Racial Differences in Access to Kidney Transplantation

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Previous work has documented large differences between black and white populations in overall kidney transplantation rates and in transplantation waiting times. This article examines access to transplantation using three measures: time from renal failure to transplant; time from renal failure to wait listing; and time from wait listing to transplantation. This study concludes the following: First, no matter what measure of transplant access is used, black end stage renal disease (ESRD) beneficiaries fare worse than white, Asian-American, or Native American ESRD beneficiaries. Second, because the rate of renal failure exceeds the number of cadaver organs, access to kidney transplantation will deteriorate in future years for all races.

INTRODUCTION

Kidney transplantation has long been considered the optimal treatment therapy for persons with ESRD. Dialysis, although itself a life-extending therapy, exacts its own toll on persons with renal failure. Hemodialysis therapy requires the patient to be attached to a machine three times a week for 3-4 hours each session (U.S. Renal Data System, 1995). Adverse reactions such as cramps and hypotension can be a problem, as well as shunt-access failure requiring additional vascular-access procedures. Although recombinant human erythropoetin has improved hematocrit levels among dialysis patients, anemia remains a serious comorbidity for these patients. Continuous ambulatory peritoneal dialysis frees the patient from the machine but requires an exchange of peritoneal dialysate fluid four times daily. Continuous cycling peritoneal dialysis reduces the number of daytime exchanges but requires a machine assist at night. In addition, peritonitis is a continual problem for both forms of peritoneal dialysis (Port et al., 1992).

Transplantation frees patients from the various limitations imposed by dialysis regimens. Patients must take immunosuppressive drugs as long as the grafted kidney continues to function. Although these drugs can have adverse side effects, not the least of which is an impaired immune system, it is generally agreed that the quality of life for patients with a functioning kidney graft is superior to that on dialysis (Evans et al., 1985). In addition, kidney transplantation represents a net savings in costs, both to the government and in total health care expenditures (Eggers, 1992). In recent years, improved graft survival rates have further enhanced the desirability of transplantation (U.S. Renal Data System, 1995).

There are insufficient cadaver kidney organs to transplant all persons who could benefit (Evans, Orians, and Ascher, 1992). Consequently, the equitable allocation of this scarce resource has been of great concern to ESRD patients, providers, and policymakers (Kasiske, Neylan, and Riggio, 1991). Part of the rationale behind the creation of the Organ Procurement and Transplantation Network (OPTN) in 1984 was to ensure that organs were allocated in
Despite this concern, inequities remain. Numerous authors have documented the fact that black persons with ESRD are much less likely to get a transplant or will wait longer to get a transplant than do white persons (Kjellstrand, 1988; Eggers, 1988; Held et al., 1988; Kallich, Wyant, and Krushat, 1990; Sanfilippo et al., 1992; Gaylin et al., 1993). One of the differences among the studies cited is the manner in which access to transplantation was measured. For example, because living donor transplant rates are far lower among black persons than among white persons, the inclusion of living donor transplants in the calculation of rates greatly affects the black/white ratio. Kjellstrand merely compared the racial distribution of dialysis patients with the racial distribution of all transplant (cadaver and living donor) patients. Eggers calculated the percent of ESRD patients with a functioning kidney (cadaver or living donor) graft. The others used multivariate time-to-event models. Held et al. calculated access from the time of renal failure until (cadaver) transplant. Gaylin et al. used the same model but added a number of comorbidity factors and included living donor transplants. Sanfilippo et al. and Kallich, Wyant, and Krushat used the national OPTN wait list data to measure access (to cadaver transplant) in terms of median waiting time from the time a person enters the wait list until transplant. Despite these differences in methods, all researchers find similar results with respect to race—black beneficiaries have less access to kidney transplantation than do white ESRD beneficiaries.

One aspect of access to kidney transplantation that has not been measured to date is access to the national OPTN wait list. This is because the national registry of ESRD patients (the HCFA ESRD Program Management and Medical Information System [PMMIS]) has not been linked with the OPTN wait list. HCFA records do not contain information on when someone gets on the wait list; OPTN data do not contain information on ESRD persons who do not enroll onto the wait list. This article reports on the results of a matching of HCFA and OPTN data files and the development of a new measure of transplantation access. The analyses shed new light on the process of kidney transplantation and the places in the process where racial discrepancies are greatest.

METHODS AND DATA

Two data sets were matched for this analysis: the OPTN wait list data sets and the HCFA ESRD PMMIS. A description of these two data sets follows:

OPTN Wait List Data

The OPTN wait list data consist of two files, the current active wait list file and the removals file, which contains information on persons no longer on the active list. Both files were updated through May of 1994. The wait list file contained 26,025 records and the removals file had 76,417 records. Persons can be listed on both files and/or multiply listed on either file due to a number of reasons. For example, a person can be listed at more than one transplant center, in which case he/she would appear more than once on the active file. Similarly, a person who has received two transplants would appear twice on the removals file. Also, persons awaiting a transplant following a failed
first transplant would be on both the active wait list and the removals list. Combining the two files and removing duplicate records resulted in an unduplicated file of 85,659 people.

**HCFA ESRD PMMIS**

The ESRD PMMIS is a longitudinal file of ESRD patients entitled to Medicare benefits that is maintained by HCFA's Bureau of Data Management and Strategy. In addition to the basic enrollment data available for all Medicare beneficiaries, such as gender, race,\(^2\) date of birth, date of death, and entitlement dates, the PMMIS contains information unique to ESRD beneficiaries. The medical evidence form (HCFA-2728) is used to determine date and cause of renal failure. All kidney transplants are reported on the Form HCFA-2745.\(^3\) The ESRD PMMIS file used in this study was updated through April 1994. This update of the ESRD PMMIS contained 582,330 people, the complete count of Medicare ESRD patients ever entitled since 1978.

**Match of HCFA and OPTN Records**

The OPTN and HCFA data sets were matched on the basis of Medicare Health Insurance Claim (HIC) number. According to the 1992 annual ESRD facility survey, Medicare beneficiaries account for about 90-92 percent of all kidney transplants (Health Care Financing Administration, 1994). Therefore, it would seem that the match rate would not exceed 90 or 92 percent. Of the 85,659 persons included in the OPTN files, 74,135 (86.5 percent) matched the ESRD PMMIS on HIC. Given that reporting lags are greater in the ESRD PMMIS than in the OPTN files, there are undoubtedly more people in the OPTN files who will match the ESRD PMMIS once it gets fully updated.

Table 1 shows the match rate by year of OPTN entry. The match rate for 1992 and earlier years ranges from 88-90 percent (compared with the maximum expected match of 90 to 92 percent) but drops to 81.3 percent for 1993. Generally, the ESRD PMMIS is not considered completely updated until at least 15 months after the end of a year (i.e., April 1995 update for calendar year 1993). Therefore, it appears that the OPTN/ESRD PMMIS match is at least 95 percent successful—sufficient for analyses of transplantation access.

Given the successful match of OPTN and HCFA data, an analytical file was created to develop measures of transplant access. The Medicare ESRD incident cohort from 1988-92 was used in the analysis. Incident cases who received transplants prior to this time may be missed due to the relatively recent start-up of the OPTN data system. Incident cases after this time may be missing due to lags in updating the HCFA PMMIS.

For the analyses based on the ESRD incident population, the study was limited to persons under 55 years of age (\(n = 79,527\)). Although transplantation is increasingly being made available to older persons with ESRD, it still is predominantly a therapy for younger persons. People 55 years of age or over account for two-thirds of incident ESRD cases but only 17 percent of all transplants. It was felt that the inclusion of the older ESRD population would skew the access measures downward due to the inclusion of a large number of ESRD patients who, at this point in the develop-

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\(^2\) Although the OPTN database contains information on Hispanic ethnicity, the ESRD PMMIS did not add this item until mid-1995. Because the HCFA population served as the denominator for most of the analyses, it was not possible to break out this population separately.

\(^3\) The HCFA-2745 was used to collect data by HCFA prior to June 1994. At that time, the role of data collection was assumed by OPTN. Since then, all kidney transplant data have been collected by OPTN and routinely forwarded to HCFA.
Table 1
Percent of OPTN Registrants Matched to Medicare ESRD Enrollment File, by Year of OPTN Entry

| Year          | OPTN Entries | Percent Match With HCFA ESRD PMMIS |
|---------------|--------------|-----------------------------------|
| Before 1987   | 4,556        | 87.8                              |
| 1987          | 7,525        | 88.2                              |
| 1988          | 10,539       | 88.3                              |
| 1989          | 10,528       | 89.4                              |
| 1990          | 10,943       | 89.6                              |
| 1991          | 11,325       | 89.8                              |
| 1992          | 12,508       | 87.9                              |
| 1993          | 13,026       | 81.3                              |

NOTES: OPTN is Organ Procurement and Transplantation Network. ESRD is end stage renal disease. HCFA is Health Care Financing Administration. ESRD PMMIS is ESRD Program Management and Medical Information System.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List and Removal Data Sets, May 1994 Update.

ment of renal therapy, could not be serious candidates for transplantation. For the analyses in which the denominator was wait list enrollment, no age selection was done. It was felt that enrollment in the OPTN was prima facie evidence that a person was an eligible candidate.

MEASURES

Three measures of access to transplantation were derived for this analysis. In all three cases, a time-to-event model was used with measure-specific censoring.

Access to Transplantation

This is the most direct and, ultimately, the most relevant measure of access. This is roughly defined as the percent of ESRD patients who get a transplant. This measure can be calculated directly from ESRD PMMIS data and does not require a link with OPTN data. The start date is the date of renal failure, taken from the medical evidence form. The outcome of interest is a transplant, either cadaveric or living donor. Patients are censored either at death or the end of the observation period (April 30, 1994).

Access to the OPTN Transplant Waiting List

This is, for most persons, the intermediate step between renal failure and a cadaveric transplant. In order to compete for the limited number of cadaver kidneys, one has to be wait listed. In essence, it measures one's eligibility to get a cadaver transplant. This requires linkage of HCFA and OPTN data. A major weakness of this measure is that it does not deal with the issue of living donor transplants. In 1993, 26 percent of kidney transplants were living donor transplants, up from 20 percent in 1985. The start date is the date of renal failure, taken from the medical evidence form. The end point is the earliest date of enrollment on the OPTN wait list. Censoring events include death, end of observation period, and any transplant (usually living donor) that may have occurred without first wait listing.

Access to Transplantation After Being Wait Listed

This is the logical followup to the previous measure. After having achieved the intermediate step of being wait listed, it measures what percent of patients actually get a transplant, or how long it takes to get a transplant. This measure can be calculated directly from OPTN data and has been the subject of a number of studies of transplant access. The start date is the date of wait listing. The end point is a cadaver transplant. Living donor transplants were used as censoring events for this measure because a living related donor transplant is not the outcome for which the wait list is

4 The access measures were also calculated including all age groups. The results of the racial comparisons remained the same.
designed. Other censoring events included death, end of observation period, and any disenrollment from the OPTN wait list.\(^5\)

Descriptive tables of the time-to-event models showing bivariate effects of race, age, sex, and primary cause of renal failure are presented. In addition, proportional hazards models were constructed for each measure. As noted in the results section, the data do not support the proportionality assumption for this hazards model. However, the proportional hazards model does give a reasonable average estimate of covariate effects over the entire time span included in the analysis.

RESULTS

Table 2 shows a demographic breakdown by race of the Medicare ESRD population included in the study. There were a total of 79,527 persons under 55 years of age who initiated renal replacement therapy during these years. Black persons were most likely to have their renal failure attributed to hypertension (34.1 percent), whereas Native Americans had the highest percentage attributed to diabetes (59.1 percent). Males comprised the majority of persons in all racial groups, ranging from 52.8 percent for Asian-Americans to 59.8 percent for black persons. With the exception of Native Americans, there was little difference in the age distribution. Over one-half of Native Americans were over 45 years of age and their mean age was 3-4 years greater than other racial groups. Overall, the annual rate of renal failure (incidence) was 81 per million population. Incidence was comparable between Asian-American and white beneficiaries. However, compared with white persons, Native Americans were twice as likely, and black persons almost four times as likely, to suffer renal failure.

Table 3 shows the rate of transplantation for the 1988-92 Medicare ESRD incident cohort under 55 years of age. About one in six (16.1 percent) had received a transplant within 1 year of renal failure. After 3 years, over one-third of patients (36.7 percent) had received a transplant; after 5 years, almost one-half (46.1 percent) of patients had received at least one transplant.\(^6\) Access to transplantation is inversely related to age, decreasing from 45.7 percent (at 1 year following renal failure) for persons under 15 years of age to 8.1 percent for persons 45-54 years of age. Males are more likely to be transplanted than females. At 5 years post renal failure, the transplantation rate among males is 47.8 percent, compared with 44.2 percent among females. At 1 year following renal failure, white persons are almost four times more likely to have received a transplant than black persons (22.7 percent and 6.0 percent, respectively). Asian-Americans (15.5 percent) and Native Americans (12.1 percent) also have transplantation rates more than double the rate of black persons. At 5 years post renal failure, fewer than one-third of black persons (30.3 percent) have received a transplant, while well over one-half (56.7 percent) of white persons have received a transplant. Asian-Americans have the highest transplantation rate at 5 years (58.2 percent). Transplantation rates also vary across causes of renal failure. The highest rates (at 1 year) are found for cystic kidney disease (25.5 percent), obstructive nephropathy (24.9 percent), and

\(^5\) Reasons for leaving the wait list other than by receiving a transplant include death (32 percent), medically unsuitable (18 percent), moved (12 percent), refused transplant (5 percent), and all other (33 percent).

\(^6\) The 5-year transplant rate is interpretable for those who survive for 5 years. Due to the high mortality rate among dialysis patients, almost one-half will die within 5 years. Due to favorable selection, about three-fourths of persons will survive for 5 years on dialysis after being wait listed.
### Table 2
Demographic Characteristics of Medicare ESRD Incident Population 55 Years of Age or Under: 1988-92

| Characteristic       | All Persons | Asian-American | Black | White | Native American | Other/Unknown |
|----------------------|-------------|----------------|-------|-------|-----------------|---------------|
| **Total**            | 79,527      | 1,806          | 29,541| 46,678| 1,130           | 1,372         |
| **Disease**          |             |                |       |       |                 |               |
| Diabetes             | 33.3        | 23.9           | 24.5  | 39.9  | 59.1            | 14.4          |
| Glomerulonephritis   | 17.5        | 32.1           | 16.1  | 18.1  | 15.0            | 12.2          |
| Hypertension         | 18.6        | 15.9           | 34.1  | 9.9   | 8.7             | 6.2           |
| All Other            | 30.5        | 22.1           | 23.4  | 33.0  | 17.3            | 67.2          |
| **Sex**              |             |                |       |       |                 |               |
| Male                 | 58.7        | 52.8           | 59.8  | 58.5  | 56.9            | 53.3          |
| **Age**              |             |                |       |       |                 |               |
| 0-14 Years           | 2.6         | 2.9            | 1.4   | 3.3   | 2.3             | 3.6           |
| 15-24 Years          | 7.7         | 9.8            | 7.2   | 7.9   | 5.8             | 11.5          |
| 25-34 Years          | 20.3        | 18.5           | 19.8  | 20.8  | 12.3            | 19.5          |
| 35-44 Years          | 30.6        | 30.7           | 32.6  | 29.5  | 26.8            | 26.7          |
| 45-54 Years          | 38.9        | 38.2           | 39.0  | 38.4  | 53.5            | 38.7          |
| Mean Age (Years)     | 39.9        | 39.6           | 40.4  | 39.5  | 43.0            | 38.8          |
| **Rate per Million** |             |                |       |       |                 |               |
| Population           | 81          | 57             | 224   | 61    | 131             | —             |

**NOTES:** ESRD is end stage renal disease.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incident Cohort (April 1994 Update).

The lowest rates are found for hypertension (8.5 percent) and diabetes (13.3 percent). Part of the diagnostic difference is probably due to age; both hypertensive and diabetic ESRD patients tend to be older than the other diagnostic groups.

Rates of wait listing following renal failure among Medicare ESRD beneficiaries are shown in Table 4. Compared with transplantation, which occurs more evenly throughout the 5-year period, wait listing is much more likely to occur within the first year after renal failure. About one-fourth (25.8 percent) of ESRD beneficiaries are wait listed within 1 year of renal failure. Almost one-half of patients have been wait listed at the end of 5 years. That is, about one-half of all the persons who get wait listed within 5 years of renal failure do so within the first year. The effect of living donor transplantation is also shown in the wait list rates. Although children (under 15 years of age) have the highest rate of transplantation (Table 3), they are less likely to be wait listed than any other age group except those 45 to 54 years of age. Therefore, this measure is somewhat misleading as a measure of access to transplantation for pediatric ESRD patients.

As with transplantation rates in general (Table 3), black ESRD beneficiaries are the least likely to get wait listed of all racial groups, with only 17.8 percent wait listed in the first year of renal failure. Asian-Americans are the most likely to be wait listed (37.9 percent in the first year) compared with 30.5 percent among white persons. Wait listing rates by diagnosis mirror those of transplantation, again reflecting in part, age differences among causes of renal failure.

Transplantation rates after wait listing are shown in Table 5. This table differs from the previous two in that the cohort consists of persons wait listed during the 1988-92 period. It includes some persons whose renal failure occurred prior to 1988. It also includes...
Table 3
Cumulative Transplantation Rate Following Renal Failure for Medicare ESRD Beneficiaries 55 Years of Age or Under, by Selected Demographic Characteristics

| Characteristic      | n     | 1 Year | 3 Years | 5 Years |
|---------------------|-------|--------|---------|---------|
| **Total**           | 79,527| 16.1 (0.2) | 36.7 (0.3) | 46.1 (0.4) |
| **Age**             |       |        |         |         |
| Under 15 Years      | 2,041 | 45.7 (1.1) | 74.0 (1.1) | 80.3 (1.2) |
| 15-24 Years         | 6,183 | 30.1 (0.6) | 57.4 (0.7) | 68.9 (0.8) |
| 25-34 Years         | 16,128| 22.6 (0.3) | 47.5 (0.5) | 57.7 (0.6) |
| 35-44 Years         | 24,296| 15.6 (0.2) | 37.1 (0.4) | 46.4 (0.5) |
| 45-54 Years         | 30,899| 8.1 (0.2)  | 23.6 (0.3) | 31.4 (0.4) |
| **Sex**             |       |        |         |         |
| Male                | 46,699| 16.8 (0.2) | 38.5 (0.3) | 47.8 (0.4) |
| Female              | 32,828| 15.2 (0.2) | 34.7 (0.3) | 44.2 (0.4) |
| **Race**            |       |        |         |         |
| Asian-American      | 1,806 | 15.5 (0.9) | 43.7 (1.4) | 58.2 (1.8) |
| Black               | 28,541| 6.0 (1.1)  | 20.8 (0.3) | 30.3 (0.4) |
| White               | 46,678| 22.7 (0.2) | 47.4 (0.3) | 56.7 (0.4) |
| Native American     | 1,130 | 12.1 (1.0) | 29.4 (1.5) | 36.9 (2.2) |
| Other/Unknown       | 1,372 | 6.2 (0.7)  | 15.7 (1.2) | 20.2 (1.7) |
| **Primary Diagnosis**|      |        |         |         |
| Diabetes            | 26,501| 13.3 (0.2) | 31.5 (0.4) | 39.6 (0.5) |
| Glomerulonephritis  | 13,945| 23.2 (0.4) | 49.0 (0.5) | 59.1 (0.5) |
| Hypertension        | 14,804| 8.5 (0.2)  | 27.0 (0.4) | 36.4 (0.6) |
| Cystic Kidney Disease| 3,196| 25.5 (0.6) | 53.7 (1.0) | 62.7 (1.2) |
| Interstitial Nephritis| 2,346| 22.2 (0.9) | 44.1 (1.2) | 53.4 (1.5) |
| Obstructive Nephropathy| 1,199| 24.9 (1.3) | 44.6 (1.6) | 53.8 (2.0) |
| Other               | 7,138 | 16.1 (0.5) | 37.9 (0.7) | 48.9 (1.0) |
| Unknown             | 4,284 | 19.1 (0.6) | 42.0 (0.9) | 50.9 (1.1) |
| Missing             | 6,134 | 19.0 (0.5) | 35.5 (0.7) | 44.1 (0.9) |

NOTES: ESRD is end stage renal disease. Standard errors are in parentheses.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update).

all ages. Persons over 55 years of age were excluded from Tables 2 and 3 because most ESRD beneficiaries in the upper age groups tend not to be transplant candidates. However, once they have been wait listed, it would seem to be reasonable to follow their access along with other groups.

Between 1988 and 1992, there were 41,168 Medicare beneficiaries who were wait listed on the OPTN national registry (Table 5). Almost one-half (46.0 percent) of these persons received a transplant within 1 year of wait listing, increasing to three-fourths (77.6 percent) at 3 years after being added to the list. At the end of 5 years, 86 percent of persons who did not die or otherwise leave the wait list had received at least one transplant. Age was not much of a factor in transplantation after wait listing. At 5 years, 90 percent of persons under 15 years of age at the time of wait listing had received a transplant. The lowest transplant rates were found for persons over 65 years of age (80 percent). Males had slightly higher transplant rates than did females. By diagnostic category, 1-year transplantation rates ranged from a high of 52.2 percent for cystic kidney disease to a low of 39.9 percent of persons whose renal failure was attributed to hypertension.

The highest initial rate of transplantation was experienced by white beneficiaries; over one-half were transplanted within 1 year of wait listing. However, the racial difference narrowed in subsequent years. For example, the black rate was only 68 percent as great as the white rate in the first year of wait list-
### Table 4

Cumulative Enrollment of Medicare ESRD Beneficiaries 55 Years of Age and Under on the OPTN National Wait List, by Selected Demographic Characteristics

| Characteristic         | \( n \) | 1 Year Percent | 3 Years Percent | 5 Years Percent |
|------------------------|--------|----------------|-----------------|-----------------|
| **Total**              | 79,527 | 25.8 (0.2)     | 41.5 (0.3)      | 47.2 (0.3)      |
| **Age**                |        |                |                 |                 |
| Under 15 Years         | 2,041  | 25.7 (1.0)     | 40.6 (1.2)      | 48.4 (1.3)      |
| 15-24 Years            | 6,163  | 34.4 (0.6)     | 52.6 (0.7)      | 59.4 (0.8)      |
| 25-34 Years            | 16,128 | 32.5 (0.4)     | 49.8 (0.4)      | 55.9 (0.5)      |
| 35-44 Years            | 24,296 | 28.2 (0.3)     | 44.3 (0.4)      | 49.6 (0.4)      |
| 45-54 Years            | 30,899 | 18.6 (0.2)     | 32.7 (0.3)      | 37.6 (0.4)      |
| **Sex**                |        |                |                 |                 |
| Male                   | 46,699 | 26.9 (0.2)     | 42.8 (0.3)      | 48.4 (0.3)      |
| Female                 | 32,828 | 24.3 (0.2)     | 40.0 (0.3)      | 45.8 (0.4)      |
| **Race**               |        |                |                 |                 |
| Asian-American         | 1,806  | 37.9 (1.2)     | 57.4 (1.3)      | 63.2 (1.6)      |
| Black                  | 28,541 | 17.8 (0.2)     | 34.0 (0.3)      | 40.4 (0.4)      |
| White                  | 46,678 | 30.5 (0.2)     | 46.0 (0.3)      | 51.1 (0.3)      |
| Native American        | 1,130  | 22.3 (1.3)     | 35.5 (1.6)      | 43.4 (2.1)      |
| Other/Unknown          | 1,372  | 19.9 (1.1)     | 35.3 (1.5)      | 42.1 (1.9)      |
| **Primary Diagnosis**  |        |                |                 |                 |
| Diabetes               | 26,501 | 22.7 (0.3)     | 36.9 (0.3)      | 40.9 (0.4)      |
| Glomerulonephritis     | 13,945 | 34.0 (0.4)     | 51.4 (0.5)      | 57.4 (0.5)      |
| Hypertension           | 14,804 | 22.1 (0.3)     | 38.6 (0.4)      | 45.6 (0.6)      |
| Cystic Kidney Disease  | 3,198  | 42.0 (0.9)     | 58.0 (0.9)      | 64.2 (1.1)      |
| Interstitial Nephritis | 2,346  | 28.3 (0.9)     | 43.1 (1.1)      | 49.2 (1.3)      |
| Obstructive Nephropathy| 1,189  | 20.8 (1.2)     | 33.9 (1.5)      | 40.6 (2.0)      |
| Other                  | 7,138  | 21.4 (0.5)     | 39.6 (0.7)      | 46.8 (0.9)      |
| Unknown                | 4,264  | 26.3 (0.7)     | 45.1 (0.9)      | 51.1 (1.0)      |
| Missing                | 6,134  | 23.0 (0.6)     | 37.1 (0.7)      | 41.5 (0.8)      |

**NOTES:** ESRD is end stage renal disease. OPTN is Organ Procurement and Transplantation Network. Standard errors are in parentheses.

**SOURCE:** Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List and Removal Data Sets, May 1994 Update.

Between 1988 and 1992, the number of newly treated renal failure patients in the Medicare program under 55 years of age increased at an annual rate of 6.6 percent (Health Care Financing Administration, 1994). New entries into the OPTN wait list increased from 10,339 in 1988 to 13,026 in 1993, an annual increase of 5.4 percent (Table 1). However, the number of transplants has not kept pace with the number of eligible patients. Total transplants for the population under 55 years of age increased by only 2.1 percent per year between 1988 and 1992.

### TREND EFFECTS

As is widely known, the incidence of treated renal failure continues to increase.

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7 The rates of increase for ESRD incidence and OPTN enrollment are not strictly comparable because the OPTN numbers include all age groups and persons whose renal failure occurred in prior years.
Table 5
Cumulative Transplantation Rate Following OPTN Wait Listing for Medicare ESRD Beneficiaries, by Selected Demographic Characteristics

| Characteristic   | n   | 1 Year       | 3 Years      | 5 Years      |
|------------------|-----|--------------|--------------|--------------|
| Total            | 41,168 | 46.0 (0.3) | 77.6 (0.3) | 85.8 (0.3) |
| Age              |      |              |              |              |
| Under 15 Years   | 943  | 58.6 (1.7)  | 58.5 (1.7)  | 90.0 (1.7)  |
| 15-24 Years      | 3,103 | 48.4 (0.9)  | 81.9 (0.9)  | 89.5 (1.0)  |
| 25-34 Years      | 8,203 | 48.0 (0.6)  | 79.2 (0.6)  | 87.3 (0.7)  |
| 35-44 Years      | 10,881 | 46.7 (0.5)  | 76.5 (0.5)  | 86.7 (0.6)  |
| 45-54 Years      | 9,702  | 43.7 (0.5)  | 75.4 (0.8)  | 84.2 (0.7)  |
| 55-64 Years      | 6,607  | 43.6 (0.6)  | 75.5 (0.7)  | 82.9 (1.0)  |
| 65-74 Years      | 1,786  | 43.7 (1.2)  | 71.3 (1.5)  | 80.0 (2.8)  |
| 75 Years or Over | 43   | 49.4 (7.9)  | 79.6 (8.8)  | 79.8 (8.8)  |
| Sex              |      |              |              |              |
| Male             | 25,000 | 47.4 (0.3) | 79.2 (0.3) | 87.7 (0.4)  |
| Female           | 16,168 | 43.8 (0.4) | 75.1 (0.4) | 83.0 (0.5)  |
| Race             |      |              |              |              |
| Asian-American   | 1,207  | 40.4 (1.4)  | 75.9 (1.5)  | 88.6 (1.8)  |
| Black            | 10,427 | 34.6 (0.5)  | 69.0 (0.6)  | 81.0 (0.8)  |
| White            | 28,513 | 51.0 (0.3)  | 81.6 (0.3)  | 85.2 (0.4)  |
| Native American  | 500   | 37.4 (2.2)  | 70.2 (2.7)  | 84.8 (3.1)  |
| Other/Unknown    | 521   | 22.7 (1.9)  | 41.4 (2.6)  | 45.2 (3.4)  |
| Primary Diagnosis|      |              |              |              |
| Diabetes         | 10,662 | 47.5 (0.5)  | 77.5 (0.6)  | 86.1 (0.8)  |
| Glomerulonephritis| 9,210  | 47.3 (0.5)  | 79.7 (0.5)  | 87.9 (0.6)  |
| Hypertension     | 7,254  | 39.9 (0.5)  | 74.2 (0.7)  | 83.9 (0.9)  |
| Cystic Kidney Disease | 3,207 | 52.4 (0.9)  | 85.2 (0.8)  | 91.1 (0.9)  |
| Interstitial Nephritis | 1,453 | 47.0 (1.3)  | 80.1 (1.3)  | 89.2 (1.7)  |
| Obstructive Nephropathy | 577  | 45.5 (2.1)  | 79.2 (2.1)  | 89.7 (2.7)  |
| Other            | 2,875  | 43.9 (1.0)  | 74.0 (1.1)  | 82.6 (1.3)  |
| Unknown          | 2,499  | 49.5 (1.0)  | 79.4 (1.0)  | 87.3 (1.2)  |
| Missing          | 3,221  | 42.5 (0.9)  | 70.8 (1.0)  | 77.9 (1.1)  |

NOTES: OPTN is Organ Procurement and Transplantation Network. ESRD is end stage renal disease. Standard errors are in parentheses.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1965-92 Incidence Cohort (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List and Removal Data Sets, May 1994 Update.

Financing Administration, 1994). In addition, the total transplant number includes retransplants, which obscure the measure of access to initial transplant. These patterns cannot help but have a negative effect on the measures of access to transplantation. Trend effects are explored in the tables which follow.

Table 6 shows the transplant rate within 1 year of renal failure by ESRD incident year. Of the 13,962 persons under 55 years of age whose renal failure occurred in 1988, 18.6 percent received a transplant within 1 year of their renal failure date. This transplant rate declined in each of the following years to 13.5 percent in 1992. The decline was evident across all age, sex, and race groups. There were a couple of exceptions within the diagnostic categories. Persons whose renal failure was attributed to either interstitial nephritis or obstructive nephropathy actually had higher rates of transplantation in 1992 than in 1988.

Access to the OPTN wait list did not change noticeably during the 1988-92 time period (Table 7). The rate of wait listing within 1 year of renal failure was fairly constant across all years, ranging from a low of 25.1 percent in 1990 to a high of 26.7 percent in 1988.
Table 6
Transplantation Within 1 Year of Renal Failure for Medicare ESRD Beneficiaries 55 Years of Age or Under, by Selected Demographic Characteristics and Year of Renal Failure

| Characteristic                  | 1988      | 1989      | 1990      | 1991      | 1992      |
|--------------------------------|-----------|-----------|-----------|-----------|-----------|
|                                | n         | Percent   | n         | Percent   | n         | Percent   | n         | Percent   | n         | Percent   |
| Total                          | 13,962    | 18.6 (0.3)| 15,116    | 17.3 (0.3)| 15,820    | 16.0 (0.3)| 16,842    | 15.8 (0.3)| 17,787    | 13.5 (0.3)|
| Age                            |           |           |           |           |           |           |           |           |           |           |
| Under 15 Years                 | 388       | 48.9 (2.6)| 392       | 48.2 (2.6)| 433       | 41.8 (2.4)| 440       | 48.7 (2.4)| 388       | 40.7 (2.5)|
| 15-24 Years                    | 1,215     | 33.9 (1.4)| 1,251     | 32.1 (1.3)| 1,210     | 29.5 (1.3)| 1,210     | 29.1 (1.3)| 1,277     | 25.9 (1.2)|
| 25-34 Years                    | 2,954     | 24.1 (0.8)| 3,228     | 23.3 (0.8)| 3,263     | 23.0 (0.8)| 3,334     | 23.3 (0.7)| 3,349     | 19.7 (0.7)|
| 35-44 Years                    | 4,151     | 24.1 (0.8)| 4,749     | 16.8 (0.6)| 4,879     | 15.6 (0.5)| 5,252     | 15.2 (0.5)| 5,535     | 13.0 (0.5)|
| 45-54 Years                    | 5,254     | 9.8 (0.4) | 5,766     | 8.8 (0.4) | 6,035     | 7.5 (0.3) | 6,606     | 7.7 (0.3) | 7,238     | 7.1 (0.3) |
| Sex                            |           |           |           |           |           |           |           |           |           |           |
| Male                           | 8,150     | 19.8 (0.5)| 8,884     | 18.1 (0.4)| 9,376     | 16.9 (0.4)| 9,917     | 16.1 (0.4)| 10,372    | 13.7 (0.3)|
| Female                         | 5,812     | 16.8 (0.5)| 6,232     | 16.3 (0.5)| 6,444     | 14.6 (0.4)| 6,925     | 15.5 (0.4)| 7,415     | 13.2 (0.4)|
| Race                           |           |           |           |           |           |           |           |           |           |           |
| Asian-American                 | 295       | 19.7 (2.3)| 316       | 19.0 (2.2)| 378       | 11.1 (1.6)| 373       | 15.7 (1.9)| 444       | 13.5 (1.6)|
| Black                          | 4,783     | 7.5 (0.4) | 5,460     | 6.5 (0.3) | 5,544     | 5.8 (0.3) | 6,137     | 5.5 (0.3) | 6,617     | 5.2 (0.3) |
| White                          | 8,426     | 25.2 (0.9)| 8,907     | 24.3 (0.5)| 9,382     | 22.5 (0.4)| 9,799     | 22.7 (0.4)| 10,164    | 19.2 (0.4)|
| Native American                | 201       | 10.8 (2.2)| 206       | 13.9 (2.4)| 216       | 11.7 (2.2)| 240       | 13.8 (2.3)| 287       | 10.5 (1.9)|
| Other/Unknown                  | 257       | 8.8 (1.8) | 227       | 5.2 (1.5) | 300       | 6.8 (1.5) | 233       | 5.1 (1.3) | 295       | 5.3 (1.3) |
| Primary Diagnosis              |           |           |           |           |           |           |           |           |           |           |
| Diabetes                       | 4,241     | 16.5 (0.6)| 5,035     | 14.7 (0.5)| 5,278     | 13.0 (0.5)| 5,821     | 13.1 (0.5)| 5,126     | 10.5 (0.4)|
| Glomerulonephritis             | 2,816     | 25.2 (0.9)| 2,799     | 25.6 (0.8)| 2,803     | 22.7 (0.8)| 2,835     | 22.5 (0.8)| 2,692     | 19.9 (0.8)|
| Hypertension                   | 2,423     | 9.8 (0.6) | 2,722     | 8.7 (0.6) | 2,884     | 8.8 (0.5) | 3,185     | 8.2 (0.5) | 3,590     | 7.4 (0.4)|
| Cystic Kidney Disease          | 616       | 28.8 (1.8)| 607       | 24.7 (1.8)| 608       | 25.2 (1.8)| 682       | 26.4 (1.7)| 683       | 22.6 (1.6)|
| Intestinal Nephritis           | 429       | 20.4 (2.0)| 418       | 23.5 (2.1)| 492       | 19.9 (1.6)| 537       | 24.3 (1.9)| 470       | 22.8 (2.0)|
| Obstructive Nephropathy        | 207       | 22.3 (3.0)| 213       | 23.5 (3.0)| 215       | 24.2 (3.0)| 271       | 26.9 (2.9)| 293       | 21.6 (2.5)|
| Other                          | 1,150     | 17.6 (1.2)| 1,343     | 18.2 (1.1)| 1,400     | 16.6 (1.0)| 1,587     | 15.6 (1.0)| 1,658     | 13.3 (0.9)|
| Unknown                        | 847       | 17.8 (1.4)| 860       | 18.5 (1.4)| 812       | 20.1 (1.4)| 906       | 19.3 (1.3)| 905       | 19.4 (1.3)|
| Missing                        | 1,433     | 22.5 (1.1)| 1,179     | 19.1 (1.2)| 1,235     | 18.5 (1.1)| 1,024     | 18.9 (1.3)| 1,170     | 15.4 (1.1)|

NOTES: ESRD is end stage renal disease. Standard errors are in parentheses.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update).

Diagnostic categories had steady rates of wait listing during these years.

Transplantation within 1 year of wait listing has decreased markedly, as shown in Table 8. In 1988, over one-half (55.4 percent) of persons entering the OPTN wait list received a transplant within 1 year of wait listing. By 1992, the percent of persons transplanted within 1 year had declined to 38.5 percent. Declines in transplant rates were seen across all age, gender, race, and diagnostic categories. The declines were not uniform by race. In 1988, the median waiting time before transplantation (not shown) for white and black persons was 308 days and 439 days, respectively. By 1992, median wait time could not be calculated for black persons in 1992 due to insufficient follow-up time.

1991, wait times for white persons had increased by 25 percent to 384 days but had increased by 61 percent for black persons to 705 days. During the same period, median wait times increased by 12 percent for Native Americans (483 and 543 days, respectively) and by 27 percent for Asian-Americans (435 and 551 days, respectively).

MULTIVARIATE ANALYSES

Table 9 shows the results of the proportional hazards models. Race had a

8 Median wait time could not be calculated for black persons in 1992 due to insufficient follow-up time.

9 As previously noted, the univariate analyses, particularly for post wait listing transplantation, show that the proportionality assumption underlying this hazards model is not met. The coefficients, therefore, represent the average hazard during the entire time span. Relative hazard rates at the beginning and end of the time span are likely to be different, especially for racial groups.
Table 7
Enrollment on OPTN Wait List Within 1 Year of Renal Failure for Medicare ESRD Beneficiaries
55 Years of Age or Under, by Selected Demographic Characteristics and Year of Renal Failure

| Characteristic          | 1988  | 1989  | 1990  | 1991  | 1992  |
|------------------------|-------|-------|-------|-------|-------|
|                        | n     | Percent | n     | Percent | n     | Percent | n     | Percent | n     | Percent |
| Total                  | 13,962 | 26.7 (0.4) | 15,116 | 26.2 (0.4) | 15,820 | 25.1 (0.4) | 16,842 | 25.6 (0.3) | 17,787 | 25.6 (0.3) |
| Age                    |       |         |       |         |       |         |       |         |       |         |
| Under 15 Years         | 388   | 25.9 (2.3) | 392   | 28.5 (2.3) | 433   | 25.5 (2.1) | 440   | 24.5 (2.1) | 388   | 24.3 (2.2) |
| 15-24 Years            | 1,215 | 35.7 (1.4) | 1,251 | 33.9 (1.4) | 1,210 | 32.6 (1.4) | 1,210 | 34.8 (1.4) | 1,277 | 35.2 (1.4) |
| 25-34 Years            | 2,954 | 32.1 (0.9) | 3,228 | 33.0 (0.6) | 3,263 | 31.6 (0.8) | 3,334 | 34.8 (0.9) | 3,349 | 33.1 (0.8) |
| 35-44 Years            | 4,151 | 30.3 (0.7) | 4,479 | 33.0 (0.7) | 4,879 | 27.1 (0.7) | 5,252 | 28.0 (0.6) | 5,535 | 27.2 (0.6) |
| 45-54 Years            | 5,254 | 18.6 (0.6) | 5,766 | 18.2 (0.5) | 6,035 | 18.3 (0.5) | 6,605 | 18.5 (0.5) | 7,238 | 19.1 (0.5) |
| Sex                    |       |         |       |         |       |         |       |         |       |         |
| Male                   | 8,150 | 27.1 (0.5) | 8,884 | 27.7 (0.5) | 9,376 | 26.8 (0.5) | 9,917 | 26.5 (0.5) | 10,372 | 26.5 (0.4) |
| Female                 | 5,812 | 26.2 (0.6) | 6,232 | 24.2 (0.6) | 6,444 | 22.7 (0.5) | 6,925 | 24.4 (0.5) | 7,415 | 24.3 (0.5) |
| Race                   |       |         |       |         |       |         |       |         |       |         |
| Asian-American         | 295   | 38.8 (2.9) | 316   | 40.3 (2.8) | 378   | 37.8 (2.5) | 373   | 39.1 (2.6) | 444   | 34.5 (2.3) |
| Black                  | 4,783 | 19.1 (0.6) | 5,460 | 16.8 (0.5) | 5,544 | 17.5 (0.5) | 5,137 | 17.6 (0.5) | 5,617 | 18.2 (0.5) |
| White                  | 8,426 | 30.8 (0.5) | 8,907 | 31.8 (0.5) | 9,382 | 29.4 (0.5) | 9,799 | 26.5 (0.5) | 10,164 | 29.2 (0.5) |
| Native American        | 201   | 26.7 (3.2) | 206   | 24.4 (3.0) | 216   | 19.0 (2.7) | 240   | 21.6 (2.7) | 257   | 20.6 (2.5) |
| Other/Unknown          | 257   | 20.6 (2.6) | 227   | 15.1 (2.5) | 300   | 19.9 (2.4) | 293   | 19.2 (2.4) | 295   | 23.7 (2.5) |
| Primary Diagnosis      |       |         |       |         |       |         |       |         |       |         |
| Diabetes               | 4,241 | 24.9 (0.7) | 5,035 | 23.7 (0.6) | 5,278 | 20.9 (0.6) | 5,821 | 22.1 (0.6) | 6,126 | 22.5 (0.5) |
| Glomerulonephritis     | 2,616 | 34.2 (0.9) | 2,799 | 34.7 (0.9) | 2,803 | 32.6 (0.9) | 2,835 | 34.0 (0.9) | 2,892 | 34.6 (0.9) |
| Hypertension           | 2,423 | 21.6 (0.9) | 2,722 | 21.5 (0.8) | 2,894 | 23.1 (0.8) | 3,185 | 21.9 (0.7) | 3,590 | 22.3 (0.7) |
| Cystic Kidney Disease  | 616   | 40.1 (2.0) | 607   | 39.5 (2.0) | 608   | 41.4 (2.0) | 682   | 47.2 (1.9) | 683   | 41.5 (1.9) |
| Interstitial Nephritis | 429   | 25.5 (2.1) | 418   | 27.6 (2.2) | 492   | 29.1 (2.1) | 537   | 29.8 (2.0) | 470   | 29.0 (2.1) |
| Obstructive Nephropathy| 207   | 28.5 (3.2) | 213   | 17.7 (2.7) | 215   | 19.5 (2.8) | 271   | 19.6 (2.5) | 293   | 21.3 (2.4) |
| Other                  | 1,150 | 23.0 (1.3) | 1,343 | 22.2 (1.2) | 1,400 | 21.8 (1.2) | 1,587 | 19.6 (1.1) | 1,658 | 20.9 (1.1) |
| Unknown                | 847   | 27.4 (1.6) | 800   | 26.6 (1.6) | 812   | 29.5 (1.6) | 900   | 32.8 (1.6) | 935   | 29.9 (1.6) |
| Missing                | 1,453 | 23.9 (1.2) | 1,179 | 26.8 (1.3) | 1,328 | 22.4 (1.2) | 1,024 | 20.4 (1.3) | 1,170 | 22.0 (1.2) |

NOTES: OPTN is Organ Procurement and Transplantation Network. ESRD is end stage renal disease. Standard errors are in parentheses.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List and Removal Data Sets, May 1994 Update.

significant impact on all three measures of transplant access. Black persons are only 37 percent as likely as white persons to get a transplant (including living donor). They are only 64 percent as likely as white persons to get on the wait list and only 66 percent as likely to get a cadaver transplant after being wait listed. Native Americans also trail white persons in all three access measures, but not to the same degree as black persons. Asian-Americans have lower rates than white persons for all transplantation and wait longer for a cadaver transplant after wait listing. However, they are 32 percent more likely than white persons to register on the wait list. The lower overall transplantation rate for Asian-Americans is contrary to the results shown in Table 3. This is probably due to the fact that fewer Asian-Americans are diabetic, thus inflating their unadjusted rate relative to white persons.

Other covariates operated in the expected directions. Age is negatively related to overall transplantation. Age is less strongly related to getting on the wait list and the age effect becomes even less pronounced for transplantation after being wait listed. Males are higher than females on all three measures of access. Causes of renal failure are similar to age in their effects. There are relatively strong effects on the first two measures, but little effect on access after wait listing.
Table 8
Transplantation Within 1 Year of Enrollment in OPTN for Medicare ESRD Beneficiaries, by Selected Demographic Characteristics and Year of Wait Listing

| Characteristic | 1988 | 1989 | 1990 | 1991 | 1992 |
|---------------|------|------|------|------|------|
| 1988          | 6,710| 55.4 (0.6) | 7,521| 49.6 (0.6) | 8,242| 46.4 (0.6) | 8,830| 43.5 (0.5) | 9,765| 38.5 (0.5) |
| Age Under 15 Years | 170| 66.5 (3.7) | 163| 59.7 (3.9) | 157| 55.7 (4.1) | 192| 55.9 (3.7) | 181| 52.2 (4.1) |
| 15-24 Years | 583| 58.2 (2.1) | 654| 53.5 (2.0) | 620| 48.4 (2.1) | 605| 44.8 (2.1) | 641| 37.3 (2.0) |
| 25-34 Years | 1,407| 52.0 (1.4) | 1,621| 50.3 (1.3) | 1,582| 46.7 (1.2) | 1,508| 44.0 (1.1) | 2,022| 43.7 (1.0) |
| 35-44 Years | 1,860| 55.0 (1.2) | 2,036| 51.5 (1.1) | 2,177| 48.0 (1.1) | 2,354| 44.5 (1.1) | 2,458| 37.4 (1.0) |
| 45-54 Years | 1,508| 53.7 (1.3) | 1,762| 46.7 (1.2) | 1,908| 44.0 (1.1) | 2,102| 40.3 (1.1) | 2,422| 38.0 (1.0) |
| 55-64 Years | 966| 52.0 (1.7) | 1,137| 47.4 (1.5) | 1,337| 45.4 (1.4) | 1,492| 42.0 (1.3) | 1,675| 36.1 (1.2) |
| 65-74 Years | 213| 55.5 (3.5) | 273| 44.3 (3.1) | 355| 42.3 (2.7) | 395| 48.2 (2.6) | 550| 37.7 (2.2) |
| 75 Years or Over | 100.0| 0.0 (0.0) | 5| 40.0 (21.9) | 6| 83.3 (15.2) | 11| 54.6 (15.0) | 18| 25.8 (11.1) |
| Sex Male | 4,118| 57.6 (0.8) | 4,605| 50.7 (0.8) | 5,065| 48.6 (0.7) | 5,310| 44.2 (0.7) | 5,902| 39.4 (0.7) |
| Female | 2,592| 51.8 (1.0) | 3,016| 48.0 (0.9) | 3,177| 42.9 (0.9) | 3,520| 42.4 (0.9) | 3,863| 37.2 (0.8) |
| Race Asian-American | 188| 46.8 (3.8) | 215| 41.6 (3.4) | 275| 41.1 (3.0) | 236| 37.3 (3.2) | 293| 37.4 (2.9) |
| Black | 1,550| 45.9 (1.3) | 1,898| 39.6 (1.2) | 2,025| 35.8 (1.1) | 2,319| 31.4 (1.0) | 2,635| 26.2 (0.9) |
| White | 4,818| 59.2 (0.7) | 5,326| 54.1 (0.7) | 5,732| 51.1 (0.7) | 6,063| 48.9 (0.7) | 6,574| 44.2 (0.6) |
| Native American | 78| 43.8 (5.8) | 100| 41.5 (5.0) | 101| 34.0 (4.9) | 98| 39.8 (5.1) | 123| 30.7 (4.3) |
| Other/Unknown | 76| 37.8 (5.7) | 82| 24.8 (4.9) | 109| 23.1 (4.1) | 114| 17.8 (3.7) | 140| 25.8 (3.3) |
| Primary Diagnosis Diabetes | 1,623| 55.4 (1.3) | 1,999| 51.1 (1.2) | 2,129| 47.3 (1.1) | 2,352| 46.0 (1.1) | 2,755| 41.5 (1.0) |
| Glomerulonephritis | 1,581| 56.4 (1.3) | 1,773| 51.4 (1.2) | 1,883| 48.3 (1.2) | 1,901| 44.6 (1.2) | 2,072| 41.5 (1.0) |
| Hypertension | 1,099| 51.1 (1.5) | 1,220| 44.1 (1.5) | 1,477| 41.4 (1.3) | 1,619| 37.1 (1.2) | 1,839| 31.9 (1.1) |
| Cystic Kidney Disease | 504| 62.7 (2.2) | 642| 51.9 (2.0) | 615| 54.8 (2.0) | 609| 47.9 (1.9) | 747| 47.4 (1.9) |
| Intestinal Nephritis | 255| 54.9 (3.1) | 264| 50.7 (3.2) | 280| 46.0 (3.1) | 333| 43.0 (2.8) | 321| 42.6 (2.8) |
| Obstructive Nephropathy | 95| 55.3 (5.2) | 107| 53.3 (4.9) | 113| 45.8 (4.8) | 119| 45.5 (4.8) | 143| 48.7 (4.4) |
| Other | 455| 52.8 (2.4) | 504| 51.2 (2.3) | 561| 43.9 (2.1) | 637| 41.2 (2.0) | 698| 35.4 (1.9) |
| Unknown | 450| 60.3 (2.4) | 438| 52.9 (2.4) | 480| 50.4 (2.3) | 544| 47.9 (2.2) | 589| 39.3 (2.1) |
| Missing | 638| 52.7 (2.0) | 683| 45.2 (2.0) | 684| 41.2 (1.9) | 616| 40.4 (2.0) | 600| 32.2 (2.0) |

NOTES: OPTN is Organ Procurement and Transplantation Network. ESRD is end stage renal disease. Standard errors are in parentheses.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List Data Set, May 1994 Update.

DISCUSSION

This article has attempted to expand our knowledge of access to transplantation by examining a new measure of transplant access and comparing it with two more traditional measures of access. In order to qualify for a cadaver transplant, a person must first enroll on the national OPTN waiting list. Prior to this study, no national-level analysis of this process had been done. The successful matching of the HCFA and OPTN data bases has shown the importance of a measure of this level of access. While it remains true that black ESRD beneficiaries lag behind white ESRD beneficiaries in transplantation after wait list enrollment, a similar disparity exists in the primary step of getting on the wait list in the first place. The importance of the enrollment process is further shown in the case of Asian-Americans. This group has a lower rate of transplantation after wait listing than do white persons. However, the greater enrollment rate on the wait list means that Asian-Americans overtake white persons in cumulative transplantation rate within 5 years after renal failure.

Previous analyses of wait times on the OPTN wait list have emphasized median
Table 9
Relative Likelihood of Transplantation, Wait Listing, and Post Wait Listing Transplant, by Selected Demographic Characteristics: Results of Proportional Hazards Modeling

| Covariate       | Comparison       | Relative Risk Ratios |
|-----------------|------------------|----------------------|
|                 |                  | Time to Transplant   | Time to Wait List | Time to Transplant |
|                 |                  | Following Renal Failure | Following Renal Failure | Following Wait List |
| Black           | White            | 0.374                | 0.642             | 0.655             |
| Asian-American  | White            | 0.826                | 1.321             | 0.800             |
| Native American | White            | 0.668                | 0.828             | 0.710             |
| Under 15 Years  | 25-34 Years      | 1.911                | 0.703             | 1.293             |
| 15-24 Years     | 25-34 Years      | 1.291                | 1.033             | 1.074             |
| 35-44 Years     | 25-34 Years      | 0.705                | 0.839             | 0.953             |
| 45-54 Years     | 25-34 Years      | 0.400                | 0.559             | 0.865             |
| 55-64 Years     | NR               | NR                   | 0.850             | 0.773             |
| 65-74 Years     | NR               | NR                   | NR                | 0.931             |
| 75 Years or More| 25-34 Years      | NR                   | NR                | 0.931             |
| Male            | Female           | 1.133                | 1.080             | 1.136             |
| Diabetes        | Glomerulonephritis| 0.690               | 0.701             | 0.963             |
| Hypertension    | Glomerulonephritis| 0.754               | 0.843             | 0.852             |
| Interstitial Nephritis | Glomerulonephritis| 0.841               | 0.776             | 0.967             |
| Obstructive Nephropathy | Glomerulonephritis| 0.745               | 0.556             | 0.933             |
| Cystic Kidney Disease | Glomerulonephritis| 1.294               | 1.394             | 1.157             |
| Other           | Glomerulonephritis| 0.661               | 0.688             | 0.975             |
| Unknown         | Glomerulonephritis| 0.854               | 0.869             | 1.027             |
| Missing         | Glomerulonephritis| 0.707               | 0.669             | 0.798             |

*p > 0.001
**p > 0.01
* p > 0.05

NOTES: NR is not in model.

SOURCE: Health Care Financing Administration, Bureau of Data Management and Strategy: End Stage Renal Disease Program Management and Medical Information System, 1988-92 Incidence Cohort (April 1994 Update); United Network for Organ Sharing: Organ Procurement and Transplantation Network Wait List and Removal Data Sets, May 1994 Update.

wait times. While median wait time is an adequate single measure of access, it does not show how relative access can change over time. By tracking patients out as far as 5 years from initial OPTN enrollment, this study has shown that there is a certain amount of equalization in access across racial groups over time. UNOS (the private organization which operates the OPTN under contract to the government) has long recognized the problem of equitable access to transplantation for minority patients. Recently, UNOS has revised the point system for organ allocation to decrease the weight given to donor/recipient human leukocyte antigen (HLA) matching and increased the weight given to time on the wait list. Both of these measures should serve to increase minority access rates (Gaston et al., 1993).

The fact remains, however, that no matter what measure of transplant access is used, black beneficiaries fare worse than either white, Asian-American, or Native American beneficiaries. They are the least likely to get on the national wait list, and have longer wait times once they do get wait-listed. Consequently, their overall transplant rates lag far behind the other racial groups. In addition, wait times following OPTN enrollment increased more for black patients than for any other racial group between 1988 and 1991.

The analyses presented in this article do not address the reasons behind transplant

10 HLA are the major "tissue type" proteins present on cells that are responsible for rejection by one person of the tissues of another person. As such, they present one of the major barriers to organ transplantation.

11 Black persons have the lowest rate of transplantation from living donors, also contributing to their low overall rate.
access problems. Many others have addressed these issues. For example, Sanfilippo et al. (1992), Kallich, Wyant, and Krushat (1990), and Gaston et al. (1993) have shown that biological factors play a significant role in the ability to match cadaver kidneys with persons on the OPTN. Others have shown that attitudinal factors play a part in the low transplant rates among black persons (Callender, 1991; Kasiske, Neylan, and Riggio, 1991; Kutner, 1987).

A number of other issues also were not addressed by this study. For example, these analyses were only concerned with initial transplantation. Repeat transplantation following rejection is another access issue. About 13 percent of kidney transplants are repeat transplants (Health Care Financing Administration, 1994). Other issues important to our understanding of transplant access include multiple listing (patients registering with more than one transplant center) and economic and sociological factors affecting decisions to enter and continue with the transplant process. Current studies which are addressing some of these issues include a Robert Wood Johnson study of physician attitudes and patient preferences about transplantation and an Agency for Health Care Policy and Research study of multiple listing on the OPTN.

The importance of initially getting on the wait list suggests that measures designed to increase black enrollment on the OPTN (such as education and outreach efforts) should improve access to transplantation for black persons. However, the trend data clearly show the crucial limiting factor of the organ shortage. The incidence of treated renal failure and the enrollment on the OPTN continue to grow at rates greater than the number of available organs. Consequently, post-enrollment transplant wait times have increased. Without significant increases in cadaver donation rates, wait times will continue to increase for all racial groups.

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