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Perspectives on the New Kidney Disease Education Benefit: Early Awareness, Race and Kidney Transplant Access in a USRDS Study

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Abstract

Education services for Stage-IV chronic kidney disease patients were added in 2010 as a Part B covered benefit under the Medicare Improvements for Patients and Providers Act. Desired outcomes include early pursuit of kidney transplantation by more patients and reduction of racial disparities in access to transplantation. During 2005–2007, a United States Renal Data System (USRDS) special study surveyed 1123 patients in a national cohort who had recently started dialysis, identified themselves as black or white, and were reported by their physician as potentially eligible transplant candidates. Patients were asked if kidney transplantation had been discussed with them before they initiated renal replacement therapy, and survey responses were linked with subsequent wait listing and transplant events in USRDS registry files. Kaplan–Meier analyses showed a significant association between early transplant awareness and subsequent wait listing. Adjusted Cox models showed a significant race/early transplant awareness interaction, however, with the impact of early awareness on wait listing much stronger for whites. Ongoing support and education about kidney transplantation for patients after dialysis start could help to build on early education and foster greater quality improvement in patient outcomes.

Keywords

Access to transplantation; African Americans; kidney transplantation; patient education; United States Renal Data System; waiting list

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Introduction

Multiple studies have found that many patients lack early exposure to information about kidney transplantation (KT) as a treatment choice (1–4). Section 152(b) of the Medicare Improvements for Patients and Providers Act, 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 (CKD) patients. The goal is to provide comprehensive information regarding management of comorbidities, prevention of uremic complications and options for treatment in advance of patients' starting renal replacement therapy. CKD patients should hear advantages and disadvantages of each treatment option and have an opportunity to actively participate in choice of therapy, including KT (5,6). Although the benefit is not designed to have a direct effect on KT rates, patients' increased interest in and efforts to pursue KT are desired outcomes (6,7). Because limited early exposure to information about transplantation as a treatment choice may pose an especially important barrier to KT access in minority communities (1,3,8–10), there is also optimism that racial disparity in access to KT will be reduced (7).

We used survey responses from patients who participated in a United States Renal Data System (USRDS) special study to explore potential outcomes that might be associated with the new KDE benefit. The Comprehensive Dialysis Study (CDS) asked a national sample of patients who initiated dialysis 2005–2007 whether KT had been discussed with them before dialysis start. We linked participants' survey responses with subsequent wait listing events in USRDS registry files.

Methods

Study population

The CDS is a special USRDS study of patients with end-stage renal disease (ESRD) who had recently initiated dialysis therapy (11). Outpatient dialysis units were selected from a listing of 4410 clinics (<https://www.cms.gov/DialysisFacilityCompare>), excluding pediatric facilities and facilities located outside the 50 states and the District of Columbia. The list of dialysis units was sorted by ESRD Network, adjacent states within Network and number of annual incident patients per facility (SAS PROC SURVEYSELECT). A sample of 335 facilities were selected using equal probability systematic random sampling. Use of 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/nonchain affiliation, types of dialysis (hemodialysis [HD], peritoneal dialysis [PD]) offered and ESRD Network.

Patients aged ≥18 who initiated maintenance dialysis between June 1, 2005 and June 1, 2007 at one of the selected dialysis clinics were reported to the USRDS Coordinating Center by the Standard Information Management System of the Centers for Medicare and Medicaid Services (CMS) when they had been receiving dialysis for at least 2 months but no more than 3 months. 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. 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.

CDS participants (n = 1643) were affiliated with 296 different dialysis clinics, located across all 18 ESRD Networks and in all states except Alaska and Vermont. When interviewed, 1594 CDS respondents identified themselves as black or white. Self-reported race closely matched information about respondents' race that was reported on the ESRD Medical Evidence Report (Form CMS-2728-U3). Of the 1594 respondents, 1127 were reported by their providers on the Medical Evidence Report as having been “informed of kidney transplant options”, that is, potentially transplant eligible. Black and white CDS participants who were reported as not informed of transplant options were designated on the Medical Evidence Report as medically unfit (n = 82), unsuitable due to age (n = 64), psychologically unfit (n = 3), declines information (n = 4), has not been assessed (n = 237), other unspecified reason (n = 28) or multiple reasons that most often included medically unfit and unsuitable due to age (n = 27); no Form CMS-2728-U3 information was available for 22 patients (Table S1). Of the 1127 potentially transplant eligible patients, this study focuses on 1123 who provided answers to the specific survey questions discussed in the Measures section below.

Measures

During the phone interview, CDS participants were asked: “Was kidney transplantation discussed with you before you started your regular treatment for kidney failure?” Later in the interview, participants were asked: “Has kidney transplantation been discussed with you since you started dialysis?” Responses were categorized as 1 = yes; 0 = no/not sure. Participants reported the highest education level they had completed, whether they were currently living alone and whether they had smoked at least 100 cigarettes in their life, and they completed the Medical Outcomes Study Short Form-12 (MOS SF-12) health status survey, which yields a Physical Component Summary (PCS) score (<http://www.sf-36.org/tools/sf12.shtml>).

Patient demographic and clinical characteristics obtained from 2010 USRDS standard analysis files (SAFs) included date of birth, sex, race, weight and 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, initial type of dialysis used and hemoglobin, serum creatinine and serum albumin values at treatment start. Date of placement on a kidney transplant waiting list and date of receipt of a kidney transplant (if applicable) were ascertained from Waitlist and Transplant SAFs.

Statistical analysis

Characteristics of patients who reported that KT was discussed with them before they started dialysis (n = 616) were compared with characteristics of patients who did *not* report that KT

was discussed with them before they started dialysis ($n = 507$) (Table 1). Variance estimation accounted for stratification by ESRD Network and patient clustering within dialysis units.

A Kaplan–Meier plot describes the association of predialysis KT discussion with waiting list placement (Figure 1). The analysis start date was defined as date of first regular dialysis (between June 1, 2005 and June 1, 2007), and the study end date was September 30, 2009, the latest date for which event dates were available in the USRDS 2010 SAFs. Patients were censored at death and the end of follow-up, and patients who were not wait listed and received living donor transplants were censored at the date of transplant. Patients preemptively wait listed (before dialysis start) were assigned a value of 0 time to wait listing. Predictors of waiting list placement were investigated in a proportional hazards model (more accurately, discrete logistic model to accommodate ties) that included patient sociodemographic, clinical and treatment modality characteristics. The interaction between race and other variables was investigated, and the interaction of early discussion with race was included in the model (Table 2).

Statistical analyses were conducted using SAS 9.2 (SAS Institute, Cary, NC, USA). The CDS was approved by institutional review boards at the location of the USRDS Coordinating Center and Special Studies Centers (University of Minnesota, Emory University, UCSF and UC-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 individual patients.

Results

Approximately half of the patients in the CDS cohort of potentially eligible transplant candidates reported that KT had been discussed with them before they started regular treatment for kidney failure. Similar proportions of blacks (53.5%) and whites (55.4%) reported that KT had been discussed with them. In addition, patients who reported early discussion of KT did not differ significantly in educational level from those who did not report early discussion. However, patients who reported that KT was discussed with them before dialysis start were younger, were more likely to be employed and to have private health insurance, had higher average hemoglobin and serum albumin levels, were more likely to have received predialysis nephrology care, were less likely to use HD (more likely to use PD) as their initial dialysis treatment modality and reported higher overall physical health status compared to patients who did not report that KT was discussed with them before dialysis start (Table 1).

Over a mean follow-up time of 1235 days, 29.7% of black patients and 31.7% of white patients in the study cohort were wait listed for a kidney transplant. Of 333 transplant eligible (i.e. reported as having been informed of their transplant options) black patients, 178 reported pre-dialysis transplant discussion and of these 63 were listed, while 155 did not report predialysis transplant discussion and of these 36 were listed. Of 790 transplant eligible white patients, 438 reported predialysis transplant discussion and of these 177 were listed, while 352 did not report predialysis transplant discussion and of these 73 were listed.

Examination of *time to wait listing* in Figure 1 shows that both black and white patients who had early exposure to KT information were more likely to be wait listed compared with their same race peers who did not report this early exposure, but this difference was greater among whites than among blacks. In a Cox proportional hazards model predicting patients' wait listing (Table 2), the interaction of predialysis KT discussion and race was significant ($p < 0.0001$). Among whites, patients who reported predialysis KT discussion were more likely to be wait listed than those who did not report this discussion (HR 1.83 [95% CI 1.36–2.46]; $p < 0.0001$), while the association between early KT discussion and wait listing was not statistically significant among blacks. Similarly, among patients who reported predialysis KT discussion, whites were more likely than blacks to be wait listed (HR 1.76 [95% CI 1.29–2.40]; $p = 0.0004$).

Table 2 also indicates that younger age, higher educational level, employment and private health insurance and BMI < 30 were associated with likelihood of wait listing. In the Cox model, no significant interactions were observed between race and these variables. Because the likelihood of transplantation varies across regions of the United States (12), the region of the country in which the patient was located was also considered in the model but no significant association with wait listing was observed.

Subgroup analyses were also conducted for blacks and whites separately. For each race group, early KT discussion was incorporated along with all other risk factors included in Table 2 as covariates in the model investigating wait listing. The HR of early discussion (yes/no) for whites was 1.82 ($p = 0.0001$) while the HR of early discussion (yes/no) for blacks was 1.35 ($p = 0.19$), very similar to the findings reported in Table 2, suggesting that differential early KT discussion effects by race cannot be explained by other risk factors included in Table 2.

Table 3 shows the proportions of black and white patients in the study cohort who were *wait listed or received a deceased donor transplant by 1 year following treatment start*, a Healthy People 2010/2020 objective, again demonstrating that early transplant awareness was beneficial for both blacks and whites but that whites were more likely to experience early wait listing or transplantation. Among blacks, 21.1% of patients who reported predialysis KT discussion were wait listed or transplanted by 1 year, compared with 13.8% of those who did not report predialysis KT discussion. Among whites, 31.3% of patients who reported predialysis KT discussion were wait listed or transplanted by 1 year, compared with 11.5% of those who did not report predialysis KT discussion.

Discussion

Few multicenter studies have investigated patients' receipt of information about KT prior to their initiation of renal replacement therapy (2,13), and none have limited the study cohort to patients reported to be potentially transplant eligible. In a national cohort of incident dialysis patients who participated in the CDS and were reported by their providers as potentially transplant eligible, we found that only half of the patients recalled having KT discussed with them before they started dialysis. However, blacks and whites in this cohort were equally likely to recall having had KT discussion. There was also no difference in the educational

level of patients who reported/did not report that KT had been discussed with them. When we examined subsequent wait listing in the study cohort, early KT discussion was associated with earlier wait listing for both blacks and whites, but the effect was significantly greater for white patients.

Although no race or educational level differences characterized CDS participants who did and did not report that KT was discussed with them before they started treatment for kidney failure, patients who reported that KT had been discussed with them predialysis were younger, had higher average hemoglobin and serum albumin levels and rated their physical health status (SF-12 PCS) higher. In addition to being younger and generally healthier, they were also more likely to have private insurance—all characteristics that are viewed as enhancing the probability of KT success (14). Patients who reported that KT was discussed with them before they started treatment for kidney failure were more likely to have received predialysis nephrology care, but it is of interest that two-thirds of those who did not report predialysis discussion of KT did receive predialysis nephrology care (Table 1).

Even when patients were reported as potentially transplant eligible and said that they had received early KT information, wait listing was slower among blacks than among whites. Wait listing is a proxy for completion of transplant evaluation, and our finding of racial disparity is consistent with data from other research. Alexander and Sehgal found that, compared with their white counterparts, medically suitable black patients were more likely to remain possibly or definitely interested in KT rather than going on to complete a pretransplant workup (15). Others have also reported that more time is required for black patients to complete the medical evaluation for transplantation (16,17). Reasons for delayed wait listing among black patients are not fully known but likely include biologic, social, cultural and medical circumstances.

The ability to link responses from a national sample of incident dialysis patients with kidney transplant wait list events in USRDS files is a strength of this study. At the same time, we must acknowledge several study limitations. First, we used the designation “informed of transplant options” on the Medical Evidence Report as an indicator that a patient was potentially transplant eligible and could reasonably be included in our study cohort (Table S1). This designation is not a validated measure of potential transplant eligibility, although almost all of the CDS participants with this designation did report that KT had been discussed with them before and/or after dialysis start. We acknowledge that the Medical Evidence Report is completed near treatment start and patients' transplant eligibility may change over time. We also found that 237 patients were reported “has not been assessed”, although the proportion of black patients in this group was not significantly greater than the proportion of black patients reported “informed of transplant options” (34% vs. 30%; $p = 0.30$).

In addition, 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 (2). Whether the discussion was initiated by the provider or took place following a patient query is not known, nor is the

provider status, for example, physician versus nurse. We acknowledge that provider characteristics, even more than patient characteristics, may influence becoming informed about transplantation. Conditions for Coverage for ESRD Facilities specified by CMS require that accredited dialysis clinics provide evidence of transplant education, track patients' transplant referrals and status on the waiting list and regularly communicate with transplant facilities (18), but substantial variation in patients' completion of KT access stages has been observed among dialysis clinics (19).

Crucial future research should focus on specifying the content of KDE services, identifying the recipients of these services and following patient outcomes. Although KDE services are supposed to be tailored to individual patient needs and a standardized KDE curriculum has not been prescribed by CMS, providers are mandated to develop and administer outcomes assessments of KDE services and make these available to CMS upon request (5). Patients who receive KDE services can be identified in Medicare claims (HCPCS Level II codes G0420 and G0421), and treatment modality history can be followed in the USRDS. If patients with whom the option of KT is discussed have fears and reservations about the transplant procedure and about what is needed to successfully manage life with a transplant (20,21), remaining on dialysis may be a preference. However, both health status and preferences may change over time, and patients who are wait listed can accrue valuable wait time. Ongoing support and education about KT for patients after dialysis start may be able to build on early education and perhaps help to narrow racial disparities in time to wait listing. For example, the "Explore Transplant" program designed by Waterman and colleagues (exploretransplant@dom.wustl.edu) requires meetings with patients while they are undergoing dialysis to help them consider what might motivate them to pursue transplantation, address commonly held concerns about transplantation and about involving a living donor, share real-life stories of donors and recipients and outline a series of actions that an interested patient can take (10). It is also recognized that transplant resource advocates can have a valuable role working in conjunction with the referring physician to connect patients with the transplant center and with needed resources (3).

Interestingly, over the 1235 day follow-up period of our study, we observed no race difference in patients' receipt of an organ from a living donor. Abecassis et al. argue that with early education, timely transplant evaluation and identification of potential living donors, early transplantation can be an option for substantially more patients (22). Outcomes associated with early education opportunities that are facilitated by the new KDE benefit and reinforced/supported in the dialysis setting pose an important research agenda.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

BMI	body mass index
CDS	Comprehensive Dialysis Study
CKD	chronic kidney disease
CMS	Centers for Medicare and Medicaid Services
ESRD	end-stage renal disease
KDE	kidney disease education
KT	kidney transplantation
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
USRDS	United States Renal Data System

Figure 1. Kaplan–Meier analysis of CDS study cohort waiting list placement, by race and predialysis discussion of kidney transplantation.

Table 1
Patient characteristics and predialysis KT discussion among potentially transplant eligible CDS participants (N = 1123)^I

Patient characteristics	Patients who reported that KT was discussed with them before dialysis start (N = 616)	Patients who did <i>not</i> report that KT was discussed with them before dialysis start (N = 507)	p-Value
Black,%	28.9	30.6	0.52
High school education or above,%	80.1	77.1	0.24
Younger age (<65 years),%	70.8	59.6	< 0.0001
Male,%	56.3	53.5	0.35
Working full or part time,%	18.0	11.8	0.007
Private health insurance	34.4	23.9	< 0.0001
Living alone,%	19.6	22.3	0.28
Ever smoked,%	60.0	58.9	0.71
Weight, mean (SD), kg	85.2 (22.7)	84.1 (22.8)	0.47
BMI, mean (SD), kg/m ²	29.76 (7.9)	29.82 (7.9)	0.92
Diabetes,%	51.6	53.9	0.46
No. of comorbid cardiovascular conditions, mean (SD)	0.8 (1.0)	0.9 (1.1)	0.06
Not able to ambulate or transfer independently,%	1.5	3.4	0.05
Serum creatinine, mean (SD), mg/dL	6.9 (3.2)	6.9 (3.6)	0.95
Hemoglobin, mean (SD), g/dL	10.4 (1.7)	9.9 (1.8)	<0.0001
Serum albumin, mean (SD), g/dL	3.3 (0.7)	3.1 (0.7)	<0.0001
Had predialysis nephrology care,%	84.5	68.2	<0.0001
On hemodialysis,%	87.8	95.3	<0.0001
MOS SF-12 PCS score, mean (SD)	38.9 (11.6)	37.4 (11.8)	0.03

KT = kidney transplantation; CDS = Comprehensive Dialysis Study; BMI = body mass index; MOS SF-12 PCS = Medical Outcomes Study Short-Form 12 Physical Component Summary.

^IResponse to CDS survey question about predialysis KT discussion was missing for 4 patients.

Table 2
Multivariable Cox proportional hazards models predicting CDS participants' placement on a kidney transplant waiting list¹

Risk factor	Waiting list placement	
	Hazard ratio (95% CI)	p
Race and early KT discussion ²		
White: early KT discussion vs. no early discussion	1.83 (1.36, 2.46)	<0.0001
Black: early KT discussion vs. no early discussion	1.35 (0.88, 2.07)	0.17
Early KT discussion: white vs. black	1.76 (1.29, 2.40)	0.0004
No early KT discussion: white vs. black	1.30 (0.85, 1.98)	0.23
High school education or above	1.59 (1.14, 2.20)	0.006
Younger age (<65 years)	3.42 (2.44, 4.78)	<0.0001
Male	1.09 (0.85, 1.39)	0.49
Working	1.46 (1.10, 1.94)	0.01
Private health insurance	1.47 (1.14, 1.89)	0.003
Living alone	0.80 (0.60, 1.06)	0.12
Ever smoked	0.90 (0.72, 1.14)	0.38
BMI		
<20	1.49 (0.94, 2.36)	0.09
(20, 25) (reference group)	1.00	
(25, 30)	0.85 (0.63, 1.16)	0.31
30	0.69 (0.51, 0.93)	0.01
Diabetes	0.70 (0.56, 0.89)	0.004
No. of cardiovascular comorbid conditions	0.83 (0.73, 0.96)	0.01
Serum creatinine	1.02 (0.99, 1.05)	0.23
Predialysis nephrology care	1.35 (1.01, 1.81)	0.04
HD	0.75 (0.54, 1.05)	0.10
MOS SF-12 PCS score	1.01 (1.00, 1.03)	0.009

CDS = Comprehensive Dialysis Study; CI = confidence interval; BMI = body mass index; HD = hemodialysis; MOS SF-12 PCS = Medical Outcomes Study Short Form-12 Physical Component Summary.

¹ Wait listing events from dialysis start to September 9, 2009. Cox model includes 980 patients, all of whom were able to ambulate/transfer. Hemoglobin and serum albumin data were not available for 9% and 22% of respondents, respectively. Models were estimated with and without these variables and did not differ substantially; results of the model excluding these two variables are reported.

² The four possible combinations of race (white, black) and early KT discussion (yes, no) are represented by three indicator variables in the model, with the remaining combination as the reference. The reported hazard ratios are derived from the model. The study cohort included 154 white Hispanics and 8 black Hispanics. Restricting the models to non-Hispanic whites and non-Hispanic blacks gave very similar results to those shown in this table.

Table 3
Proportions of study cohort who met Healthy People 2010/2020 objective: wait listed or received deceased donor kidney transplant within 1 year of ESRD start¹

CDS survey response	Wait listed/transplanted within 1 year	
	Blacks	Whites
Reported that KT was discussed with them predialysis	21.1%	31.3%
Did not report that KT was discussed predialysis	13.8%	11.5%

ESRD = end-stage renal disease; CDS = Comprehensive Dialysis Study; KT = kidney transplantation.

¹Healthy People 2010 goal = 30%.