Chapter VIII
Geographic Variability in Access to Primary Kidney Transplantation in the United States, 1996-2005

OVERVIEW

- This chapter focuses on geographic variability in patient access to kidney transplantation in the United States over the last decade. It examines geographic differences and trends in overall rates of access to kidney transplantation, in the component rates of wait-listing, and of living and deceased donor transplantation.

- Over 700,000 patients under age 75, who began chronic dialysis treatment, received their first living donor kidney transplant, or were placed on the waiting list preemptively were included in the study. Relative rates of wait-listing and transplantation by State were calculated using Cox regression models, adjusted for patient demographics.

- Results showed that there were large geographic differences in access to the kidney transplant waiting list; and, once wait-listed, to a kidney transplant. Adjusted wait-list rates ranged from 37% lower to 64% higher than the national average.

- The living donor transplant rate ranged from 57% lower to 166% higher than the national average. The deceased donor transplant rate among wait-listed patients ranged from 60% lower to 150% higher than the national average.

- In general, States with higher wait-listing rates tended to have lower transplantation rates and States with lower wait-listing rates showed trends towards higher transplant rates. However, six States demonstrated both high wait-listing and high deceased donor transplantation rates while six others, plus the District of Columbia and Puerto Rico, were below the national average for both parameters.

INTRODUCTION

In the United States, access to the kidney transplant waiting list and to living donor transplantation, among patients with advanced renal disease, and access to deceased donor transplantation among wait-listed patients varies markedly by demographic characteristics, etiology of End-Stage Renal Disease (ESRD), insurance, and place of residence at wait-listing. Prior studies have shown that the recipients of renal transplants have better survival than comparable dialysis patients (1-4) and have a better quality of life (5-9) than do patients on dialysis. In addition, transplant recipients with longer dialysis exposures have a higher subsequent rate of graft failure and patient mortality than transplant recipients with shorter dialysis experiences (10-11). Although the final rule governing the operation of the Organ Procurement and Transplantation Network (OPTN), published in 1998, requires that patients with similar diagnoses and disease progression have similar access to transplantation (12), a large number of previous studies have documented the effect of various patient characteristics on rates of referral (13-19), wait-listing (17-23), living donor renal transplantation (23-28) and deceased donor renal transplantation (17-19, 21, 23, 26-35), and have shown that certain patient demographic groups including minorities, females, older patients, diabetics, and those with only Medicare or Medicaid insurance are relatively less likely to gain access to the waiting list and to receive a renal transplant (13-35). A few studies have examined geographic patterns in access to transplantation (36-38) and identified large variations in opportunity within the United States. This chapter examines geographic differences and trends in overall rates of access to kidney transplantation in the component rates of wait-listing, and of living and deceased donor transplantation that are not explained by adjustments for patient-specific demographic variables, insurance, or disease state. It also explores interactions between these rates and the opportunity in the United States for kidney transplantation.

STUDY METHODS

This chapter summarizes a special study employing data from the Centers for Medicare and Medicaid Services (CMS) and the Organ Procurement and Transplantation Network/Scientific Registry of Transplant Recipients (OPTN/SRTR). The CMS database includes information on all dialysis patients in the United States. The OPTN/SRTR database includes data on all wait-listed kidney transplant candidates and recipients in the United States and is described further in companion chapters in this report. Both data sources were supplemented with vital status information from the Social Security Death Master File (39). Since transplants are rarely performed on patients older than 75

years, the following wait-listing and transplant data discussions are limited to patients younger than 75 at time of entry into the study.

The study population consisted of 703,202 patients under the age of 75, who either began chronic dialysis treatment (N=657,541), received a living donor kidney transplant without being placed on the OPTN kidney or kidney pancreas waiting list (N=5,902), or were placed on the OPTN kidney or kidney-pancreas waiting list for a first transplant prior to initiating chronic dialysis (preemptive wait-listing) (N=39,849) between 1996 and 2005. For purposes of this study, States were defined as the fifty States plus Puerto Rico and the District of Columbia. Patients who had started dialysis, previously received a transplant, or were placed on the waiting list prior to 1996 were excluded from this study population. Patients living in a U.S. territory other than Puerto Rico or with an unknown State of residence were also excluded. Patients placed on the kidney waiting list prior to the start of dialysis were considered to have ESRD beginning on the date of wait-listing. Patients who were added to the waiting list on the same date that they underwent a living donor kidney transplant were not counted as having been placed on the waiting list.

This study examined by State and nationally: 1) wait-listing rates among ESRD patients, 2) living donor kidney transplant rates among ESRD patients, 3) deceased donor transplant rates among wait-listed patients, and 4) overall (deceased and living donor) transplant rates among ESRD patients. Patients were followed from the onset of ESRD to the date of wait-listing, from the onset of ESRD to the date of transplantation, and from the date of wait-listing to transplantation. The study end-date was December 31, 2005. Follow-up for wait-listing rates and deceased donor transplant rates was censored at death, living donor transplant, or end of study. Follow-up for living donor transplant rates was censored at death, deceased donor transplant, or end of study. Follow-up for overall transplant rates was censored at death or end of study.

Multivariable analyses using Cox proportional hazards models, adjusted for patient demographics that are captured in the CMS and OPTN/SRTR databases, were used to calculate adjusted rates of wait-listing and transplantation for each State. Adjustments for waiting list rates, living donor transplant rates, and overall transplant rates were patient age, race, ethnicity, sex, cause of ESRD, incidence year (dialysis, living donor transplant, wait-listing), comorbid conditions, and insurance type. Adjustments for analyses of deceased donor transplant rates were patient age at wait-listing, race, ethnicity, sex, ESRD cause, wait-listing year, comorbid conditions at wait-listing, insurance type at wait-listing, blood type, panel reactive antibody (PRA) at wait-listing, and candidate human leukocyte antigens (HLA). Results are displayed as the relative rates for each State compared to the overall or national average reference rate of 1.0. The national average is taken as the average rate over the States, the District of Columbia, and Puerto Rico.

Changes in rates (wait-listing rate, living donor transplant rate, and deceased donor transplant rate) over the ten-year period of the study were estimated by fitting a Cox model to the national data with year of entry included in the analysis as a covariate for each of the three rates of interest. This gave estimates of the overall average annual changes in the national rates of wait-listing, living donor transplantation, and deceased donor transplantation. The average five-year changes in rate were taken as the fifth power of the annual changes. Similarly, separate models were fitted to the data from each State to obtain State-specific average five-year increases in the rates.

TRENDS IN WAIT-LISTING AND KIDNEY TRANSPLANATION DURING THE PAST DECADE

Table VIII-1 shows the study population by entry criterion and by year of ESRD diagnosis. Between 1996 and 2005, the number of patients per year starting dialysis as their first form of ESRD therapy increased progressively from 56,855 to 70,604, and the yearly number of patients preemptively wait-listed more than doubled, from 2,720 to 6,381. The pattern for patients receiving a living donor kidney transplant prior to initiation of dialysis (preemptive living donor kidney transplant) was different, though. The number of patients receiving a preemptive living donor transplant without being wait-listed rose from 489 in 1996 to a peak of 678 in 2004, but that total dropped by 19% to 547 in 2005. The total percentage of incident ESRD patients who entered the study prior to initiation of dialysis on the basis of either preemptive wait-listing or preemptive living donor transplantation rose steadily over the past decade from 6.5% in 1996 to 8.9% in 2005. Furthermore, during that same interval, an additional 5,699 patients, who were preemptively wait-listed, subsequently went on to receive a preemptive living donor kidney transplant (Table VIII-2).

Table VIII-2 shows that among the 703,202 patients, a total of 159,279 (23%) were placed on the waiting lists for a kidney or kidney-pancreas transplant by December 31, 2005. Of these wait-listed candidates, 25% (39,849) were wait-listed prior to initiating dialysis and 61% (96,429) received a living or deceased donor kidney transplant by December 31, 2005. Of those transplanted, 43% (44,033) received a living and 57% (58,298) a deceased donor transplant. Approximately 26% (11,601) of the living donor transplant recipients and 11% (6,284) of the deceased donor recipients were transplanted prior to starting dialysis; 13% (5,902) received a living donor transplant without being wait-listed.

Table VIII-1. Study Population by Entry Criterion and Year, 1996-2005

Entry criterion		1996-2005	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005
Began Dialysis	N	657,451	56,855	59,652	62,458	64,758	66,056	67,953	68,476	69,914	70,725	70,604
	%	93.5%	94.7%	94.7%	94.4%	94.3%	93.9%	93.9%	93.6%	92.9%	92.2%	91.1%
Preemptively Wait-listed	N	39,849	2,720	2,826	3,251	3,338	3,650	3,698	4,030	4,656	5,299	6,381
	%	5.7%	4.5%	4.5%	4.9%	4.9%	5.2%	5.1%	5.5%	6.2%	6.9%	8.2%
Received Preemptive LD Transplant, never wait-listed	N	5,902	489	482	483	587	621	688	674	653	678	547
	%	0.8%	0.8%	0.8%	0.7%	0.9%	0.9%	1.0%	0.9%	0.9%	0.9%	0.7%
Total	N	703,202	60,064	62,960	66,192	68,683	70,327	72,339	73,180	75,223	76,702	77,532

Source: SRTR Analysis, May 2006.

Table VIII-2. Outcomes of Study Population by Entry Criterion, 1996-2005

				Preemptive Transplants		Not Preemptive Transplants	
Entry criterion	N	Wait-listed	All Transplants	Living Donor	Deceased Donor	Living Donor	Deceased Donor
Began Dialysis	657,451	119,430	73,172	-	-	28,708	44,464
Preemptively Wait-listed	39,849	39,849	23,257	5,699	6,284	3,724	7,550
Received Preemptive Living Donor Transplant , never wait-listed	5,902	-	5,902	5,902	-	-	-
Total	703,202	159,279	102,331	11,601	6,284	32,432	52,014

Source: SRTR Analysis, May 2006.

Table VIII-3 shows the number and percentage of patients that were wait-listed and the percentage of patients that received a transplant during the study period by State of residence. The percentage of ESRD patients per State that were wait-listed ranged nearly 3-fold from 13% to 32%, while the percentage that were wait-listed preemptively varied more than 17-fold from 0.7% to 12%. Similar patterns were observed among kidney transplant recipients. The percentage by State of all ESRD patients receiving a kidney transplant ranged from 8% to 30% and the percentage of transplants among all ESRD patients that were preemptive ranged from 0.3% to 10%. The percentage of ESRD patients that received a living donor transplant ranged from 3% to 20%, while the percentage of ESRD patients that received a deceased donor transplant ranged from 4% to 14%. Overall, the ratio of living donor to deceased donor transplantation was 0.8. The State ratio ranged from 0.4 to 1.9, with thirty-eight States having more deceased donor transplants than living donor transplants. Among wait-listed patients, the percentage of patients receiving a deceased donor transplant ranged from 21% to 67%. As expected, there were strong correlations between the percentage preemptively wait-listed and the overall percentage wait-listed ($r=0.93$, $p<0.0001$), between the percentage preemptively wait-listed and the overall percentage transplanted ($r=0.63$, $p<0.0001$), and between the percentage preemptively receiving a transplant and the overall percentage transplanted ($r=0.93$, $p<0.0001$). Additionally, there was a positive correlation between living donor and deceased donor transplant rates ($r=0.66$, $p<0.0001$).

Access to the Waiting List

The number of patients placed on the kidney waiting list has increased considerably over the past decade (35). However, after adjusting for patient age, race, ethnicity, sex, ESRD cause, year of starting dialysis, comorbid conditions, and insurance type, there are large geographic differences in access to the kidney transplant waiting list (Figure VIII-1). These rates ranged from 37% lower than the national average to 64% higher (RR=0.63 to 1.64). The States in the lowest

Table VIII-3. Percent of Patients Placed on the Waiting List and Receiving a Transplant by State, 1996-2005

State	N	Wait-listed (%)	Pre-emptive WL (%)	All Tx (%)	Pre-emptive Tx (%)	LD Tx (%)	DD Tx (%)	DD Tx Among WL (%)
All	**703,202**	**22.6**	**5.7**	**14.6**	**2.5**	**6.3**	**8.3**	**36.6**
AK	737	24.6	4.9	23.2	4.3	13.7	9.5	38.7
AL	13,790	21.9	4.9	11.4	2.1	5.6	5.8	26.5
AR	6,679	14.4	2.5	13.1	1.9	5.6	7.5	52.2
AZ	12,107	20.5	4.3	13.8	2.0	7.1	6.6	32.4
CA	81,907	32.4	9.1	13.8	2.2	5.8	8.0	24.7
CO	6,394	31.2	9.4	19.5	3.3	8.9	10.6	33.9
CT	6,935	19.6	4.6	14.1	3.2	8.1	6.0	30.4
DC	3,569	18.1	4.4	7.9	1.3	4.0	3.9	21.3
DE	2,179	27.3	8.6	16.6	3.3	7.5	9.1	33.3
FL	38,935	17.4	3.6	13.2	2.1	3.9	9.3	53.7
GA	24,114	15.2	3.2	10.4	1.6	3.6	6.8	44.6
HI	3,853	23.6	5.2	10.5	1.5	4.3	6.3	26.5
IA	4,906	24.6	7.2	24.5	6.2	12.0	12.5	51.0
ID	1,852	22.7	5.7	23.5	4.2	11.8	11.7	51.5
IL	33,006	25.6	7.7	16.3	3.3	6.9	9.4	36.9
IN	13,694	19.1	4.5	15.2	2.7	5.5	9.7	51.0
KS	4,957	16.6	4.1	15.6	2.8	5.9	9.7	58.8
KY	9,542	15.5	3.2	13.9	2.5	4.8	9.1	58.9
LA	16,286	15.4	2.8	9.7	1.3	3.2	6.5	42.2
MA	11,366	27.8	6.1	19.5	3.7	10.5	9.0	32.4
MD	16,890	27.3	8.1	16.2	3.1	8.0	8.2	30.2
ME	2,068	23.0	5.0	20.5	4.3	9.9	10.6	46.0
MI	25,717	24.1	7.0	15.5	3.0	8.2	7.3	30.4
MN	7,894	30.7	12.0	30.3	9.8	19.9	10.4	33.9
MO	13,392	19.1	4.4	13.9	2.1	5.2	8.7	45.5
MS	9,758	16.8	2.1	8.8	1.1	3.2	5.6	33.5
MT	1,343	28.1	7.1	24.7	4.2	12.6	12.1	43.2
NC	23,377	17.8	3.9	10.6	1.7	4.7	5.9	33.0
ND	1,082	27.9	10.1	29.8	9.8	18.4	11.4	40.7
NE	3,237	21.1	5.4	18.4	3.5	8.4	10.0	47.4
NH	1,760	24.4	5.0	22.5	4.4	12.2	10.3	42.1
NJ	22,632	26.9	8.8	14.9	3.0	7.2	7.8	28.9
NM	4,482	18.3	4.1	12.0	1.9	5.3	6.6	36.4
NV	4,319	26.2	6.6	15.4	2.3	6.3	9.1	34.7
NY	48,380	23.0	5.5	13.4	2.3	6.5	6.8	29.7
OH	29,755	17.9	4.1	15.1	2.7	7.0	8.2	45.7
OK	8,396	17.1	3.1	12.2	1.4	3.7	8.5	49.5
OR	5,469	17.6	2.9	21.6	3.6	10.6	11.0	62.8
PA	31,168	28.1	8.9	17.8	3.1	5.9	11.9	42.4
PR	9,468	12.6	0.7	7.9	0.3	3.3	4.6	36.2
RI	1,982	24.0	5.8	21.6	3.4	12.1	9.5	39.7
SC	13,284	16.2	3.3	10.9	1.8	3.3	7.6	46.5
SD	1,595	29.3	8.8	23.3	5.2	10.5	12.8	43.6
TN	14,858	18.3	3.0	13.3	1.9	5.3	8.0	43.5
TX	55,691	19.6	2.8	12.6	1.4	4.3	8.3	42.4
UT	2,756	19.7	5.4	30.4	7.0	17.2	13.2	66.9
VA	19,192	24.0	6.0	14.4	2.5	7.5	7.0	29.0
VT	908	26.0	8.5	19.7	4.5	9.0	10.7	41.1
WA	9,506	24.8	6.5	20.6	3.3	8.7	11.9	48.0
WI	10,416	31.1	10.8	24.7	6.9	11.0	13.7	43.9
WV	4,956	18.9	3.7	14.7	2.3	5.5	9.2	48.6
WY	663	26.7	6.3	21.7	4.7	10.6	11.2	41.8

Tx: Transplant. DD: Deceased donor. LD: Living donor. WL: Waiting List. Source: SRTR Analysis, May 2006.

quartile had relative wait-listing rates that were less than 0.81 (all statistically significant, p<0.05), while the States in the highest quartile had relative rates above 1.23 (all statistically significant, p<0.05).

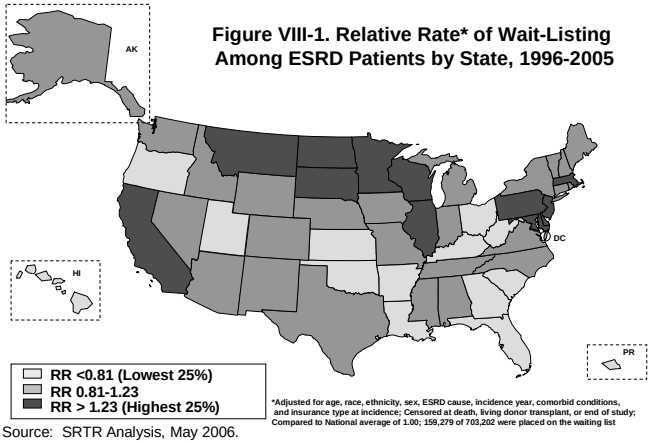


Figure VIII-1. Relative Rate* of Wait-Listing Among ESRD Patients by State, 1996-2005

Source: SRTR Analysis, May 2006.

Between 1996 and 2005, the average five-year increase in the wait-listing rate was 10%. However, this increase was not uniform across the United States. It is notable that approximately one-third of the States demonstrated a minimal to large five-year decline in the wait-listing rate (-0.4% to -33%). In contrast, about one-third of the States realized a 15% or greater five-year increase in their wait-listing rate (Figure VIII-2).

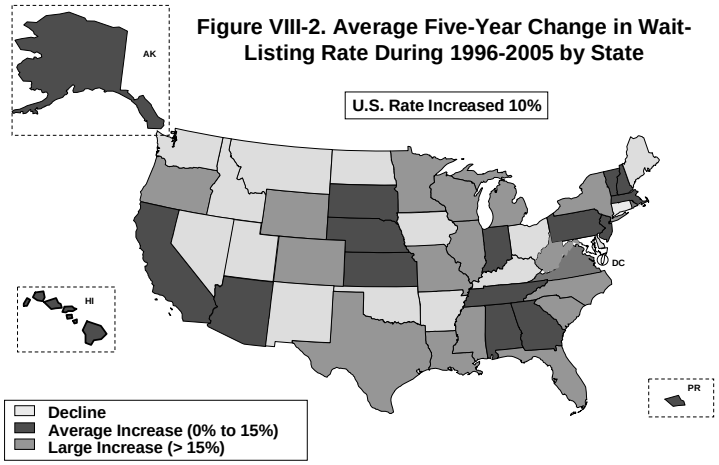


Figure VIII-2. Average Five-Year Change in Wait-Listing Rate During 1996-2005 by State

Source: SRTR Analysis, May 2006.

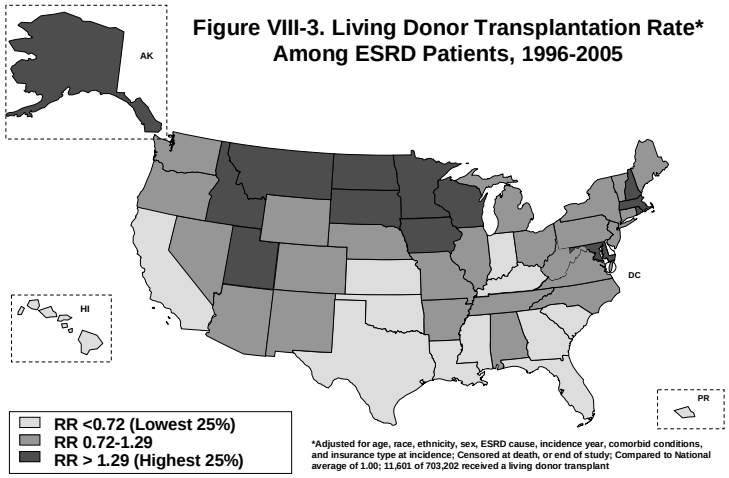


Figure VIII-3. Living Donor Transplantation Rate* Among ESRD Patients, 1996-2005

Source: SRTR Analysis, May 2006.

Access to a Living Donor Transplant

The number of living donor kidney transplants has increased over the past decade (35), but, as seen in Figure VIII-3, the opportunity for living donor transplantation varies widely by State. The living donor transplant rate, after adjusting for patient age, race, ethnicity, sex, ESRD cause, starting year of dialysis, comorbid conditions, and insurance type, ranged from 57% lower to 166% higher than the national average (RR=0.43-2.66). The States in the lowest quartile had living donor transplant rates more than 28% lower than the national average (all statistically significant, p<0.05), while the States in the highest quartile had relative rates above 129% of the national average (all statistically significant, p<0.05).

During 1996-2005, there was an average five-year increase in the living donor transplant rate of 12%. Approximately one-third of the States had an average five-year decline in the living donor transplant rate, while during this time period nearly one-third had more than a 20% increase in the five-year rate (Figure VIII 4).

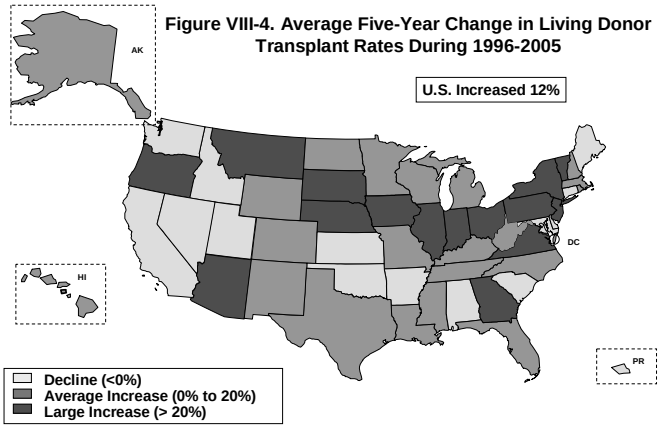


Figure VIII-4. Average Five-Year Change in Living Donor Transplant Rates During 1996-2005

Source: SRTR Analysis, May 2006.

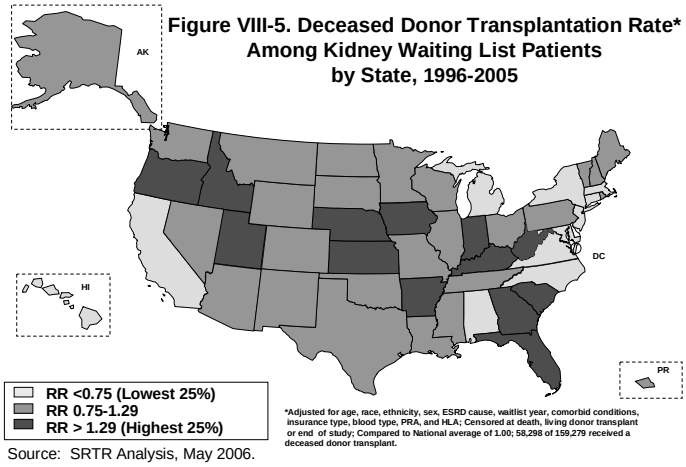


Figure VIII-5. Deceased Donor Transplantation Rate* Among Kidney Waiting List Patients by State, 1996-2005

Source: SRTR Analysis, May 2006.

Access to a Deceased Donor Transplant

There are also large and meaningful geographic differences in deceased donor kidney transplantation rates for wait-listed patients, ranging from 60% lower to 150% higher than the national average (RR=0.40 to 2.50), after adjusting for patient age, race, ethnicity, sex, ESRD cause, wait-list year, comorbid conditions, insurance type, blood type, PRA, and HLA antigens (Figure VIII-5). The States in the lowest quartile had deceased donor transplant rates below 75% of the national average (all statistically significant, p<0.05), while the States in the highest quartile had relative rates above 129% of the national average (all statistically significant, p<0.05).

Although the number of deceased donor transplants has increased by 8% over the past decade, the number of patients on the waiting list has doubled (35). As a consequence of these two dynamics, there has been a 12% average five-year decrease in the U.S. deceased donor transplant rate among wait-listed patients from 1996 to 2005. Only 18 States had an increase in the average five-year deceased donor transplant rate, while 19 States had more than a 25% average five-year decrease in this rate (Figure VIII-6).

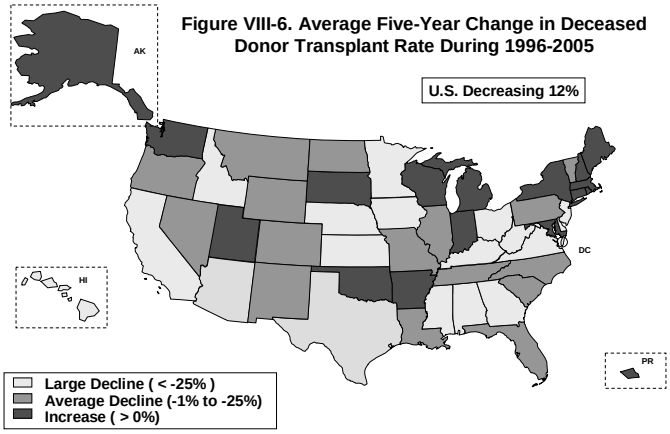


Figure VIII-6. Average Five-Year Change in Deceased Donor Transplant Rate During 1996-2005

Source: SRTR Analysis, May 2006.

The majority of States (N=31) are served by a single Organ Procurement Organization (OPO). Twelve States do not have an OPO headquartered within their State and share an OPO with another State, while nine States have two or more OPOs. Table VIII-4 shows that compared to States with one OPO, wait-list rates are higher both in States that have no OPOs headquartered in the State and in States with two or more OPOs (RR=1.22 and 1.12, respectively, both p<0.0001). Table VIII-4 also shows that compared to States with one OPO, States that share an OPO have a 58% higher rate of living donor kidney transplantation (RR=1.58, p<0.0001), and a 14% higher adjusted rate of deceased donor kidney transplantation (RR=1.14, p<0.0001). In contrast, States that have two or more OPOs have an 18% lower living donor adjusted transplant rate (RR=0.82, p<0.0001), and an 8% lower adjusted deceased donor kidney transplant rate (RR=0.92, p<0.0001). Similarly, Table VIII-5 shows that States that had more transplant programs had higher wait-list rates and lower deceased donor transplant rates. Compared to

Table VIII-4. Relative Rate of Waiting List and Deceased and Living Donor Transplantation by State OPO Density, 1996-2005

OPOs Residing in the State	States	Patients	Waitig list RR*	p-value	Living Donor Transplant RR*	p-value	Deceased Donor Transplant RR**	p-value
None***	12	21,125	1.22	<0.0001	1.58	<0.0001	1.14	<0.0001
1 OPO	31	347,590	1.00	Ref	1.00	Ref	1.00	Ref
2-4 OPOs****	9	334,487	1.12	<0.0001	0.82	<0.0001	0.92	<0.0001

*Adjusted for patient age, race, ethnicity, sex, ESRD cause, year of starting dialysis, and insurance type; **Adjusted for patient age, race, ethnicity, sex, ESRD cause, wait-listing year, insurance type, blood type, PRA, and HLA antigens; ***Shares OPO with another State (AK, DE, ID, ME, MT, ND, NH, RI, SD, VT, WV, WY); ****CA, FL, NC, NY, OH, PA, TN, TX, WI

Source: SRTR Special Analysis, May 2006.

Table VIII-5. Relative Rate of Waiting List and Deceased and Living Donor Transplantation by State Transplant Program Density, 1996-2005

Transplant Programs Residing in the State	States	Patients	Waiting list RR*	p-value	Living Donor Transplant RR*	p-value	Deceased Donor Transplant RR**	p-value
0-3 programs	28	150,238	0.93	<0.0001	1.04	0.002	1.01	0.36
4-8 programs***	17	268,980	1.00	Ref	1.00	Ref	1.00	Ref
9-15 programs****	4	115,218	1.07	<0.0001	1.18	<0.0001	0.78	<.0001
15+ programs*****	3	168,766	1.30	<0.0001	0.82	<0.0001	0.76	<.0001

*Adjusted for patient age, race, ethnicity, sex, ESRD cause, year of starting dialysis, and insurance type; **Adjusted for patient age, race, ethnicity, sex, ESRD cause, wait-listing year, insurance type, blood type, PRA, and HLA antigens; *** AZ, CO, GA, IA, WI, DC, MN, WA, NC, LA, NJ, OK, VA, IL, MO, FL, TN; ****MA, MI, OH, NY; *****PA, CA,TX.

Source: SRTR Special Analysis, May 2006.

Table VIII-6. Relative Rate of Deceased Donor Transplantation by State Residence and Waiting List Center Similarity, 1996-2005

State of Residence and Waiting List the Same?	# Patients	% Patients	Deceased Donor Transplant RR*	p-value
Yes	137,386	86.3	1.00	Ref
No	21,893	13.8	1.04	<0.0001

*Adjusted for patient age, race, ethnicity, sex, ESRD cause, wait-listing year, insurance type, blood type, PRA, and HLA antigens

Source: SRTR Analysis, May 2006.

States that have between four and eight transplant programs, States that have more than nine programs have higher wait-list rates (RR=1.07 for 9-15 programs and 1.30 for 15+ programs, both p<0.0001) and lower deceased donor transplant rates (RR=0.78 for 9-15 programs and 0.76 for 15+ programs, both p<0.0001). States with less than three programs have a 7% lower rate of wait-listing (RR=0.93, p<0.0001). There was not a consistent pattern between the number of transplant programs and the living donor transplant rate.

Most patients (86.3%) are wait-listed for their initial, primary listing in the same State as their State of residence (Table VIII-6). However, the population of kidney transplant recipients that were wait-listed for their initial, primary listing in a State other than their State of residence had a higher deceased donor transplant rate than those who were wait-listed within their State of residence for their initial, primary listing (RR=1.04, p<0.001).

Examining the Relationship Between Wait-Listing Rates and Deceased Donor Transplantation Rates

Figures VIII-7 and VIII-8 show the States grouped into four categories based on the adjusted relative wait-listing rates and deceased donor transplantation rates, conditional upon wait-listing. The reference relative rate (RR = 1.0) was set at the national average. The four categories were: 1) both wait-listing and deceased donor transplant rates were below the national average (Quadrant I), 2) wait-listing rates were below and deceased donor transplant rates above the national average (Quadrant II), 3) wait-listing rates were above and deceased donor transplant rates below the national average (Quadrant IV), and 4) both wait-listing and deceased donor transplant rates were above the national average (Quadrant III). Only six States (Iowa, Maine, Pennsylvania, Rhode Island, South Dakota, and Wisconsin) had both wait-listing and deceased donor transplant rates that were above the national average, while six States (Arizona, Connecticut, Hawaii, Mississippi, North Carolina, and New Mexico) and the District of Columbia and Puerto Rico had both

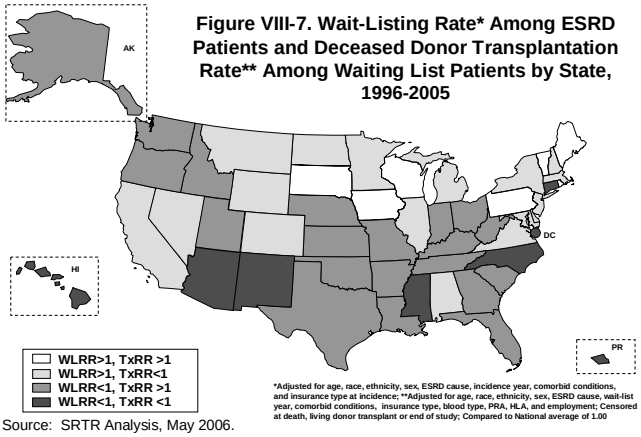


Figure VIII-7. Wait-Listing Rate* Among ESRD Patients and Deceased Donor Transplantation Rate Among Waiting List Patients by State, 1996-2005**

Source: SRTR Analysis, May 2006.

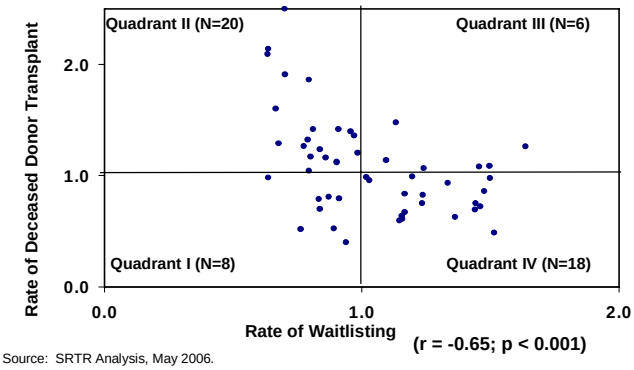
wait-listing and deceased donor transplant rates that were below the national average. There was a negative correlation (r=-0.65, p<0.0001) between wait-listing rates and deceased donor transplant rates after placement on the waiting list.

(Figure VIII-8). In general, States with higher wait-listing rates tended to have lower transplantation rates and States with lower wait-listing rates showed trends for higher transplant rates. A separate study of wait-listing and deceased donor transplant rates in the decades' two five-year periods (1996-2000 and 2001-2005) demonstrated similar correlations (r=-0.691, p<0.0001 and r=-0.688, p<0.0001, respectively).

Overall Access to a Transplant

Figure VIII-9 illustrates that the overall kidney transplant (deceased and living combined) rate among all ESRD patients, after adjusting for patient age, race, ethnicity, sex, ESRD cause, year of starting dialysis, comorbid conditions, and insurance type, ranged from 52% lower to 107% higher than the national average (RR=0.48-2.07). The States in the lowest quartile had relative transplant rates below 0.85 (all

Figure VIII-8. Correlation of Wait-Listing Rates Among ESRD Patients and Deceased Donor Transplantation Rates Among Waiting List Patients by State, 1996-2005



Source: SRTR Analysis, May 2006.

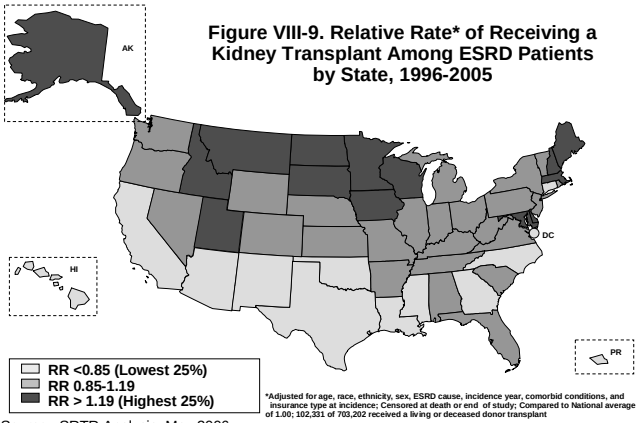


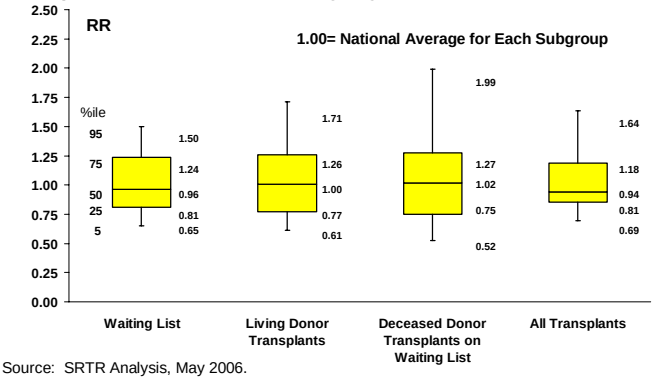
Figure VIII-9. Relative Rate* of Receiving a Kidney Transplant Among ESRD Patients by State, 1996-2005

Source: SRTR Analysis, May 2006.

statistically significant, p<0.05), while the States in the highest quartile had relative rates above 1.19 (all statistically significant, p<0.05).

Figure VIII-10 shows the distribution of adjusted (as described for each above) relative rates by access metric. These box plots summarize the State-to-State variability in access rates. When compared to the national average and despite adjustments for patient demographics, there are

Figure VIII-10. Percentiles of Adjusted Relative Access Rates Compared to the National Average by Access Measure, 1996-2005

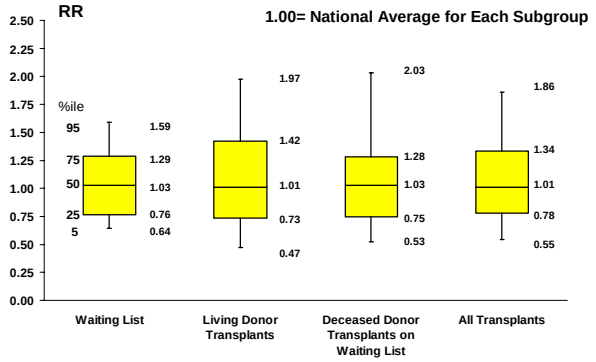


Source: SRTR Analysis, May 2006.

substantial State-to-State differences between the 5th and the 95th percentiles in all four measures: access to the waiting list, from 35% less to 50% greater, access to living donor kidney transplantation, from 39% less to 71% greater, access to deceased donor kidney transplantation, from 48% less to 99% greater, and in overall access to kidney transplantation from 31% less to 64% higher.

The question could be raised as to whether averages should be adjusted for variables such as race, ethnicity, and insurance that are recognized barriers to access. Figure VIII-

Figure VIII-11. Percentiles of Adjusted Relative Access Rates Compared to the National Average, Without Adjusting for Race, Ethnicity, or Insurance Status, 1996-2005



Source: SRTR Analysis, May 2006.

11 shows the relative rates by access measure without these adjustments. Without adjustment there was little difference in the observed ranges of variability, and there was little change in the rankings among the States for each access measure (data not shown).

SUMMARY

These results reveal, after adjustment for insurance status and for important patient demographic and clinical variables, both medically and statistically significant geographic differences in access to the kidney transplant waiting list, and to living donor and deceased donor kidney transplantation. During the study period, there was a modest upward trend in preemptive wait-listing practices, but more than 90% of the study population became eligible for analysis as a consequence of initiation on dialysis. Twenty-three percent of the 703,202 evaluable patients under age 75 in this study were wait-listed and an additional 5,902 underwent a preemptive living donor transplant without being added to the deceased donor kidney transplant waiting list. One quarter of those added to the kidney transplant waiting list were wait-listed prior to initiating dialysis. Almost fifteen percent of the total study population ultimately received a living donor (6%) or deceased donor (8%) kidney transplant.

Access to kidney transplantation varied markedly by State for unadjusted observed rates of overall wait-listing, preemptive wait-listing, overall transplantation, preemptive transplantation, and living donor and deceased donor transplantation. With adjustment for patient case mix and for insurance, there remained statistically significant differences in access by State to the kidney transplant waiting list, and to either a living or deceased donor kidney transplant.

In general and even with adjustments, States with higher wait-listing rates had lower transplantation rates and States with lower wait-listing rates had higher transplant rates ($r = -0.65$, $p<0.0001$). Six States demonstrated both wait-listing rates and deceased donor transplant rates above and six States (plus the District of Columbia and Puerto Rico) had both wait-listing rates and deceased donor transplant rates below the national average.

This study does not imply that those States with higher than average wait-listing or transplantation rates are optimally meeting the needs of their ESRD population, but only that they perform in these regards at rates that exceed the national average. These data do highlight that 20 of the 26 States with higher than average transplantation rates have lower than average wait-list rates for their ESRD populations. Conversely, the benefits of wait-listing are diminished in 18 of the 24 States with higher wait-listing rates by the concomitant existence of lower than average rates for transplantation once wait-listed.

Although this investigation demonstrates the existence of State-to-State disparities within the United States in access to kidney transplantation, it does not identify underlying causes. It may be that much of these differences reflect variables, not captured in existing databases, that might reflect regional differences in practice patterns among primary care physicians, nephrologists, and transplant programs or differing levels of development of healthcare infrastructure in portions of the country. These disparities may also reflect different attitudes towards illness, in general, or towards renal failure, in particular, among patient populations that are specific to individual States. A careful investigation of those States that demonstrate high rates of wait-listing, coupled with high rates of living and deceased donor transplantation, may prove valuable in planning interventions aimed at fostering access to transplantation for the ESRD population.

Potential interventions could be undertaken to improve both wait-listing and transplantation metrics. To succeed, such strategies will need to be wide-ranging and include monitoring of appropriately adjusted referral and wait-listing rates among dialysis units, referral of eligible deaths among donor hospitals, OPO performance in converting referred eligible donors to actual donors, transplant center acceptance rates for allocated organs, and donor service area discard rates. These disparities warrant the coordination of efforts and interventions by the dialysis community, organ procurement and transplant professional communities, government, and patient advocacy groups.

This study documents the degree of geographic disparity that currently exists within the United States in access to the kidney transplant waiting list, and to living donor and deceased donor kidney transplantation. These disparities are not explained by differences in insurance, or by adjustments for important patient demographic variables including age, race, sex, and cause of ESRD. Posttransplant patient and graft survival outcomes have been shown to be negatively

correlated with duration of dialysis exposure (10). Thus, it may be reasonable to extrapolate that these disparities contribute to morbidity and mortality among effected ESRD patients. In addition, and importantly, the final rule charges the transplant community with assuring comparable opportunities for transplantation for patients with similar diagnoses and disease progression. It is evident from these data that this obligation is not being adequately fulfilled.

REFERENCES

1. Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LY, Held PJ, Port FK. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. N Engl J Med 1999; 341: 1725-30.

2. Port FK, Wolfe RA, Mauger EA, Berling DP, Jiang K. Comparison of survival probabilities for dialysis patients vs cadaveric renal transplant recipients. JAMA. 1993;270(11):1339-1343.

3. Merion RM, Ashby VB, Wolfe RA, Distant DA, Hulbert-Shearon TE, Metzger RA, Ojo AO, Port FK. Deceased-donor characteristics and the survival benefit of kidney transplantation. JAMA. 2005 Dec 7;294(21):2726-33.

4. Meier-Kriesche HU, Ojo AO, Port FK, Arndorfer JA, Cibrik DM, Kaplan B. Survival improvement among patients with end-stage renal disease: trends over time for transplant recipients and wait-listed patients. J Am Soc Nephrol. 2001 Jun;12(6):1293-6.

5. Fiebiger W, Mitterbauer C, Oberbauer R. Health-related quality of life outcomes after kidney transplantation. Health Qual Life Outcomes. Jan 8 2004;2(1):2.

6. Lazzaretti CT, Carvalho JG, Mulinari RA, Rasia JM. Kidney transplantation improves the multidimensional quality of life. Transplant Proc. May 2004;36(4):872-873.

7. Muehrer RJ, Becker BN. Life after transplantation: new transitions in quality of life and psychological distress. Semin Dial. Mar-Apr 2005;18(2):124-131.

8. Russell JD, Beecroft ML, Ludwin D, Churchill DN. The quality of life in renal transplantation--a prospective study. Transplantation. Oct 1992;54(4):656-660.

9. Cameron JI, Whiteside C, Katz J, Devins GM. Differences in quality of life across renal replacement therapies: a meta-analytic comparison. Am J Kidney Dis. 2000;35(4):629-37.

10. Meier-Kriesche HU, Port FK, Ojo AO, Rudich SM, Hanson JA, Cibrik DM, Leichtman AB, Kaplan B: Effect of waiting time on renal transplant outcome. Kidney Int 58: 1311–1317, 2000

11. Goldfarb-Rumyantzev A, Hurdle JF, Scandling J, Wang Z, Baird B, Barenbaum L, Cheung AK. Duration of end-stage renal disease and kidney transplant outcome. Nephrol Dial Transplant. 2005 Jan;20(1):167-75. Epub 2004 Nov 16.

12. Department of Health and Human Services. Organ Procurement and Transplantation Network; Final Rule. In: Federal Register 42 CFR, Part 121, October 20, 1999: 56649–56661.

13. Ayanian JZ, Cleary PD, Weissman JS, Epstein AM. The effect of patients' preferences on racial differences in access to renal transplantation. N Engl J Med 1999; 341:1661-9.

14. Ayanian JZ, Cleary PD, Keogh JH, Noonan SJ, David-Kasdan JA, Epstein AM. Physicians' beliefs about racial differences in referral for renal transplantation. Am J Kidney Dis. 2004 Feb;43(2):350-7.

15. Soucie JM, Neylan JF, McClellan W. Race and sex differences in the identification of candidates for renal transplantation. Am J Kidney Dis 1992; 9: 414-9.

16. Hicks LS, Cleary PD, Epstein AM, Ayanian JZ. Differences in health-related quality of life and treatment preferences among black and white patients with end-stage renal disease. Qual Life Res. 2004 Aug;13(6):1129-37.

17. Gaston RS. Improving access to renal transplantation. Semin Dial. 2005 Nov-Dec;18(6):482-6.

18. Epstein AM, Ayanian JZ, Keogh JH, et al. Racial disparities in access to renal transplantation--clinically appropriate or due to underuse or overuse? New England Journal of Medicine. 2000;343(21):1537-1544.

19. Alexander GC, Sehgal AR. Barriers to cadaveric renal transplantation among blacks, women, and the poor. JAMA 1998; 280: 1148-52.

20. Garg PP, Furth SL, Fivush BA, Powe NR. Impact of gender on access to the renal transplant waiting

list for pediatric and adult patients. J Am Soc Nephrol 2000; 11: 958-64.

21. Wolfe RA, Ashby VB, Milford EL et al. Differences in access to cadaveric renal transplantation in the United States. Am J Kidney Dis 2000, 36: 1025-1033.

22. Wolfe RA, Ashby VB, Leichtman AB, Port FK, Ojo AO, Delmonico FL, Williams Jr WW, Higgins RD, Alveranga DY, Held PJ: Differences in health insurance are associated with access to the kidney transplant waitlist. (abstract). Am J Transplant 3(suppl 5):334, 2003

23. Bloembergen WE, Mauger EA, Wolfe RA, Port FK. Association of gender and access to cadaveric renal transplantation. Am J Kidney Dis 1997; 30: 733-8.

24. Kayler, LK., Rasmussen, CS, Dykstra, DM., Ojo, AO, Port, FK., Wolfe, RA, Merion, RM. Gender Imbalance and Outcomes in Living Donor Renal Transplantation in The United States. Am J Transplant. 2003 Jan 3 (4), 452-458.

25. Ojo AO, Port FK. Influence of race and gender on related donor renal transplantation rates. Am J Kidney Dis 1993; 22: 835-41.

26. Narva A, Stiles S, Karp S, Turak A. Access of Native Americans to renal transplantation in Arizona and New Mexico. Blood Purif 1996; 14: 293-304.

27. Kjellstrand CM. Age, sex, and race inequality in renal transplantation. Arch Intern Med 1988; 148: 1305-9 .

28. 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.

29. Eggers PW. Effect of transplantation on the Medicare end-stage renal disease program. N Engl J Med 1988; 318: 223-9.

30. 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: 2594-2600.

31. Webb RL, Port FK, Gaylin DS, Agodoa LY, Greer J, Blagg CR. Recent trends in cadaveric renal transplantation. Clin Transpl 1990; 75-87.

32. Port FK, Held PJ, Wolfe RA, Garcia JR, Rocher LL. The impact of non-identical ABO cadaveric renal transplantation on waiting times and graft survival. Am J Kidney Dis 1991; 17: 519-23.

33. Leichtman AB, Ashby VB, Wolfe RA, Port FK, Ojo AO, Delmonico FL, Williams WW, Higgins RD, Alveranga DY, Held PJ. Kidney transplantation rates from the waitlist reveal disparities in access by insurance status. Am J Transplantation 2003; 3(Suppl 5): 334.

34. Merion RM, Guidinger MK, Newmann JM, Ellison MD, Port FK, Wolfe RA. Prevalence and outcomes of multiple-listing for cadaveric kidney and liver transplantation. Am J Transplant. 2004 Jan;4(1):94-100.

35. Roberts JP, Wolfe RA, Bragg-Gresham JL, Rush SH, Wynn JJ, Distant DA, Ashby VB, Held PJ, Port FK. Effect of changing the priority for HLA matching on the rates and outcomes of kidney transplantation in minority groups. N Engl J Med. 2004 Feb 5;350(6):545-51.

36. Ashby VB, Held PJ, Port FK, Wolfe RA. Geographic differences in access to the waitlist and cadaveric renal transplantation in the U.S. J Am Soc Nephrol 1999; 10: 719A (abstract).

37. Ashby VB, Leichtman AB, Wolfe RA, et al. Racial differences, by State, in access to wait-listing and renal transplantation in the United States. Am J Transplantation 2001; 1(Suppl 1): 357 (abstract).

38. Ellison MD, Edwards LB, Edwards EB, Barker CF. Geographic differences in access to transplantation in the United States. Transplantation 2003; 76(9):1389-94.

39. Social Security Administration Death Master File. Federal Computer Products Center, National Technical Information Service, U.S. Department of Commerce, Springfield, VA