorbid conditions seen with higher frequency in Hispanic and Black individuals, including obesity, type 2 diabetes mellitus, and underlying vascular disease, may affect the eligibility of potential donors (40).

Although preemptive transplantation may reflect earlier access to nephrology care, all patients receiving dialysis have a nephrologist. Nonetheless, rates of transplantation remained substantially lower among Black and Hispanic patients after initiating kidney treatments, suggesting additional barriers. In our models, employment and private insurance were strongly associated with higher transplantation rates; however, adjustment for clinical and economic variables explained only part of the observed differences. ESRD networks varied with regard to transplantation rates in Black and Hispanic individuals, suggesting that health inequities differ by region, which has been previously reported with regard to transplant education and referral among eligible patients (47,48).

A strength of this study is the large national dataset followed over an extended period of time, with adjustment for several clinical, economic, and geographic factors. Limitations of this report arise from its retrospective design and lack of genetic information. Our results regarding age at dialysis onset may not be applicable currently because recent advances have improved ADPKD diagnosis and treatment. Risk stratification for disease progression has been developed with the use of age-based height-corrected total kidney volume, and disease-modifying therapy with vasopressin V2 receptor antagonists began in April of 2018. It will be critical to ensure that new therapies that alter the natural history of ADPKD do not lead to widening of care disparities as more advantaged groups may have greater access and uptake (49,50).

In conclusion, there are significant disparities in the age at onset of kidney failure, dialysis modality, and access to transplantation for Black and Hispanic patients with ADPKD in all regions of the United States. Compared with White patients, Black and Hispanic patients with ADPKD have earlier age of onset of kidney failure and less access to kidney transplantation. National and local resources need to focus on education and outreach, and they need to clarify these systemic disadvantages to achieve health equity for all patients.

Disclosures

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Author Contributions

A.B. Chapman, R.L. McGill, and M.R. Saunders conceptualized the study; R.L. McGill was responsible for formal analysis; A.L. Hayward and M.R. Saunders were responsible for methodology; A.L. Hayward was responsible for software; A.B. Chapman and R.L. McGill provided supervision; A.B. Chapman, A.L. Hayward, R.L. McGill, and M.R. Saunders wrote the original draft; and A.B. Chapman, A.L. Hayward, R.L. McGill, and M.R. Saunders reviewed and edited the manuscript.

Supplemental Material

This article contains supplemental material online at http://cjasn.asnjournals.org/lookup/suppl/doi:10.2215/CJN.00840122/-/DCSupplemental.

Supplemental Table 1. Baseline characteristics of adult patients without ADPKD from 2000 to 2018 by race and ethnicity.

Supplemental Table 2. Transplantation outcomes of patients with ADPKD by race and ethnicity prior to the 2014 Kidney Allocation System and after the 2014 Kidney Allocation System.

Supplemental Table 3. Racial and ethnic distribution of patients with ADPKD by ESRD network.

Supplemental Table 4. Transplant opportunities for Black and Hispanic patients with ADPKD compared with White patients by ESRD network.

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