

THE EFFECT OF PATIENTS' PREFERENCES ON RACIAL DIFFERENCES IN ACCESS TO RENAL TRANSPLANTATION

JOHN Z. AYANIAN, M.D., M.P.P., PAUL D. CLEARY, PH.D., JOEL S. WEISSMAN, PH.D., AND ARNOLD M. EPSTEIN, M.D.

ABSTRACT

Background In the United States, black patients undergo renal transplantation less often than white patients, but few studies have directly assessed the association between race and patients' preferences with respect to transplantation.

Methods To assess preferences with respect to transplantation and experiences with medical care, we interviewed 1392 (82.9 percent) of 1679 eligible patients with end-stage renal disease (age range, 18 to 54 years) approximately 10 months after they had begun maintenance treatment with dialysis. Participants were selected from a stratified random sample of patients undergoing dialysis in four regions of the United States (Alabama, southern California, Michigan, and the mid-Atlantic region of Maryland, Virginia, and the District of Columbia) in 1996 and 1997. Patients were followed until March 1999.

Results The interviews were conducted with 384 black women, 354 white women, 337 black men, and 317 white men. Black patients were less likely than white patients to want a transplant (76.3 percent of black women reported such a preference, vs. 79.3 percent of white women, and 80.7 percent of black men vs. 85.5 percent of white men), and they were less likely to be very certain about this preference (58.3 percent vs. 65.3 percent and 64.1 percent vs. 75.7 percent, respectively; $P < 0.01$ for each comparison with both sexes combined). However, much larger differences were evident in rates of referral for evaluation at a transplantation center (50.4 percent for black women vs. 70.5 percent for white women, and 53.9 percent for black men vs. 76.2 percent for white men; $P < 0.001$ for each comparison) and placement on a waiting list or transplantation within 18 months after the start of dialysis therapy (31.3 percent for black women vs. 56.5 percent for white women, and 35.3 percent for black men vs. 60.6 percent for white men; $P < 0.001$). These racial differences remained significant after adjustment for patients' preferences and expectations about transplantation, sociodemographic characteristics, the type of dialysis facility, perceptions of care, health status, the cause of renal failure, and the presence or absence of coexisting illnesses.

Conclusions In the United States, the preferences and expectations with respect to renal transplantation among patients with end-stage renal disease differ according to race. These differences, however, explain only a small fraction of the substantial racial differences in access to transplantation. Physicians should ensure that black patients who desire renal transplantation are fully informed about it and are referred for evaluation. (N Engl J Med 1999;341:1661-9.)

©1999, Massachusetts Medical Society.

RACIAL differences in access to effective medical procedures are a persistent problem in the United States.¹⁻⁶ Black patients are less likely than white patients to undergo renal transplantation,⁷⁻¹² coronary-artery bypass surgery and angioplasty,¹³⁻¹⁶ carotid endarterectomy,¹⁷ peripheral vascular surgery,¹⁸ total knee and hip arthroplasty,^{5,19} cataract surgery,² sigmoidoscopy,² and screening mammography.^{2,20} Although these differences have been documented repeatedly, health care providers and policy makers have been slow to improve black patients' access to medical procedures, possibly in part because the reasons for the racial differences are unclear.²¹ Racial bias is one possible explanation, but some have speculated that patients' preferences might explain racial differences in care.²² Despite the importance of this issue, only a few studies have examined the association between race and patients' preferences with regard to major procedures²³⁻²⁷; these studies have been limited by small numbers of patients and indirect measures of preferences.

Renal transplantation is a useful model for the direct assessment of patients' preferences. In 1996, more than 70,000 Americans began treatment for end-stage renal disease (ESRD), and nearly 12,000 received renal transplants.²⁸ Since people with ESRD require life-sustaining dialysis or transplantation, almost all potential candidates for transplantation, unlike candidates for most other major medical procedures, can be reliably identified and located. Transplantation is an attractive treatment option because it improves the quality of life and is less costly than life-long dialysis.²⁹⁻³¹

Despite these benefits, black patients are much less likely than white patients to be evaluated for renal transplantation and placed on a waiting list for a transplant,⁹⁻¹¹ and these differences have not been attributable to clinical factors, such as coexisting conditions or functional status.¹⁰⁻¹² To determine whether racial differences in access to transplantation are

From the Department of Medicine, Division of General Medicine and Primary Care, Section on Health Services and Policy Research, Brigham and Women's Hospital and Harvard Medical School (J.Z.A., A.M.E.); the Department of Health Care Policy, Harvard Medical School (J.Z.A., P.D.C., J.S.W.); the Institute for Health Policy, Massachusetts General Hospital (J.S.W.); and the Department of Health Policy and Management, Harvard School of Public Health (A.M.E.) — all in Boston. Address reprint requests to Dr. Ayanian at the Department of Health Care Policy, Harvard Medical School, 180 Longwood Ave., Boston, MA 02115, or at ayanian@hcp.med.harvard.edu.

explained by patients' preferences, we interviewed patients with ESRD in four regions of the United States.

METHODS

Study Sample

We studied patients with newly diagnosed ESRD who resided in Alabama, southern California, Michigan, or the mid-Atlantic region (Maryland, Virginia, and the District of Columbia), in collaboration with the ESRD Networks serving these four geographically diverse areas (Network 8, the Southern California Renal Disease Council, the Renal Network of the Upper Midwest, and the Mid-Atlantic Renal Coalition, respectively). These organizations are funded by the Health Care Financing Administration to monitor and improve the quality of care provided to patients with ESRD. The study protocol was approved by the Human Studies Committee of Harvard Medical School and by the Health Care Financing Administration.

Each renal network identified all patients between the ages of 18 and 54 years who had begun to receive maintenance treatment with dialysis during the period from May 1996 through June 1997 (through September 1997 in Alabama). We focused on this age group because relatively few children undergo dialysis, and they are often treated in specialized units, and because adults over the age of 54 years are much more likely than younger adults to have coexisting illnesses that preclude transplantation.¹² We selected a stratified random sample of black women, black men, white women, and white men within each region, for a total of 1933 patients. We excluded 254 patients for the following reasons: they had died (100 patients) or moved out of their region (25) within nine months after starting dialysis; they had speech, hearing, or cognitive impairments that precluded an interview (51); they did not speak English (31); they had discontinued dialysis or could not be located (19); they had undergone dialysis before May 1996 or at more than three facilities (14); they were incarcerated (11); or they lacked a Social Security number (3).

Data Collection

We interviewed patients approximately 10 months after they had started dialysis therapy, allowing sufficient time for them to become accustomed to dialysis, discuss transplantation with their physicians, and undergo evaluation for a transplant, if desired. Patients were sent a letter from the Health Care Financing Administration describing the voluntary nature of our survey, followed by our letter inviting them to participate and offering a \$20 stipend for completing the interview. Trained interviewers (Gordon Research Services, Orono, Me.) then made at least 10 attempts over a period of four weeks to interview patients by telephone at home.

We asked all patients whether they had received a kidney transplant. For patients who had not received a transplant, we asked the following questions: "Do you want to have a kidney transplant?" "How certain are you about this decision?" "Have you ever been referred to a transplant center to be examined and tested to see if it is appropriate for you to go on a transplant waiting list?" We also asked what effects the patients expected transplantation would have (as compared with dialysis) on their quality of life and survival.

To assess patients' perceptions of their medical care, we asked whether their primary nephrologist provided as much information as they desired, to what extent they agreed with that doctor about medical decisions, and to what extent they trusted that doctor's judgment.³² We also asked whether a doctor had recommended transplantation or had discussed the possibility of receiving a kidney from a family member and whether they believed that they had received worse medical care than other patients in the previous six months because of their race, income, or sex.

Respondents rated their overall health during the most recent month on dialysis from 0 ("the poorest health a person can be

in") to 100 ("the best health possible for a person of your age who has no major health problems"). Other dimensions of health status during the most recent month on dialysis (converted to a similar 100-point range) included energy (four items), emotional well-being (five items), physical activity (two items), social activity (one item), and the burden of kidney disease on daily life (nine items).³³ We also asked patients about their education, income, marital status, employment status, automobile ownership, medical insurance, and family history of kidney disease, as well as whether a family member was willing to donate a kidney to them.

We obtained data from the renal networks and the United Network for Organ Sharing on patients who had received a renal transplant or been placed on a waiting list as of March 1999; we were thus able to assess these outcomes 18 months after the start of dialysis therapy for all patients. Data on the type of dialysis facility (for-profit, not-for-profit, or government) were obtained from the Health Care Financing Administration. Renal-network staff also reviewed the medical records of 1169 surveyed patients whose records could be obtained (84.2 percent of black patients and 83.8 percent of white patients) to collect data on coexisting illnesses (coronary heart disease, congestive heart failure, peripheral vascular disease, chronic lung disease, and cancer) and referrals for evaluation at a transplantation center.

Statistical Analysis

We compared the characteristics of respondents and nonrespondents with the use of administrative data from the renal networks. Among respondents, we compared the socioeconomic and clinical characteristics of black and white patients with stratification according to sex, because prior studies have suggested that there are sex differences in access to renal transplantation.^{7,10-12} We used Student's *t*-test to compare continuous variables and Pearson's chi-square test to compare categorical variables, and we report two-tailed *P* values for all descriptive tests.

Among surveyed patients, we analyzed patients' preferences for transplantation and two primary measures of access to transplantation: whether patients reported having been referred for evaluation at a transplantation center and whether they had been placed on a waiting list or had received a transplant within 18 months after the start of dialysis. We also compared these measures within each region and among respondents who wanted a transplant and those who were "very certain" about this preference. In a secondary analysis of the 1169 patients whose medical records were available, we reclassified 64 patients (23 black women, 12 white women, 18 black men, and 11 white men) who reported that they had not been referred for evaluation but whose medical records showed evidence of a referral. In another secondary analysis, we compared waiting-list rates according to race after excluding the 56 patients (6 black women, 22 white women, 3 black men, and 25 white men) who received transplants from living donors and were not placed on a waiting list.

We used multiple logistic regression to estimate the adjusted relative odds of two outcomes for black women, white women, and black men as compared with white men: referral for evaluation at a transplantation center and placement on a waiting list for a transplant or receipt of a transplant within 18 months after the start of dialysis therapy. In a series of models, we controlled for numerous factors that might account for racial differences in access to renal transplantation, including patients' preferences (wanting a transplant and being very certain about wanting it), expectations about transplantation (quality of life and survival), perceptions of care (views of the primary nephrologist and discrimination within the previous six months), sociodemographic characteristics (region, age, education, income, health insurance, employment status, marital status, and automobile ownership), type of dialysis facility,³⁴ primary cause of renal failure, health status (overall health and the five aspects noted above), and the five coexisting illnesses specified above. Using white men as the reference group, we converted these adjusted odds ratios to absolute probabilities,³⁵ which we report with 95 percent confidence inter-

vals. This method of adjustment results in confidence intervals for all estimated probabilities except those in the reference group.

RESULTS

Characteristics of the Patients

Of 1679 eligible patients, 1392 were interviewed (response rate, 82.9 percent), including 384 black women (82.8 percent of eligible black women), 354 white women (85.7 percent of eligible white women), 337 black men (81.2 percent of eligible black men), and 317 white men (81.9 percent of eligible white men) ($P=0.33$). Respondents and nonrespondents did not differ significantly according to age, region, rural or urban residence, body-mass index, primary cause of renal failure, or type of dialysis ($P>0.12$ for all comparisons). The median interval from the initiation of dialysis therapy to the interview was 10.2 months for black women, 9.8 months for white women, 9.4 months for black men, and 9.9 months for white men. Ten black women (2.6 percent), 48 white women (13.6 percent), 15 black men (4.5 percent), and 52 white men (16.4 percent) had received kidney transplants during this period ($P=0.001$), most commonly from living donors (9, 28, 8, and 32 patients, respectively).

Black and white respondents were similar with respect to the region, age, and presence or absence of a history of kidney disease in members of the immediate family (Table 1). However, significantly fewer black women and men than white women and men had graduated from high school or college, had relatively high incomes, were married or employed, owned an automobile, had private health insurance, or had diabetes as the primary cause of ESRD. Black women were more likely than white women to be undergoing dialysis in for-profit facilities. Black patients reported better overall health and higher energy levels during dialysis therapy than white patients but reported similar levels of emotional well-being, physical activity, and social activity and a similar burden of kidney disease in daily life. White patients were more likely than black patients to have coronary artery disease, and white men were more likely than black men to have peripheral vascular disease.

Preferences and Experiences with Care

Black patients were less likely than white patients to want a kidney transplant, to be very certain about this preference, and to expect that their quality of life would improve with transplantation (Table 2) ($P<0.01$ for each comparison with both sexes combined). Black men were less likely than white men to expect to live longer with a transplant ($P=0.04$), but black and white women had similar expectations about their survival with a transplant ($P=0.72$); when the sexes were combined, the difference between black patients and white patients was of borderline significance ($P=0.07$).

Blacks were less likely than whites to report that their primary nephrologist provided all the medical information they desired, that they agreed with this doctor about how to manage their health conditions, and that they trusted this doctor's judgment about their medical care (Table 3). Black patients were less likely to report that they had learned about transplantation before undergoing dialysis or that a physician had discussed the possibility of receiving a kidney from a family member. Black and white women were similarly likely to report that they had a family member who was willing to donate a kidney (53.9 percent and 52.0 percent, respectively; $P=0.60$), but black men were less likely than white men to report that they had a potential family donor (45.7 percent vs. 53.3 percent, $P=0.05$).

Although few patients of either race reported that a physician had advised them not to undergo transplantation, black patients were less likely to report that a physician had recommended it. Black patients were more likely than white patients to report that they had received worse medical care than other patients during the previous six months because of their race, income, or sex, but the absolute differences according to race were relatively small.

Access to Transplantation

In contrast to the relatively small differences in preferences and expectations about transplantation, black patients were much less likely than white patients to have been referred to a transplantation center for evaluation; they were also much less likely to have been placed on a waiting list or to have received a transplant within 18 months after the initiation of dialysis (Table 4). These differences were similar in magnitude and were significant ($P<0.04$) in three of the four regions (data not shown); the exception was southern California, where black and white women had similar rates of referral (57.0 percent and 60.0 percent, respectively; $P=0.70$). Among the 1169 patients whose medical records we obtained, blacks were less likely to have been referred, according to these records (55.5 percent of black women vs. 75.2 percent of white women, and 60.4 percent of black men vs. 82.3 percent of white men; $P<0.001$ for each comparison).

Among patients who wanted a transplant, blacks remained significantly less likely than whites to have been referred for evaluation and significantly less likely to have been placed on a waiting list or to have received a transplant within 18 months after the start of dialysis therapy (Fig. 1). Even among the patients who said they were very certain that they wanted a transplant, blacks were substantially less likely than whites to have been referred for evaluation (62.8 percent of black women vs. 83.6 percent of white women, and 62.0 percent of black men vs. 83.2 percent of white men; $P<0.001$ for each comparison).

TABLE 1. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF THE STUDY COHORT.*

CHARACTERISTIC	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
Region (%)			0.99			0.30
Alabama	17.2	17.2		18.7	18.9	
Michigan	29.7	30.5		24.6	29.3	
Southern California	20.8	21.2		20.5	22.1	
Mid-Atlantic region	32.3	31.1		36.2	29.7	
Mean age (yr)	42.0	42.7	0.28	41.7	41.6	0.87
Education (%)			0.001			0.001
College graduate	9.9	13.6		12.5	18.3	
High-school graduate	64.1	68.8		63.2	65.6	
Neither	26.0	17.6		24.3	16.1	
Annual income (%)			0.001			0.001
≥\$60,000	4.4	17.8		10.1	21.8	
\$40,000–\$59,999	10.9	16.9		9.2	15.5	
\$20,000–\$39,999	21.6	26.6		26.4	24.9	
\$12,000–\$19,999	20.1	16.7		19.6	17.7	
<\$12,000	28.7	11.6		23.1	13.9	
Unknown	14.3	10.4		11.6	6.3	
Married (%)	32.3	62.2	0.001	45.4	56.8	0.001
Employed (%)	13.5	24.6	0.001	18.4	32.2	0.001
Automobile owner (%)	65.6	91.2	0.001	82.8	92.7	0.001
Private health insurance (%)‡	38.5	65.5	0.001	38.6	62.8	0.001
History of kidney disease in immediate family (%)	22.9	22.4	0.74	21.1	17.0	0.42
Primary cause of ESRD (%)			0.001			0.001
Diabetes mellitus	37.0	46.0		25.8	44.2	
Hypertension	35.9	7.1		41.5	10.1	
Glomerulonephritis	9.9	13.0		14.0	20.8	
Other	17.1	33.9		18.7	24.9	
Type of dialysis facility (%)			0.04			0.72
For-profit	68.0	61.3		66.2	66.6	
Not-for-profit	25.0	33.3		24.9	26.2	
Government	7.0	5.4		8.9	7.3	
Score for health status during dialysis§						
Overall health	65.0	58.6	<0.001	65.7	60.7	0.004
Energy	46.3	39.2	<0.001	48.2	43.6	0.006
Emotional well-being	61.2	61.7	0.75	65.1	66.0	0.58
Physical activity	32.8	30.2	0.25	38.3	41.0	0.30
Social activity	55.7	57.6	0.39	58.4	57.7	0.77
Burden of kidney disease on daily life	36.3	34.4	0.30	37.0	35.1	0.32
Coexisting illness (%)¶						
Coronary heart disease	14.3	21.7	0.02	12.6	24.3	0.001
Congestive heart failure	9.7	12.6	0.25	11.9	11.6	0.91
Peripheral vascular disease	6.9	9.2	0.28	4.9	9.7	0.03
Chronic lung disease	3.1	2.0	0.40	2.8	3.7	0.54
Cancer	4.1	3.4	0.67	2.5	2.2	0.87

*Percentages may not sum to 100, because of rounding. ESRD denotes end-stage renal disease.

†Pearson's chi-square test or Student's t-test was used for comparisons of black and white patients with stratification according to sex.

‡Patients with private health insurance may or may not have had Medicare or Medicaid coverage.

§Health status was scored on scales from 0 (poor) to 100 (excellent).

¶Data are based on medical records for 321 black women (83.6 percent of black women), 294 white women (83.1 percent of white women), 286 black men (84.9 percent of black men), and 268 white men (84.5 percent of white men).

and were substantially less likely to have been placed on a waiting list or to have received a transplant within 18 months after the start of dialysis therapy (44.2 percent vs. 71.4 percent and 45.4 percent vs. 70.8 percent, respectively; $P < 0.001$ for each comparison). After the exclusion of the 56 patients who received transplants from living donors and were not placed on a waiting list, black women and men were less likely than white women and men to have been

placed on a waiting list within 18 months after the initiation of dialysis therapy (30.2 percent vs. 52.7 percent and 34.1 percent vs. 57.2 percent, respectively; $P < 0.001$).

With adjustment for patients' preferences with respect to transplantation and numerous other potential confounders, black women and men were still significantly less likely than white men to have been referred for evaluation and placed on a waiting list

TABLE 2. PATIENTS' PREFERENCES AND EXPECTATIONS WITH REGARD TO TRANSPLANTATION, ACCORDING TO RACE AND SEX.*

VARIABLE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
	percent			percent		
Want to receive a renal transplant			0.13			0.04
Yes	76.3	79.3		80.7	85.5	
No	9.4	11.1		5.7	6.9	
Not sure	14.3	9.6		13.6	7.6	
“Very certain” about preference for a renal transplant	58.3	65.3	0.05	64.1	75.7	0.001
Expected quality of life with transplantation as compared with dialysis			0.09			0.06
Better	84.1	90.1		85.8	91.8	
About the same	6.8	3.7		6.8	4.1	
Worse	1.6	1.4		3.3	1.0	
Not sure	7.5	4.8		4.1	3.1	
Expected survival with transplantation as compared with dialysis			0.72			0.04
Longer	57.8	61.6		57.0	66.6	
About the same	22.4	20.3		21.7	19.9	
Shorter	3.4	2.5		4.4	3.1	
Not sure	16.4	15.5		16.9	10.4	

*Percentages may not sum to 100, because of rounding.

†Pearson's chi-square test was used to compare black and white patients with stratification according to sex.

TABLE 3. PATIENTS' PERCEPTIONS OF MEDICAL CARE, ACCORDING TO RACE AND SEX.*

PERCEPTION OF CARE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
	percent			percent		
Primary nephrologist provides sufficient information	73.2	81.4	0.008	74.0	83.4	0.004
Agrees with primary nephrologist's medical decisions			0.004			0.007
Completely	50.1	53.3		47.9	50.0	
Mostly	24.5	30.9		24.4	33.8	
Somewhat or not at all	25.3	15.8		27.7	16.2	
Trusts primary nephrologist's judgment			<0.001			0.003
Completely	52.2	64.2		54.5	58.2	
Mostly	24.0	24.4		23.8	29.8	
Somewhat or not at all	23.8	11.4		21.7	12.0	
Learned about transplantation before starting dialysis	28.7	39.3	0.002	24.3	40.1	<0.001
A physician discussed option of receiving kidney from a family member	66.7	75.9	0.006	66.5	80.8	<0.001
A physician recommended transplantation	59.7	75.3	<0.001	63.4	77.9	<0.001
A physician advised patient not to undergo transplantation	5.0	7.9	0.10	4.5	7.6	0.09
Received worse care than others in past 6 months						
Because of race	3.4	1.7	0.14	5.7	1.6	0.006
Because of sex	3.4	1.1	0.04	3.3	1.3	0.08
Because of income	6.4	2.3	0.007	7.4	3.5	0.03
Any of the above	8.6	4.0	0.01	10.4	5.1	0.01

*Percentages may not sum to 100, because of rounding.

†Pearson's chi-square test was used to compare black and white patients with stratification according to sex.

TABLE 4. PROBABILITY OF ACCESS TO RENAL TRANSPLANTATION BY BLACK WOMEN, WHITE WOMEN, AND BLACK MEN, AS COMPARED WITH WHITE MEN.*

VARIABLE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	BLACK MEN (N=337)	WHITE MEN (N=317)
	percent (95% confidence interval)			
Referred for evaluation				
Unadjusted probability	50.4 (42.3–58.5)	70.5 (62.8–77.1)	53.9 (45.5–62.1)	76.2
Adjusted probability				
Adjusted for preferences and expectations	53.4 (44.8–61.9)	73.0 (65.2–79.6)	55.2 (46.4–63.8)	76.2
Adjusted for sociodemographic factors and type of dialysis facility	59.6 (50.7–67.8)	72.0 (64.1–78.8)	59.8 (50.9–68.1)	76.2
Adjusted for perceptions of care	49.6 (41.3–57.9)	69.1 (61.2–76.1)	53.8 (45.3–62.2)	76.2
Adjusted for health status and cause of renal failure	53.8 (45.0–62.2)	72.7 (65.1–79.2)	56.5 (47.5–65.0)	76.2
Adjusted for all the above	62.5 (52.5–71.5)	74.2 (65.7–81.2)	62.2 (52.3–71.2)	76.2
Adjusted for all the above and coexisting conditions†	59.9 (48.2–70.6)	75.1 (65.4–82.9)	61.2 (49.8–71.5)	78.2
Placed on waiting list or received transplant within 18 months				
Unadjusted probability	31.3 (25.0–38.3)	56.5 (48.9–63.9)	35.3 (28.5–42.9)	60.6
Adjusted probability				
Adjusted for preferences and expectations	33.6 (26.5–41.5)	61.1 (52.7–68.8)	36.5 (28.9–44.7)	60.6
Adjusted for sociodemographic factors and type of dialysis facility	40.8 (32.8–49.4)	59.1 (50.8–66.9)	41.1 (33.0–49.6)	60.6
Adjusted for perceptions of care	31.4 (25.0–38.7)	55.9 (48.1–63.4)	36.3 (29.3–44.1)	60.6
Adjusted for health status and cause of renal failure	34.7 (27.7–42.6)	59.7 (51.8–67.1)	38.6 (30.9–46.8)	60.6
Adjusted for all the above	44.7 (35.1–54.7)	64.0 (54.9–72.2)	46.0 (36.4–55.8)	60.6
Adjusted for all the above and coexisting conditions†	44.6 (33.7–55.8)	64.7 (54.3–73.8)	48.7 (37.9–59.6)	62.7

*Logistic regression was used to adjust for the specified factors, as described in the Methods section. Odds ratios (for the comparison with white men) were converted to probabilities.³⁵

†Data are for 1169 patients for whom data on coexisting conditions (coronary heart disease, congestive heart failure, peripheral vascular disease, chronic lung disease, and cancer) were available.

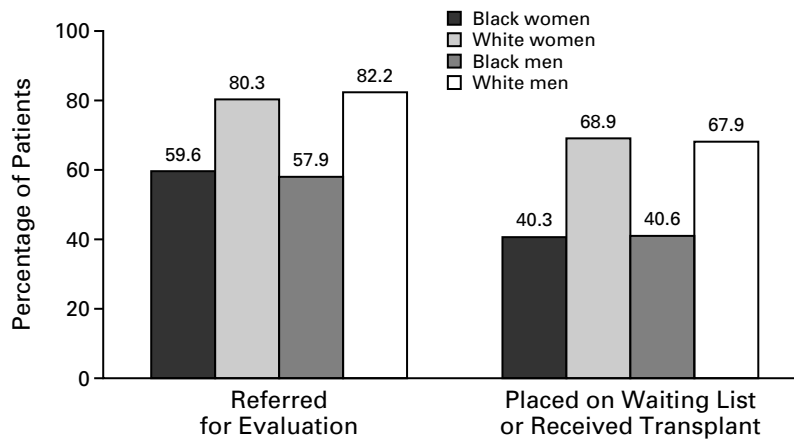


Figure 1. Referral for Evaluation at a Transplantation Center and Placement on a Waiting List or Receipt of a Renal Transplant within 18 Months after the Start of Dialysis among Patients Who Wanted a Transplant, According to Race and Sex.

The data are based on a total of 293 black women, 280 white women, 271 black men, and 271 white men. Racial differences were statistically significant among the women and among the men ($P < 0.001$ for each comparison).

for a transplant or to have received a transplant within 18 months after the start of dialysis therapy (Table 4). Racial differences in access remained significant after we also controlled for coexisting illnesses among patients whose medical records were available. These potential confounders together explained less than half the absolute unadjusted difference in access to transplantation according to race. Sex was not a significant predictor of access to transplantation among black or white patients. With the exclusion of patients who received transplants from living donors and were not placed on a waiting list, black women and men were still significantly less likely than white men to be placed on a waiting list, after adjustment for all other variables in the full logistic-regression model (data not shown).

After adjustment for all the variables we have described, patients undergoing dialysis at the for-profit facilities in our study did not differ significantly from patients undergoing dialysis at not-for-profit facilities with respect to the proportions of patients who had been referred for evaluation at a transplantation center (odds ratio, 0.99; 95 percent confidence interval, 0.71 to 1.38; $P=0.95$). Whereas Garg et al., as reported elsewhere in this issue of the *Journal*,³⁴ found a significantly lower likelihood of having been placed on a waiting list among patients treated at for-profit dialysis centers, we did not find such an association within 18 months after the start of dialysis therapy, after excluding the patients who received transplants from living donors without having been placed on a waiting list (adjusted odds ratio, 0.90; 95 percent confidence interval, 0.65 to 1.26; $P=0.55$).

Significant predictors of referral in the full multivariable model included wanting a transplant and being very certain about this preference, being younger, being a college graduate, having private insurance, reporting better physical functioning, reporting a greater burden of kidney disease on daily life, and residing in Michigan. Significant predictors of placement on a waiting list or receipt of a transplant within 18 months after the start of dialysis therapy included wanting a transplant and being very certain about this preference, expecting to live longer with a transplant, being younger, being a college graduate, having private insurance, being employed, owning an automobile, reporting less energy and better physical functioning while on dialysis, and reporting greater agreement with nephrologists' medical decisions. Patients in southern California were less likely than other patients to be on a waiting list for a transplant or to have received one. In the secondary multivariable analysis of patients whose medical records were available, those with a history of congestive heart failure, peripheral vascular disease, chronic lung disease, or cancer were significantly less likely than others to be on a waiting list for a transplant or to have received one.

DISCUSSION

We assessed whether patients' preferences explained racial differences in access to renal transplantation. Our findings that blacks were much less likely than whites to have been referred for evaluation at a transplantation center and were much less likely to have been placed on a waiting list or to have received a transplant were consistent with the results of previous studies.⁹⁻¹¹ In our study, blacks were less likely than whites to want a transplant or to be very certain about this preference, but these views explained only a small part of the racial differences in rates of referral and of placement on a waiting list or transplantation. Racial differences in access to transplantation remained significant after adjustment for sociodemographic factors, health status, perceptions of care, and coexisting illnesses.

If racial differences in the rates of procedures reflected the preferences of well-informed patients, then such differences might represent acceptable variations in care. Among the patients in our study who desired transplantation, however, black patients were less likely than white patients to have been evaluated and placed on a waiting list or given a transplant. Although few patients reported recent discrimination on the basis of their race, income, or sex, we believe blacks may be more likely than whites to encounter problems in communicating with their physicians and may have less trust in the health care system,^{36,37} as suggested by our data and the preliminary results of one qualitative study.³⁸

Our findings build on other studies that have reported indirect measures of patients' preferences with respect to major procedures according to race. In the Coronary Artery Surgery Study, black laborers were less likely than white laborers to undergo recommended surgery, possibly reflecting their preferences or other factors such as financial barriers.²³ In smaller studies involving hypothetical recommendations to undergo invasive cardiovascular or cerebrovascular procedures, black patients tended to be less willing than white patients to accept these recommendations^{24,25} or the risk associated with surgery.²⁶ In a survey of patients with end-stage renal disease, blacks had more reservations than whites about transplantation, but the patients' desire to undergo transplantation was not assessed directly.²⁷ Our data on patients' preferences and experiences with regard to a major procedure complement a recent study involving simulated patients in which physicians were found to be less likely to recommend coronary angiography for black women than for other patients, despite similar clinical characteristics.³⁹

The strengths of our study include the size and geographic diversity of our sample, the high response rate, and direct reports of patients' preferences and experiences with regard to medical care. We also confirmed patients' reports of whether they were re-

ferred for transplantation by obtaining medical records for more than four fifths of the respondents. However, some patients may not have accurately recalled other information that they reported. Another limitation of our study is that we did not assess barriers to transplantation after patients were referred for evaluation — for example, by determining their ability and willingness to travel to transplantation centers or to complete diagnostic testing.¹¹ Racial differences in patients' preferences should also be evaluated for other major procedures — such as coronary-artery bypass surgery and carotid endarterectomy — that are often performed in patients older than those we studied.

Racial differences in access to renal transplantation are pervasive,⁹ but they are not immutable.⁴⁰ Approaches to improving black patients' access include providing more systematic education about transplantation, offering greater encouragement to undergo evaluation for transplantation and to consider potential living donors, and monitoring and informing physicians and medical groups about racial differences in referral rates among their own patients. By making renal transplantation available to all clinically appropriate candidates who desire it, such efforts would foster greater effectiveness and racial equity in the use of this valuable procedure.

Supported by a grant from the Robert Wood Johnson Foundation. Dr. Ayanian was a Generalist Physician Faculty Scholar of the Robert Wood Johnson Foundation.

We are indebted to the directors of the four ESRD Networks that participated in this study (Nancy Armistead of the Mid-Atlantic Renal Coalition, Diane Carlson of the Renal Network of the Upper Midwest, Jerry Fuller of Network 8, and Douglas Marsh of the Southern California Renal Disease Council) for advice on the study design, recruitment of patients, and interpretation of findings; to Jan Deane, Brenda Dyson, Tina Hirsh, Cindy Horansky, Barbara Meier, Vickie Peters, Colette Snyder, Marcy Stoots, and Cecilia Torres for reviewing medical records; to Joseph Keogh, M.D., and Susan Noonan, M.D., for directing the review of medical records; to Nancy Bauer, Emily Berry, and Christine Kreider of Gordon Research Services for coordinating the telephone interviews; to Berkeley Keck of the United Network for Organ Sharing for providing data about waiting lists for renal transplants; to Rena Conti, JoAnn David-Kasdan, Allison Dimond, Deby Hordon, and Johanna Myers for research assistance; to Karen Fung and Loraine Scampini for statistical programming; to Mary Beth Landrum, Ph.D., and Alan Zaslavsky, Ph.D., for statistical advice; and to Glenn Chertow, M.D., and Barbara McNeil, M.D., Ph.D., for their review of a draft of the manuscript.

REFERENCES

- Elixhauser A, Harris DR, Coffey RM. Trends in hospital procedures performed on black patients and white patients: 1980-87. Provider studies research note 20. Rockville, Md.: Agency for Health Care Policy and Research, April 1994. (AHCPR publication no. 94-0003.)
- Escarce JL, Epstein KR, Colby DC, Schwartz JS. Racial difference in the elderly's use of medical procedures and diagnostic tests. *Am J Public Health* 1993;83:948-54.
- Mort EA, Weissman JS, Epstein AM. Physician discretion and racial variation in the use of surgical procedures. *Arch Intern Med* 1994;154:761-7.
- Gornick ME, Eggers PW, Reilly TW, et al. Effects of race and income on mortality and use of services among Medicare beneficiaries. *N Engl J Med* 1996;335:791-9.
- Giacomini MK. Gender and ethnic differences in hospital-based procedure utilization in California. *Arch Intern Med* 1996;156:1217-24.
- Ayanian JZ. Heart disease in black and white. *N Engl J Med* 1993;329:656-8.
- Kjellstrand CM. Age, sex and race inequality in renal transplantation. *Arch Intern Med* 1988;148:1305-9.
- Held PJ, Pauly MV, Bovbjerg RR, Newmann J, Salvatierra O Jr. Access to kidney transplantation: has the United States eliminated income and racial differences? *Arch Intern Med* 1988;148:2594-600.
- Eggers PW. Racial differences in access to kidney transplantation. *Health Care Financ Rev* 1995;17:89-103.
- Soucic JM, Neylan JF, McClellan W. Race and sex differences in the identification of candidates for renal transplantation. *Am J Kidney Dis* 1992;19:414-9.
- Alexander GC, Sehgal AR. Barriers to cadaveric renal transplantation among blacks, women, and the poor. *JAMA* 1998;280:1148-52.
- Gaylin DS, Held PJ, Port FK, et al. The impact of comorbid and sociodemographic factors on access to renal transplantation. *JAMA* 1993;269:603-8.
- Wenneker MB, Epstein AM. Racial inequalities in the use of procedures for patients with ischemic heart disease in Massachusetts. *JAMA* 1989;261:253-7.
- Ayanian JZ, Udvarhelyi IS, Gatsonis CA, Pashos CL, Epstein AM. Racial differences in the use of revascularization procedures after coronary angiography. *JAMA* 1993;269:2642-6.
- Whittle J, Conigliaro J, Good CB, Lofgren RP. Racial differences in the use of invasive cardiovascular procedures in the Department of Veterans Affairs medical system. *N Engl J Med* 1993;329:621-7.
- Peterson ED, Shaw LK, DeLong ER, Pryor DB, Califf RM, Mark DB. Racial variation in the use of coronary-revascularization procedures: are the differences real? Do they matter? *N Engl J Med* 1997;336:480-6.
- Oddone EZ, Horner RD, Monger ME, Matchar DB. Racial variations in the rates of carotid angiography and endarterectomy in patients with stroke and transient ischemic attack. *Arch Intern Med* 1993;153:2781-6.
- Guadagnoli E, Ayanian JZ, Gibbons G, McNeil BJ, LoGerfo FW. The influence of race on the use of surgical procedures for treatment of peripheral vascular disease of the lower extremities. *Arch Surg* 1995;130:381-6.
- Wilson MG, May DS, Kelly JJ. Racial differences in the use of total knee arthroplasty for osteoarthritis among older Americans. *Ethn Dis* 1994;4:57-67.
- Burns RB, McCarthy EP, Freund KM, et al. Black women receive less mammography even with similar use of primary care. *Ann Intern Med* 1996;125:173-82.
- Kasike BL, Neylan JF III, Riggio RR, et al. The effect of race on access and outcome in transplantation. *N Engl J Med* 1991;324:302-7.
- Horner RD, Oddone EZ, Matchar DB. Theories explaining racial differences in the utilization of diagnostic and therapeutic procedures for cerebrovascular disease. *Milbank Q* 1995;73:443-61.
- Maynard C, Fisher LD, Passamani ER, Pullum T. Blacks in the Coronary Artery Surgery Study (CASS): race and clinical decision making. *Am J Public Health* 1986;76:1446-8.
- Schechter AD, Goldschmidt-Clermont PJ, McKee G, et al. Influence of gender, race, and education on patient preferences and receipt of cardiac catheterizations among coronary care unit patients. *Am J Cardiol* 1996;78:996-1001.
- Whittle J, Conigliaro J, Good CB, Joswiak M. Do patient preferences contribute to racial differences in cardiovascular procedure use? *J Gen Intern Med* 1997;12:267-73.
- Oddone EZ, Horner RD, Diers T, et al. Understanding racial variation in the use of carotid endarterectomy: the role of aversion to surgery. *J Natl Med Assoc* 1998;90:25-33.
- Ozminkowski RJ, White AJ, Hassol A, Murphy M. Minimizing racial disparity regarding receipt of a cadaver kidney transplant. *Am J Kidney Dis* 1997;30:749-59.
- Renal Data System. USRDS 1998 annual data report. Bethesda, Md.: National Institute of Diabetes and Digestive and Kidney Diseases, April 1998.
- Evans RW, Manninen DL, Garrison LP Jr, et al. The quality of life of patients with end-stage renal disease. *N Engl J Med* 1985;312:553-9.
- Eggers PW. Effect of transplantation on the Medicare end-stage renal disease program. *N Engl J Med* 1988;318:223-9.
- Idem*. Comparison of treatment costs between dialysis and transplantation. *Semin Nephrol* 1992;12:284-9.
- Kao AC, Green DC, Zaslavsky AM, Koplan JP, Cleary PD. The relationship between method of physician payment and patient trust. *JAMA* 1998;280:1708-14.

- 33.** Hays RD, Kallich JD, Mapes DL, Coons SJ, Carter WB. Development of the Kidney Disease Quality of Life (KDQOL) Instrument. *Qual Life Res* 1994;3:329-38.
- 34.** Garg PP, Frick KD, Diener-West M, Powe NR. Effect of the ownership of dialysis facilities on patients' survival and referral for transplantation. *N Engl J Med* 1999;341:1653-60.
- 35.** Zhang J, Yu KF. What's the relative risk? A method of correcting the odds ratio in cohort studies of common outcomes. *JAMA* 1998;280:1690-1.
- 36.** Satcher D. Does race interfere with the doctor-patient relationship? *JAMA* 1973;223:1498-9.
- 37.** Levy DR. White doctors and black patients: influence of race on the doctor-patient relationship. *Pediatrics* 1985;75:639-43.
- 38.** Saha S, Robertson M, Rhodes LA, Chrisman NJ, Deyo RA. Race and the use of coronary artery bypass surgery: insight from patient narratives. *J Gen Intern Med* 1999;14:Suppl 2:67. abstract.
- 39.** Schulman KA, Berlin JA, Harless W, et al. The effect of race and sex on physicians' recommendations for cardiac catheterization. *N Engl J Med* 1999;340:618-26. [Erratum, *N Engl J Med* 1999;340:1130.]
- 40.** McCauley J, Irish W, Thompson L, et al. Factors determining the rate of referral, transplantation, and survival on dialysis in women with ESRD. *Am J Kidney Dis* 1997;30:739-48.