

# Impact of Race on Predialysis Discussions and Kidney Transplant Preemptive Wait-Listing

Nancy G. Kutner<sup>a</sup> Rebecca Zhang<sup>a</sup> Yijian Huang<sup>a</sup> Kirsten L. Johansen<sup>a, b</sup><sup>a</sup>United States Renal Data System, Rehabilitation/Quality of Life Special Studies Center, Emory University, Atlanta, Ga., and <sup>b</sup>Nephrology Section, San Francisco VA Medical Center and Department of Medicine, University of California, San Francisco, Calif., USA

## Key Words

Education · Kidney transplantation · Preemptive wait-listing · Race · United States Renal Data System

## Abstract

**Background/Aims:** US registry data have consistently shown that blacks are less likely than whites to be wait-listed before beginning dialysis. **Methods:** The Comprehensive Dialysis Study (CDS) was a special study conducted by the US Renal Data System (USRDS) in which a national cohort of patients who began maintenance dialysis therapy in 2005–2007 were asked whether kidney transplantation (KT) had been discussed with them before they started dialysis. Using responses from black and white CDS participants and information from the USRDS, we investigated preemptive wait-listing as a function of patient-reported predialysis KT discussion. **Results:** Among those reporting early KT discussion, 31.0% of patients preemptively wait-listed were black, compared to 27.5% of those not preemptively wait-listed. Two thirds of preemptively wait-listed patients had received nephrology care more than 12 months before starting dialysis and reported that KT was discussed with them 12 months or more before dialysis. Early KT discussion and higher serum albumin and hemoglobin levels remained significant predic-

tors of preemptive wait-listing in an adjusted logistic regression analysis. Among those preemptively wait-listed, 33% of blacks and 60% of whites had received a transplant by September 30, 2009 (study end date). **Conclusion:** Early KT discussion appeared to reduce barriers to black patients' waiting list placement before the start of dialysis, which in turn may facilitate earlier access to a deceased donor organ transplant.

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## Introduction

Transplantation is the renal replacement therapy that offers patients with kidney failure the best opportunity to maximize survival and quality of life [1, 2]. About two thirds of kidney transplant recipients receive an organ from a deceased donor rather than from a living donor [3]. In the current system for allocating deceased donor organs, waiting time is the major determinant. Waiting

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## KARGER

Fax +41 61 306 12 34  
E-Mail [karger@karger.ch](mailto:karger@karger.ch)  
[www.karger.com](http://www.karger.com)© 2012 S. Karger AG, Basel  
0250–8095/12/0354–0305\$38.00/0Accessible online at:  
[www.karger.com/ajn](http://www.karger.com/ajn)Nancy G. Kutner, PhD  
Department of Rehabilitation Medicine  
Emory University  
Atlanta, GA 30322 (USA)  
Tel. +1 404 712 5561, E-Mail [nkutner@emory.edu](mailto:nkutner@emory.edu)

time accrues from the date of a patient's placement on the waiting list. Thus, the sooner a patient is registered, the sooner accrual of waiting time can begin. Preemptive wait-listing, i.e. placing a patient on the kidney waiting list before he/she requires dialysis, may therefore facilitate earlier receipt of a deceased donor transplant [4].

In a national cohort of patients placed on kidney transplant waiting lists in the mid-1990s, Kasiske et al. [4] found that black patients were less than half as likely as white patients to be wait-listed prior to initiation of dialysis. Keith et al. [5] reported a similar race difference for a national cohort of patients placed on waiting lists from 2001 through 2004. The race disparity in predialysis wait-listing of patients observed in these studies was independent of multiple covariates including education, employment and private insurance. However, no information was available in these national registry studies about whether patients were exposed to information about kidney transplantation (KT) as a potential treatment option prior to dialysis.

The Comprehensive Dialysis Study (CDS) was a special study conducted by the US Renal Data System (USRDS) in which a national cohort of patients who began maintenance dialysis therapy in 2005–2007 was surveyed [6]. CDS respondents were asked whether KT had been discussed with them before they started dialysis. Using survey responses from black and white CDS participants and information from the USRDS, we investigated preemptive wait-listing as a function of patient-reported predialysis KT discussion.

## Patients and Methods

### *Study Population*

Outpatient dialysis units throughout the US were selected from the 4,410 clinics listed in the April 2005 Dialysis Facility Compare database of the Centers for Medicare and Medicaid Services (CMS) after merging with information from the USRDS End-Stage Renal Disease (ESRD) Facility File. Pediatric facilities and facilities located outside the 50 states and the District of Columbia were excluded. The list of dialysis units was sorted by ESRD Network, by adjacent states within the network and by the size measure of annual incident patients per facility (SAS Proc Surveyselect). A sample of 335 facilities was selected using equal probability systematic random sampling. Systematic random sampling in conjunction with the sorted facility list yielded implicit geographical stratification (network and state within network) for the sample facilities. The selected units matched the total population of clinics closely on number of patients and dialysis stations, facility type (free-standing, hospital-based), dialysis chain/non-chain affiliation, types of dialysis modalities offered (hemodialysis, peritoneal dialysis) and ESRD Network.

Study eligibility required that participants had no prior transplantation or other renal replacement therapy before their current start of dialysis as their regular treatment for ESRD. Patients aged  $\geq 18$  years who initiated chronic dialysis between June 1, 2005 and June 1, 2007 at one of the selected dialysis clinics were identified to the USRDS Coordinating Center by the CMS Standard Information Management System when they had been receiving chronic dialysis for at least 2 months but no more than 3 months. Patient lists were provided monthly to the USRDS Coordinating Center, which then contacted patients to request their participation in the study. Patients who consented were asked to participate in a structured interview administered by professional interviewers using a computer-assisted telephone interviewing system. Interviewed patients were affiliated with 296 different dialysis clinics, located across all 18 ESRD Networks and in all states except Alaska and Vermont.

Of 1,643 patients interviewed, 813 provided an affirmative response to a survey question asking whether KT had been discussed with them before they started regular treatment for kidney failure. A total of 788 of these patients who identified their race as black or white are the focus of this paper (fig. 1). Self-reported race closely matched information reported on the ESRD Medical Evidence Report (Form CMS-2728-U3).

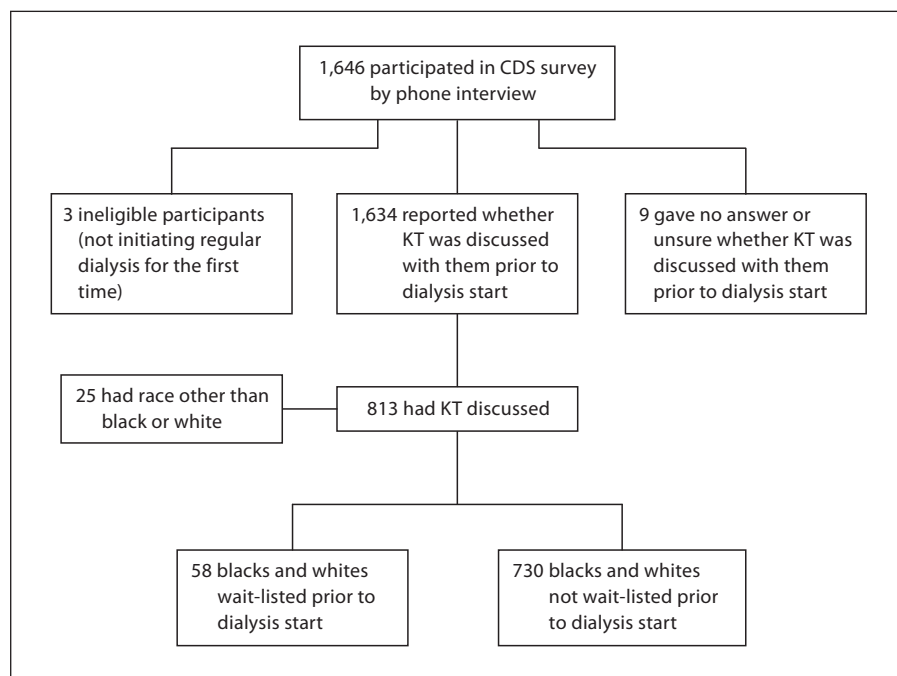
### *Measures*

During the phone interview, patients were asked the following questions: 'Was kidney transplantation discussed with you before you started your regular treatment for kidney failure? If yes, was this 12 months or more before you started?'. Responses were scored as 1 for 'yes' and 0 for 'no/not sure'. Participants were asked to indicate the highest education level they had completed, whether they were living alone or not and whether they had smoked at least 100 cigarettes in their life.

Updated patient characteristics for respondents were obtained from 2010 USRDS Standard Analysis Files (SAFs). This information included date of birth, gender, race, weight, body mass index (BMI), employment status at treatment start, diabetes, number of cardiovascular conditions (congestive heart failure, atherosclerotic heart disease, other cardiac disease, cerebrovascular disease, peripheral vascular disease), inability to ambulate or transfer, receipt of pre-ESRD care from a nephrologist, date of first ESRD service, and hemoglobin, serum creatinine and serum albumin values at the start of treatment, as documented on the ESRD Medical Evidence Report. Date of placement on a kidney transplant waiting list was ascertained from the Wait-list SAF, and date of receipt of a kidney transplant (if applicable) was ascertained from the Transplant SAF.

### *Statistical Analyses*

Using USRDS registry data, we compared the characteristics of black and white patients who reported that KT was discussed with them prior to dialysis ( $n = 788$ ) with characteristics of other black and white patients who started dialysis in the US during the same time period ( $n = 198,293$ ). Secondly, among black and white CDS participants who affirmed that KT was discussed with them prior to dialysis, patient sociodemographic, clinical and early care characteristics were compared between patients who were/were not preemptively placed on a waiting list. To account for a potential imbalance in patient characteristics between black and non-black patients, a logistic regression model was used to assess the



**Fig. 1.** Derivation of the study population.

association between race and the proportion of patients preemptively wait-listed. The model incorporated race and the other patient characteristics identified above. In all analyses, variance estimation accounted for stratification by ESRD Network and patient clustering within dialysis units. The proportion of preemptively wait-listed patients who received a transplant by September 30, 2009 (the latest date for which event dates were available in the 2010 SAF) was determined for blacks and whites.

Statistical analyses were carried out using SAS 9.2 (SAS Institute, Cary, N.C., USA). The CDS was approved by institutional review boards at the locations of the USRDS Coordinating Center (University of Minnesota), the USRDS Rehabilitation/Quality of Life Special Studies Center (Emory University) and the USRDS Nutrition Special Studies Center (University of California, San Francisco and University of California, Davis). All respondents provided informed consent. Patient anonymity was ensured at the Coordinating Center by assigning a universal USRDS identifier to all data obtained for a specific patient.

## Results

The distribution of gender, race and diabetes in the study cohort of black and white patients who reported that KT had been discussed with them before dialysis was similar to the distribution of these characteristics in the overall population of black and white incident patients who began dialysis during the same time period. At the same time, patients in the study cohort, compared to the

**Table 1.** Characteristics of the study cohort (n = 788) and the other black and white ESRD patients who started dialysis during the same time period (n = 198,293)

Characteristic	Study cohort	Other black and white US patients who started dialysis between June 1, 2005 and April 30, 2007
Age <65 years	67.9**	50.0
Men	57.6	55.8
Black	27.8	30.5
Working full- or part-time	16.4**	10.3
Private health insurance	32.2**	26.2
Not able to ambulate and/or transfer independently	1.5**	7.6
Diabetes	51.5	50.9
Number of cardiovascular conditions	0.8 ± 1.1**	1.0 ± 1.1
Weight, kg	84.5 ± 22.1**	80.4 ± 22.7
BMI	29.6 ± 7.8**	28.6 ± 7.7
Hemoglobin, g/dl	10.3 ± 1.7*	10.1 ± 1.7
Serum albumin, g/dl	3.3 ± 0.7**	3.1 ± 0.7
Serum creatinine, mg/dl	6.9 ± 3.3*	6.6 ± 3.4
Had predialysis nephrologist care	80.8**	65.1

Values are shown as means ± standard deviation or percentages, as appropriate. \* p < 0.01, \*\* p < 0.001 compared to the overall population.

**Table 2.** Patient characteristics by preemptive waiting list placement (yes/no) among black and white CDS participants who reported that KT was discussed with them prior to dialysis

Characteristic	Wait-listed before dialysis start (n = 58)	Not wait-listed before dialysis start (n = 730)	p
Age <65 years	82.8	66.7	0.01
Men	50.0	58.2	0.22
Black	31.0	27.5	0.60
At least high school education	93.1	77.5	0.09
Working	34.5	14.9	0.0003
Private health insurance	58.6	30.1	<0.0001
Living alone	20.7	20.6	0.98
Ever smoked	51.7	60.9	0.17
Not able to ambulate or transfer	0.0	1.6	<0.0001
Diabetes	29.3	53.3	0.001
Number of cardiovascular conditions	0.3 ± 0.7	0.9 ± 1.1	<0.0001
Weight, kg	83.3 ± 22.8	84.6 ± 22.0	0.67
BMI	28.3 ± 6.0	29.7 ± 7.9	0.10
Hemoglobin, mg/dl	11.2 ± 1.4	10.2 ± 1.7	<0.0001
Serum albumin, mg/dl	3.7 ± 0.5	3.3 ± 0.7	<0.0001
Serum creatinine, mg/dl	7.7 ± 2.7	6.8 ± 3.3	0.02
Predialysis nephrologist care	98.3	79.4	0.008
>12 months prior to dialysis	68.4	36.7	<0.0001
≤12 months prior to dialysis	29.8	42.7	
KT discussed ≥12 months prior to dialysis	65.5	33.7	<0.0001

Values are shown as means ± standard deviations or percentages, as appropriate.

overall population of black and white incident patients, were on average younger and healthier (fewer cardiovascular comorbid conditions; more likely to be able to ambulate and transfer independently, and higher average hemoglobin, serum albumin and serum creatinine concentrations), had higher average weight and BMI, were more likely to be employed and to have private insurance and were more likely to have received predialysis nephrologist care (table 1).

Of the 788 black and white patients who reported that KT had been discussed with them before the start of dialysis, 58 were preemptively placed on a waiting list (fig. 1). The proportion of black patients among those who were/were not preemptively wait-listed did not differ significantly (31.0 vs. 27.5%;  $p = 0.60$ ). Patients who had been preemptively wait-listed also did not differ with regard to gender, educational level, proportion living alone, smoking status, weight or BMI from those not preemptively wait-listed (table 2).

Patients who had been preemptively wait-listed did differ on a number of other characteristics from patients not preemptively wait-listed. The former were more likely to be younger, to be working and to have private health

insurance. They were less likely to have diabetes and cardiovascular comorbidity, and all were able to ambulate and transfer independently. Patients preemptively wait-listed had higher average hemoglobin, serum creatinine and serum albumin levels than those not preemptively wait-listed. Finally, patients who had been preemptively wait-listed were more likely to have received care from a nephrologist prior to the start of dialysis (98.3 vs. 79.4%;  $p = 0.008$ ), and those who had received this care were more likely to have received it over 12 months before the start of dialysis as compared to 12 months or less before the start of dialysis (68.4 vs. 36.7%;  $p < 0.0001$ ). Preemptively wait-listed patients were also more likely to report that KT had been discussed with them 12 months or more before the start of dialysis (65.5 vs. 33.7%;  $p < 0.0001$ ) (table 2).

With adjustment for covariates in a multivariable logistic regression analysis, we continued to observe no association between race and preemptive wait-listing (table 3). Discussion of KT 12 months or more before the start of dialysis, higher hemoglobin level and early predialysis nephrology care remained independent predictors of preemptive placement on the waiting list. Patients

**Table 3.** Multivariable logistic regression model predicting preemptive placement on the KT waiting list among black and white CDS participants with whom KT was discussed before the start of dialysis

	OR (95% CI)	p
Younger age	2.08 (0.79–5.47)	0.14
Male	0.78 (0.26–1.26)	0.17
Black	1.82 (0.70–4.76)	0.22
At least high school education	1.90 (0.27–13.39)	0.52
Working	0.94 (0.36–2.49)	0.90
Private health insurance	2.51 (0.88–7.16)	0.09
Living alone	1.11 (0.39–3.13)	0.85
Ever smoked	0.97 (0.46–2.05)	0.94
Diabetes	0.83 (0.38–1.84)	0.65
Number of cardiovascular conditions	0.73 (0.43–1.23)	0.24
BMI		
<20	0.59 (0.11–2.99)	0.51
20–25 (reference group)	1.00	
25–30	1.77 (0.63–4.95)	0.08
≥30	0.58 (0.22–1.52)	0.26
Hemoglobin	1.35 (1.08–1.68)	0.009
Serum albumin	2.06 (1.07–3.96)	0.03
Serum creatinine	1.04 (0.91–1.19)	0.58
Predialysis nephrologist care		
>12 months prior to RRT start (vs. ≤12 months or none)	1.89 (0.87–4.13)	0.11
KT discussed ≥12 months prior to RRT start (vs. discussed <12 months prior to RRT start)	3.23 (1.44–7.24)	0.004

RRT = Renal replacement therapy.

who reported having discussion of KT at least 12 months before the start of dialysis were over 3 times more likely to have been preemptively wait-listed [odds ratio (OR) 3.23, 95% confidence interval (CI) 1.44–7.24;  $p = 0.004$ ]. Patients with higher hemoglobin levels were one third more likely to have been preemptively wait-listed (OR 1.35, 95% CI 1.08–1.68;  $p = 0.009$ ), and patients with higher serum albumin levels were more than twice as likely to have been preemptively wait-listed (OR 2.06, 95% CI 1.07–3.96;  $p = 0.03$ ). Patients who received care from a nephrologist over 12 months before the start of dialysis (compared to no care or care for a shorter time before dialysis) were almost twice as likely to have been preemptively wait-listed (OR 1.89, 95% CI 0.87–4.13;  $p = 0.004$ ).

Finally, 33% of black patients and 60% of white patients who were preemptively wait-listed had received a transplant by the study end date of September 30, 2009.

## Discussion

Although our study cohort was generally younger and healthier than the overall population of incident dialysis patients in the USA, the representation of black patients was similar in both. All patients in the study cohort reported that KT had been discussed with them before they started their regular treatment for kidney failure, and no race difference in preemptive KT wait-listing was observed among these patients.

As table 1 indicates, patients who reported that KT was discussed with them prior to dialysis were more likely than patients in the overall population to have received early nephrology care. In their single-center study of 290 predialysis and dialysis patients who presented to a transplant evaluation clinic, Weng and Mange [7] found that the likelihood of preemptive wait-listing increased with increasing length of patients' predialysis nephrology care. Among patients who participated in the Dialysis Morbidity and Mortality Study Wave 2 in the mid-1990s and were followed for 2.3 years, Winkelmayr et al. [8] showed that surveyed patients who reported receiving early nephrology care, defined as first encountering a nephrologist >3 months prior to dialysis, had significantly greater rates of wait-listing and transplantation compared to patients who reported seeing a nephrologist closer to the start of dialysis.

A marked disparity in blacks' and whites' likelihood of preemptive wait-listing has previously been reported for the overall population of patients placed on national waiting lists in the USA. Kasiske et al. [4] examined variables associated with 41,596 patient registrations for the kidney and kidney-pancreas waiting lists between April 1, 1994 and June 30, 1996. Kasiske et al. [4] included patients who had a prior transplant, which was a significant predictor of wait-listing before dialysis. Keith et al. [5] examined variables associated with 75,979 primary kidney transplant waiting list registrations from January 2001 to December 2004. Both studies found that black patients were significantly less likely to be wait-listed before dialysis, after adjusting for the effects of age, gender, education, private insurance and size of the transplant program in which the patient was listed, all of which were significantly associated with wait-listing before dialysis. However, neither study included information about whether patients had received predialysis nephrologist care or whether KT had been discussed with patients prior to their starting dialysis.

The ability to link survey responses from a national sample of incident dialysis patients with kidney transplant

wait-listing events in USRDS files is a strength of this study, as is the relatively large sample size of patients who reported that KT was discussed with them before they started treatment for kidney failure ( $n = 788$ ). At the same time, we must acknowledge that the early KT discussion variable was dependent on respondent recall, and the content and length of the predialysis KT discussion and patient satisfaction with that discussion are not known. The latter factors have previously been shown to influence patient decision-making about dialysis treatment modalities [9]. Whether the discussion was initiated by the provider or took place following a patient query is not known, nor is the provider status, e.g. physician versus nurse. The number of preemptive wait-listing events was relatively small, limiting the power to detect differences, and by design, the CDS surveyed patients for whom dialysis was the first renal replacement therapy and therefore did not include any patients who received preemptive transplants.

Section 152(b) of the Medicare Improvements for Patients and Providers Act, which became effective January 1, 2010, added kidney disease education (KDE) services as a Medicare Part B covered benefit (42 CFR 410.48) for stage IV chronic kidney disease patients, with one goal being to provide comprehensive information regarding options for treatment in advance of patients starting renal replacement therapy [10, 11]. Limited early exposure to information about KT as a treatment choice may pose an especially important barrier to transplant access in minority communities [12–15], and there is optimism that the KDE benefit will help to reduce racial disparity in access to KT [16]. Outcomes associated with the new KDE benefit offer critical future directions for research. Patients who receive KDE services can be identified in Medicare claims (Healthcare Common Procedure Coding System Level II codes G0420 and G0421); patient receipt of early nephrology care is reported in the USRDS Medical Evidence file, and treatment modality history can be followed in the USRDS registry.

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The opportunity that KT provides for increased patient survival, quality of life and healthcare cost savings as compared to treatment by dialysis is well established [1, 2, 17]. The literature indicates that the time from treatment start to waiting list placement is typically longer for black patients than for whites [5, 18, 19]. The reasons for delayed wait-listing among black patients are not fully known but likely include biological, social, cultural and medical circumstances. Wait-listing before initiation of dialysis allows earlier accrual of waiting time, which is a major criterion for allocation of deceased donor kidneys, and better patient and graft outcomes appear to be associated with shorter time on dialysis prior to transplant [20]. Although we acknowledge that the number of preemptive wait-listing events among CDS participants was small, substantial proportions of both black and white patients who had been preemptively wait-listed had received a transplant by the end of our follow-up observation period. It will be important to monitor information about the characteristics of patients who receive predialysis KDE services and to investigate associated trends in early wait-listing, early transplantation and transplant disparities.

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## Disclosure Statement

The interpretation and reporting of the data presented here are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the US government. The authors have no conflicts of interest to report.

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