

Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor

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Context.—Cadaveric renal transplantation rates differ greatly by race, sex, and income. Previous efforts to lessen these differences have focused on the transplant waiting list. However, the transplantation process involves a series of steps related to medical suitability, interest in transplantation, pretransplant workup, and movement up a waiting list to eventual transplantation.

Objective.—To determine the relative importance of each step in explaining differences in cadaveric renal transplantation rates.

Design.—Prospective cohort study.

Setting and Patients.—A total of 7125 patients beginning long-term dialysis between January 1993 and December 1996 in Indiana, Kentucky, and Ohio.

Main Outcome Measures.—Completion of 4 separate steps during each patient-year of follow-up: (A) being medically suitable and possibly interested in transplantation; (B) being definitely interested in transplantation; (C) completing the pretransplant workup; and (D) moving up a waiting list and receiving a transplant.

Results.—Compared with whites, blacks were less likely to complete steps B (odds ratio [OR], 0.68; 95% confidence interval [CI], 0.61-0.76), C (OR, 0.56; 95% CI, 0.48-0.65), and D (OR, 0.50; 95% CI, 0.40-0.62) after adjustment for age, sex, cause of renal failure, years receiving dialysis, and median income of patient ZIP code. Compared with men, women were less likely to complete each of the 4 steps, with ORs of 0.90, 0.89, 0.80, and 0.82, respectively. Poor individuals were less likely than wealthy individuals to complete steps A, B, and C, with ORs of 0.67, 0.78, and 0.77, respectively.

Conclusions.—Barriers at several steps are responsible for sociodemographic differences in access to cadaveric renal transplantation. Efforts to allocate kidneys equitably must address each step of the transplant process.

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COMPARED WITH long-term dialysis, cadaveric renal transplantation generally offers a longer life span, a better quality of life, and lower health care costs.¹⁻³ However, the scarcity of donor organs means that only a small fraction of patients receive transplants.¹ Despite Medicare financing of kidney transplantation, blacks, women, and poor individuals are less likely to receive transplants than whites, men, and wealthy individuals.^{4,5}

The transplantation process involves a series of steps related to medical suitability, interest in transplantation, pretransplant workup, and movement up the waiting list to eventual transplantation. Some of these steps have been examined individually. For example, blacks may have less interest in transplantation than whites.⁶ Blacks also move up the waiting list at a slower rate than whites. Movement on the waiting list has been studied extensively and appears to reflect both biological factors (eg, HLA-based tissue typing) and non-biological factors (eg, transplant center characteristics).⁷ Other steps, such as the pretransplant workup, have not been examined closely. Moreover, the relative importance of each step in explaining sociodemographic differences in transplantation rates is unknown.

Knowing which steps are most important may help target interventions to allocate kidneys more equitably.

METHODS

Subjects

Eligible subjects were all patients aged 18 to 65 years beginning long-term dialysis between January 1, 1993, and December 31, 1996, in Indiana, Kentucky, and Ohio. We excluded patients with (1) human immunodeficiency virus

See also pp 1153 and 1184.

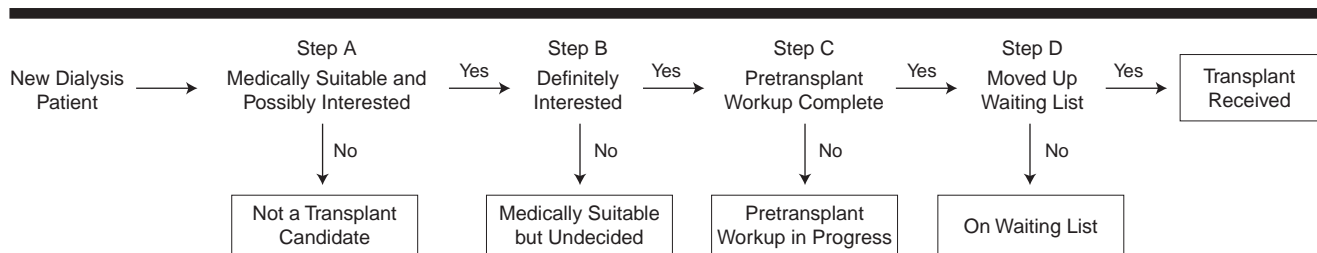
or cancer as the cause of renal failure, (2) a cadaveric renal transplantation prior to 1993, or (3) a renal transplant from a living relative at any time. To simplify the examination of racial differences, we also excluded the 2% of patients who were neither black nor white. Patients were followed up until transplant, death, or December 31, 1996.

Data

Dialysis providers are required to discuss treatment options with patients at least annually, to record the results of this discussion on a long-term program form signed by the patient, and to report this information to The Renal Network Inc, Indianapolis, Ind, a regional agency that monitors the care of patients with renal failure. Each patient's transplant status is classified using 1 of 5 possible codes: not a transplant candidate (ie, not medically suitable or not interested in transplant), medically suitable but undecided, pretransplant workup in progress, on waiting list, and transplant received. The Renal Network's patient database is updated throughout the year as dialysis providers submit long-term program forms. However, archived data are maintained only for the end of each calendar year. We obtained these year-end status codes as well as each patient's race, sex, ZIP code, age, cause of renal failure, dialysis start

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The cadaveric renal transplantation process. Boxes represent the transplant status of subjects at the end of each year of follow-up.

Table 1.—Completion of Steps A Through D by 3 Hypothetical Patients

Patient	Month/Year	Transplant Status		Step Completed*			
		Start of Year	End of Year	Step A Medically Suitable and Possibly Interested	Step B Definitely Interested	Step C Pretransplant Workup Complete and on Waiting List	Step D Moved Up Waiting List and Received Transplant
X	12/93-12/94	New dialysis patient	Undecided	Yes	No
X	12/94-12/95	Undecided	Undecided	...	No
X	12/95-12/96	Undecided	Transplant	...	Yes	Yes	Yes
Y	12/92-12/93	New dialysis patient	Not transplant candidate	No
Y	12/93-12/94	Not transplant candidate	Undecided	Yes	No
Y	12/94-12/95	Undecided	Pretransplant workshop	...	Yes	No	...
Y	12/95-12/96	Pretransplant workup	Dead
Z	12/93-12/94	New dialysis patient	Undecided	Yes	No
Z	12/94-12/95	Undecided	Not transplant candidate	...	No
Z	12/95-12/96	Not transplant candidate	Dead
Total eligible to complete step				4	7	2	1
Successfully completed step				3	2	1	1

*Ellipses indicate not applicable.

date, and date of any transplant from The Renal Network. We determined the median income of each patient's ZIP code from census data.

Statistical Analysis

We used the year-end transplant status code to examine specific steps in the transplant process. The last 3 status codes (pretransplant workup in progress, on waiting list, and transplant received) represent completion of a preceding step in the transplant process (Figure). For example, a status code of "pretransplant workup in progress" indicates the patient is interested in transplantation (step B complete). Similarly, a status code of "on waiting list" indicates that the pretransplant workup (step C) has been completed, whereas a status code of "transplant received" means the patient has moved up the waiting list and received a transplant (step D complete). The first 2 status codes (not a transplant candidate, medically suitable but undecided) are less distinct because they relate to both medical suitability and interest in transplantation. For example, the status code "not a transplant candidate" applies both to patients who are not medically suitable and to patients who are definitely not interested. Despite this limitation, each succeeding transplant status is closer to eventual transplantation. For example, patients with a status code of

"undecided" are medically suitable and possibly interested in transplantation (step A complete) and are more likely to eventually receive a transplant than patients categorized as "not a transplant candidate."

Because of the progression represented by the transplant status codes, each status indicates completion of specific steps in the transplantation process. By contrast, failure to move beyond a particular status or moving backward indicates a corresponding step has not been completed. For example, a patient who remains on the waiting list for an extended period or who goes from the waiting list to "not a transplant candidate" has not completed the final step of moving up the waiting list to transplantation.

We examined patients during each year of follow-up. Each step (A through D) was categorized as completed, not completed, or not applicable for a particular patient year. Table 1 illustrates this method for 3 hypothetical patients. Patient X began dialysis in 1994 and had a transplant status in December 1994 of "undecided." For this time interval, step A is categorized as completed because the patient is medically suitable and possibly interested in transplantation. Completion of this step makes it possible for step B to be completed in the same year. However, the patient is undecided

about transplantation and step B is categorized as not completed. Failure to complete step B makes it impossible for steps C and D to be completed in the same year. As a result, steps C and D are categorized as not applicable for that particular year. Patient X's transplant status in December 1995 was still "undecided." For this year, step A is categorized as not applicable because the patient has already completed this step. As before, completion of step A makes it possible for step B to be completed, but this did not occur. As a result, step B is categorized as not completed and steps C and D as not applicable. Patient X received a transplant in 1996 and had a transplant status in December 1996 of "transplant received." For this year, step A was categorized as not applicable and steps B, C, and D were categorized as completed.

Three points about this method are worth noting. First, a subject may be eligible to complete several steps in the same year as indicated by patient X's completion of steps B, C, and D from December 1995 through December 1996. Second, a patient who dies during a particular year will not have a year-end transplant status code. As a result, that year cannot contribute to the analyses, although earlier years will contribute as illustrated by patients Y and Z in Table 1. Third, it is possible that a patient will

receive a transplant, reject the organ, and return to dialysis in the same year. Because our goal was to examine access to transplantation, we considered the year-end status code of such patients as "transplant received" for our analyses.

Using patient-years as the unit of analysis, we calculated the proportion of patients completing each step. Only steps categorized as completed or not completed were used for these analyses. For example, in Table 1, a total of 4 patient-years provided information about step A. In 3 (75%) of these, the first step was successfully completed. We used either the χ^2 test or the *t* test to examine the univariate relationship between completion of each step and patient demographic and medical variables (race, sex, ZIP code income, age, cause of renal failure, and years on dialysis). Finally, we used logistic regression analysis to examine the multivariate relationship between successful completion of each step and patient demographic and medical variables.

Table 2.—Patient Characteristics (n = 7125 Subjects)

Age, mean (range), y	50 (18-65)
Male, %	55
Ethnicity, %	
White	65
Black	35
Cause of renal failure, %	
Diabetes	49
Hypertension	21
Glomerulonephritis	15
Other	15
ZIP code income, mean (range), thousands of \$	12 (3-37)

Because subjects generally had more than 1 year of follow-up, it may be argued that patient-years are not independent observations. To address this, we performed separate hierarchical logistic regressions accounting for the nesting of years within patients.⁸ These analyses yielded virtually identical findings and are not presented herein.

RESULTS

Patient Characteristics

Of the 9860 patients who met the eligibility criteria, 914 had incomplete demographic data, 685 had no year-end transplant status code because they died or were lost to follow-up within the first calendar year, and 1136 had missing transplant status codes. The remaining 7125 patients formed our study sample and are described in Table 2. Compared with study subjects, the 1136 patients with missing transplant status codes were more likely to be male (58% vs 55%, $P = .04$) but did not otherwise differ from the study subjects by age, race, cause of renal failure, or ZIP code income.

Transplantation Rates

A total of 882 cadaveric transplantations occurred among all subjects for a transplantation rate of 9.0 per 100 patient-years of follow-up. Transplantation rates among whites and blacks were 11.6 and 5.1, respectively, and rates among men and women were 10.4 and 7.3, respectively. Transplantation rates

for patients with ZIP code incomes of less than \$11 000, \$11 000 to \$14 000, and more than \$14 000 were 6.7, 9.4, and 12.4, respectively. As mentioned herein, these calculations exclude 18 transplantations that occurred in the same year as the patient's death.

Steps in the Transplant Process

Using patient-years as the unit of analysis, the overall completion rate was approximately 50% for steps A and D and about 35% for steps B and C (Table 3). On univariate analysis, blacks, women, and poor individuals were less likely to complete most steps in the transplant process compared with whites, men, and wealthy individuals. Racial differences were most pronounced at steps B, C, and D. For example, step B (definite interest in transplantation) was completed in 776 (30%) of 2555 eligible patient-years by black subjects compared with 1667 (39%) of 4290 eligible patient-years by white subjects ($P < .001$). Modest sex differences existed at each step. Income differences were most pronounced at steps A, B, and C. For example, step C (pretransplant workup) was completed in 387 (31%) of 1268 patient-years by individuals with incomes of less than \$11 000 compared with 381 (41%) of 927 patient-years by individuals with incomes of more than \$14 000 ($P < .001$). Age, diabetes, and length of time on dialysis were also associated with completion of several steps.

Table 3.—Univariate Relationship Between Patient Characteristics and Completion of Steps A Through D Using Patient-Years as the Unit of Analysis*

Characteristics	Step A Medically Suitable and Possibly Interested		Step B Definitely Interested		Step C Pretransplant Workup Complete and on Waiting List		Step D Moved Up Waiting List and Received Transplant	
	Eligible, No.	Successful, No. (%)	Eligible, No.	Successful, No. (%)	Eligible, No.	Successful, No. (%)	Eligible, No.	Successful, No. (%)
All patient-years	9315	4618 (50)	6845	2443 (36)	3739	1319 (35)	1902	882 (46)
Race								
White	5923	2987 (50)	4290	1667 (39)	2459	962 (39)	1360	689 (51)
Black	3392	1631 (48)	2555	776 (30)	1280	357 (28)	542	193 (36)
Sex								
Male	5033	2601 (52)	3843	1424 (37)	2142	811 (38)	1146	557 (49)
Female	4282	2017 (47)	3002	1019 (34)	1597	508 (32)	756	325 (43)
Income, \$								
<11 000	3505	1641 (47)	2498	807 (32)	1268	387 (31)	565	249 (44)
11 000-14 000	3852	1877 (49)	2787	1015 (36)	1544	551 (36)	766	376 (49)
>14 000	1958	1100 (56)	1560	621 (40)	927	381 (41)	571	257 (45)
Age, y								
18-45	2750	1827 (66)	2531	1171 (46)	1778	676 (38)	942	467 (50)
46-55	2472	1386 (56)	2069	725 (35)	1124	420 (37)	596	276 (46)
56-65	4093	1405 (34)	2245	547 (24)	837	223 (27)	364	139 (38)
Cause of renal failure								
Diabetes	4598	2139 (47)	3088	1063 (34)	1600	499 (31)	685	343 (50)
Nondiabetes	4717	2479 (53)	3757	1380 (37)	2139	820 (38)	1217	539 (44)
No. of years on dialysis								
<1	6511	4074 (63)	4074	1825 (45)	1825	553 (30)	553	210 (38)
1-2	1880	450 (24)	1823	431 (24)	1270	510 (40)	778	408 (52)
>2	924	94 (10)	948	187 (20)	644	256 (40)	571	264 (46)

*All relationships were significant ($P < .05$) except between income and completion of step D.

Table 4.—Multivariate Relationship Between Patient Characteristics and Completion of Steps A Through D

Characteristics	Odds Ratio (95% Confidence Interval)			
	Step A Medically Suitable and Possibly Interested	Step B Definitely Interested	Step C Pretransplant Workup Complete and on Waiting List	Step D Moved Up Waiting List and Received Transplant
Black	0.96 (0.87-1.06)	0.68 (0.61-0.76)	0.56 (0.48-0.65)	0.50 (0.40-0.62)
Female	0.90 (0.82-0.99)	0.89 (0.80-0.99)	0.80 (0.70-0.92)	0.82 (0.68-0.99)
Income per \$1000 decrease	0.67 (0.59-0.76)	0.78 (0.68-0.89)	0.77 (0.64-0.92)	1.01 (0.86-1.41)
Age per 10-y increase	0.58 (0.55-0.61)	0.69 (0.66-0.72)	0.84 (0.79-0.89)	0.83 (0.77-0.91)
Diabetes as cause of renal failure	0.87 (0.79-0.96)	0.94 (0.84-1.04)	0.73 (0.64-0.85)	1.23 (1.02-1.49)
Years of dialysis per 1-y increase	0.27 (0.25-0.30)	0.59 (0.55-0.63)	1.32 (1.22-1.43)	1.20 (1.09-1.33)

After multivariate adjustment (Table 4) for sex, ZIP code income, age, cause of renal failure, and years on dialysis, blacks were less likely than whites to complete steps B (odds ratio [OR], 0.68), C (OR, 0.56), and D (OR, 0.50). Women were less likely than men to complete steps A (OR, 0.90), B (OR, 0.89), C (OR, 0.80), and D (OR, 0.82). Poor individuals were less likely to complete steps A (OR, 0.67), B (OR, 0.78), and C (OR, 0.77). Age, diabetes, and years of dialysis were also independently associated with completion of several steps.

Patients unable to complete a step generally remained at a specific transplant status rather than moving backward. For example, as noted in Table 3, there were 2420 patient-years (3739 – 1319) during which step C (pretransplant workup) was not completed. Of these patient-years, 2342 (97%) had a year-end status of “pretransplant workup in progress” whereas only 78 (3%) were categorized as not a transplant candidate or as “undecided.”

We also examined our data for possible interactions among race, sex, and income. A significant interaction between race and income ($P = .01$) occurred at step C; the effect of low income as a barrier was more pronounced among whites than blacks. A significant interaction between sex and income ($P = .002$) occurred at step B; the effect of low income as a barrier was more pronounced among men than women.

COMMENT

Our results confirm the existence of substantial differences in access to cadaveric renal transplantation by race, sex, and income. More important, this is the first study to determine the relative importance of 4 key steps in the transplantation process: (A) being medically suitable and possibly interested in transplantation, (B) being definitely interested in transplantation, (C) completing the pretransplant workup, and (D) moving up a waiting list and receiving a transplant. By focusing on subjects eligible to complete each step annually over a 4-year interval, we obtained detailed

information about the individual effect of each step. We found that all 4 steps play an important role in explaining sociodemographic differences in transplantation rates. Steps B through D are the most important impediments for blacks, all 4 steps are impediments for women, and steps A through C are the most important impediments for poor individuals.

Our large, representative patient sample makes these findings especially noteworthy. We included all new patients in 3 states that collectively represent 8% of American dialysis patients. The proportion of blacks, women, and patients with diabetes in our sample is comparable with patients nationally. For example, 44% of national patients aged 20 to 64 years have diabetes compared with 49% of our subjects. In addition, the cadaveric renal transplantation rates we observed are comparable with national rates for all patients and for race and sex subgroups.¹

Importance of Results

Our findings indicate that efforts to allocate kidneys more equitably must target each step in the transplantation process. Recent work has demonstrated sociodemographic differences in access to the waiting list (equivalent to the combined effect of steps A, B, and C in our analysis).^{6,9-11} However, interventions have focused largely on patients already on the waiting list. For example, modifying the waiting list matching algorithm by adding points for waiting time has increased transplantations among blacks.¹² Other interventions have sought to increase organ donation by minorities in an effort to increase the availability of histocompatible kidneys and speed movement up the waiting list by minorities.¹³

Our findings also highlight the role of the pretransplant workup (step C), which acts as a barrier among all 3 subgroups, blacks, women, and the poor. The importance of this step has not previously been appreciated. Tasks performed at this step may include referral to transplant surgeons, evaluation and

treatment of medical conditions, and laboratory studies such as tissue typing. We found that only 3% of patients not completing this step in a given year are categorized as “not a transplant candidate” or “undecided.” Thus, failure to complete this step is generally not due to medical unsuitability or lack of interest in transplantation. Rather, it appears that many patients remain at this step for an extended period.

Our study cannot determine why specific steps serve as barriers among blacks, women, and the poor. Other investigators have speculated about a variety of patient and provider factors that may be responsible. Possible patient factors include biological and medical variables, lack of knowledge about transplantation, and concerns about surgery, adverse effects of medication, and health care costs.^{4,5-7,9,14-16} Possible provider factors include subconscious bias and financial disincentives.^{4,5,17-19} Transplant center size and proximity, as well as regional variations in matching algorithms, may also play a role.^{4,5,7,11,20} Understanding how these factors affect specific steps in the transplant process may help identify interventions to lessen sociodemographic differences in kidney transplantation rates.

Limitations

Several limitations must be considered in interpreting our findings. First, as discussed herein, the status code “not a transplant candidate” applies both to patients who are medically unsuitable and to patients who are uninterested in transplantation. This makes it difficult to separate the effect of suitability from the effect of interest, although the status code “undecided” does provide additional information about interest in transplantation. Second, the transplant status codes are archived only at the end of each year. Thus, a patient who dies during a particular year will not contribute that year’s experience to the analyses. However, we found that only 18 transplantations occurred in the same year as patient deaths compared with 882 transplantations among patients

who survived at least to the end of the transplant year. This suggests that excluding death years from our analyses probably has little effect on our conclusions. Finally, we examined patients in a 3-state area, and it is possible that other regions have different barriers to cadaveric renal transplantation among blacks, women, and poor individuals.

CONCLUSION

These limitations point out the need for a national database with uniform transplant status codes that correspond directly to distinct steps in the transplantation process. Currently, different coding systems exist among the 18 regional renal failure networks, and there

is no national repository. Such a resource would be invaluable for studying regional differences in barriers to transplantation, identifying possible interventions, and determining the impact of interventions. Even in the absence of a national effort, we encourage individual transplant and dialysis providers to examine steps in the transplantation process among their patients to identify areas for improvement. This does not mean forcing all patients through each step in the transplantation process. Rather, transplant and dialysis providers need to ensure that transplant candidates are identified equitably and then assisted through the transplantation process as expeditiously as possible. Our method for examining sequential

steps may also be applicable to other areas such as access to liver transplantation or cancer treatment.

A generous public, motivated primarily by altruism, donates organs of loved ones expecting they will be distributed equitably to needy patients.²¹ Efforts to fulfill this expectation must be pursued with the same vigor with which we seek new immunosuppressive medications or improved surgical techniques.

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