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Kidney Transplant Referral Practices in Southeastern Dialysis Units

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Abstract

Background—The Southeastern Kidney Transplant Coalition was created in 2010 to improve kidney transplantation (KTx) rates in Georgia, North Carolina, and South Carolina. To identify dialysis staff-reported barriers to transplant, the Coalition developed a survey of dialysis providers in the region.

Methods—All dialysis units in the ESRD Network (n=586) were sent a survey to be completed by the professional responsible for helping patients get transplants.

Results—One staff member at almost all (n=546) of the dialysis units in Network 6 completed the survey (93% response rate). Almost all respondents reported being very comfortable (51.47%) or comfortable (46.89%) discussing the KTx process with patients. Just over half (56%) of facilities reported discussing KTx as a treatment option with patients on an annual basis. Fewer than one quarter of respondents (19%) perceived that more than 50% of their patients were interested in kidney transplant, and most of the staff surveyed (68%) reported that <25% of their dialysis patients completed the evaluation process and been waitlisted for a kidney transplant.

Conclusion—The survey results provide insight into KTx referral practices in Southeastern dialysis units that may be contributing to low KTx rates in this region.

Keywords

Dialysis; transplant; provider; referral; South	

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Disclosures

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Author Contributions

All authors conceptualized and designed this study and participated in drafting, revising and approving this article.

Introduction

The Southeastern United States, including Georgia, North Carolina, and South Carolina, has the lowest kidney transplant (KTx) rates in the country (1). This low transplant rate may be due, in part, to low rates of referral for kidney transplantation (2). Because almost all (91%) KTx patients receive dialysis before being transplanted (2), dialysis professionals play a critical role in helping patients pursue KTx. Previous research suggests that dialysis facility staffing characteristics, such as a greater number of staff and more social workers per patient within a facility, can impact dialysis facility referral or transplantation (1, 2). However, previous research also suggests that less than half of dialysis units have a designated KTx educator (40%) or KTx education program (33%) (3) and the majority of nephrologists spend less time on KTx education than they believe is ideal (4).

The Southeastern Kidney Transplant Coalition is an interdisciplinary group of voluntary stakeholders that includes patients, interdisciplinary medical professionals, dialysis providers, patient advocacy groups, and transplant centers within the region that was created in 2010 by the Southeastern Kidney Council (End Stage Renal Disease (ESRD) Network 6) to increase the KTx rate for the more than 40,000 dialysis patients in the Network. As part of the Reducing Disparities in Access to kidNey Transplantation (RaDIANT) Community Study, Coalition members planned quantitative and qualitative analyses in order to identify the multiple barriers to transplantation specific to the Southeastern US (5).

To determine dialysis facility-level barriers to KTx in the Southeast, the Coalition conducted an environmental scan (here after called 'survey') to examine the regional beliefs, attitudes and practices of the dialysis staff members responsible for KTx in the dialysis units. This study builds on previous findings from surveys of nephrologists and nurse managers about KTx education and referral practices (3,4) and also includes information from social workers. It is also the only survey of dialysis professional practices related to KTx in an entire ERSD network conducted after the 2008 implementation of the Conditions for Coverage for End Stage Renal Disease Facilities (6), at which point dialysis units were formally tasked with providing KTx education and assistance to patients. This exploratory study provides initial insight into dialysis unit KTx practices in the area of the country with the lowest KTx rates and can inform future dialysis facility-level interventions to improve KTx referral rates in the Southeast and beyond.

Materials and Methods

To determine the reasons for low KTx rates in the Southeastern US, Coalition members collaboratively developed a twenty-five item survey instrument (Appendix 1). Coalition members made suggestions for survey questions, the authors created a draft survey, and the survey was reviewed by the full Coalition and revised based on this additional feedback. Survey questions used in this study included yes/no and multiple choice questions. The survey included questions related to the dialysis facility practices that help patients with the KTx referral process and self-reported KTx outcomes for the patients in their unit (i.e. the percentage of patients in the unit who are eligible or interested in a KTx and how many patients have been referred and waitlisted for a KTx). In 2012, ESRD Network 6 staff sent

the electronic survey (via Survey Monkey) to all dialysis units (n= 586) in Georgia (GA), North Carolina (NC), and South Carolina (SC) that are served by the Network. The survey was emailed to each dialysis facility's medical director and asked the director to have the "person at the dialysis unit who is responsible for KTx" complete and return the survey either through the mail or online. The project was approved by the Institutional Review Board of the University of South Carolina and Emory University.

Statistical Analysis

Demographic statistics for each dialysis facility were obtained through linkage of the survey with the publically available, 2008–2011 Dialysis Facility Report published by the University of Michigan Kidney Epidemiology and Cost Center through a contract with the Centers for Medicare & Medicaid Services (CMS), using a facility-specific CMS Certification Number. To investigate if there were significant differences in facility characteristics across state, we stratified the demographic statistics by GA, NC, and SC. The F-test or the non-parametric Kruskal-Wallis test was used to determine if the differences in dialysis facility characteristics varied across states. Descriptive statistics for each survey question was also generated. SAS® version 9.3 (SAS Institute, Cary, NC) was used for all analyses.

Results

A total of 546 (93%) dialysis facilities in the Southeastern Kidney Council completed the surveys. The majority of respondents were nurse managers (51.01%) and social workers (21.76%). Among all the dialysis facilities that completed the survey, the median number of patients per facility was 43.00 (IQR 30.00, 67.00), the median of average patient age was 61.71 (IQR 58.45, 65.00) years, the patient population was predominately African American (60.00; IQR 38.46, 75.00), 71.43 (IQR 53.85, 100.00) of patients were unemployed, 87% of facilities were for-profit, and the median standardized transplantation ratio was 0.61 (IQR 0.33, 0.94). A comparison between Georgia, North Carolina, and South Carolina reveals a significant difference in the median number of patients in a facility (p<.001) and the median number of patients age < 70 years waitlisted (p=0.01). Georgia had fewer patients and fewer staff per facility. North Carolina had a high median percentage of dialysis patients age <70 years waitlisted for a transplant (19.77%) compared to Georgia (17.57%), or South Carolina (15.15%) (Table 1).

The nephrologist/medical director was reported to be the primary decision maker for determining whether a patient should be referred for KTx in the majority of surveyed dialysis facilities (74.18%). Almost all respondents reported being very comfortable (51.47%) or comfortable (46.89%) discussing the kidney transplantation process with patients and 82.23% of facilities report having a dedicated staff member that discusses the transplant process with patients. However, when asked how often their dialysis facility discusses KTx as a treatment option with their patients, 41 facilities (7.5%) reported having this discussion only at admission and only 56% (n=306) reported discussing transplant once a year. Although most facilities (87.36%) report offering a patient and caregiver support group, more than 60% report rarely or never having transplant recipients return to their

facility to share their experiences. The majority (83%) of dialysis units do not send all patients to the KTx center for evaluation.

Table 2 describes the items captured on information facility staff received from KTx centers, and patient education attributes of the dialysis facilities. When the dialysis facility staff were asked to report how often they received written information on a transplant center's listing criteria or the kidney transplantation referral process, approximately 65% reported receiving this information in the past year. There were no significant differences across states regarding facilities receiving information on listing criteria (p=0.06), the kidney transplantation referral process (p=0.09), or having a patient education protocol in place (p=0.67).

The majority (83.70%) of dialysis facilities report having a kidney transplantation education protocol in place but less than 60% offer video education, or computer/internet access in the treatment area (see Table 2). Brochures, posters and physician/staff discussions about KTx were among the more popular educational materials used in facilities in this region (Table 3). Sending dialysis patients to transplant centers for education, videos/DVDs along with internet resources are the least popular modes of kidney transplant education.

A section of the survey asked staff to report the percentage of patients they perceived were either eligible for KTx, interested in KTx, referred for KTx, or had completed evaluation and were waitlisted for transplantation. Only 23% of dialysis facility staff perceive that > 50% of their patients are eligible for KTx (see Figure 1). Even fewer facilities (19%) perceive that >50% of their patients are interested in KTx and most staff (68%) reported they perceived <25% of their dialysis patients had completed the evaluation process and been waitlisted for a kidney transplant.

Discussion

This study is the first to conduct a survey on KTx referral practices among the dialysis staff members designated to be responsible for KTx in the majority of dialysis facilities in an ESRD Network. With a 93% response rate, this survey offers an initial understanding of the dialysis facility staff perception of practices related to KTx in the U.S. region with the lowest KTx referral rates. While results may only be generalizable to this geographical area and are limited to the self-report of one staff member of each dialysis unit, our needs assessment and findings may offer insight to inform future research both within and beyond the Southeast. Since the majority of ESRD patients receive dialysis before KTx (7) it is critically important to understand the current practices of dialysis professionals related to KTx referrals in order to best inform quality improvement efforts to address barriers to transplant.

Encouragingly, almost no respondents (1.64%) indicated that they were *not* comfortable discussing the KTx process with their patients. This suggests that overall, dialysis staff members deemed responsible for KTx by the medical directors of the dialysis units felt equipped to discuss KTx with their patients.. Our study also found that dialysis facilities are using a variety of patient education modalities to help patients understand KTx.

However, these results suggest several areas for improvement to help increase the KTx rate in this region. More than a third of respondents (35%) reported that they have not received information about listing criteria or KTx referral from their regional transplant center in the past year. Transplant centers are encouraged to frequently provide local dialysis facilities comprehensive information about their contraindications to KTx and how patients can most easily be referred for KTx, as mandated in the Centers for Medicaid & Medicare (CMS) conditions of participation for all transplant centers (8). Accordingly, dialysis facilities can also contact the transplant centers to request the most current information and assistance for their patients. In addition, some dialysis units (16.3%) need to establish protocols for educating patients about KTx as a treatment option and do this annually (35%) so that they adhere to the CMS Conditions for Coverage mandate that all dialysis units must develop a plan to help patients pursue transplant and track the transplant referral and review all treatment options every year (6). This is a significant concern, as patient discussion with dialysis staff about KTx is significantly related to patient access to transplantation (9), and a recent study determined that there is significant discordance between dialysis provider report of delivering patient discussion about KTx and patient recollection of such discussions (9,10), so the KTX education reported in our study may actually be underestimated. One way to do this may be to designate a transplant champion in every dialysis unit- in this study almost 20% (17.7%) of dialysis units do not have a dedicated staff member that discusses the transplant process with patients.

Previous research suggests that a majority of dialysis patients [71.6% (11)- 94% (12)] are interested in getting a KTx. In our study, only 19% of the dialysis professionals completing this survey thought that >50% of their patients were interested in KTx. Further work is needed to examine this possible misalignment between staff perception and patient interest in KTx.

In our study, about one-third (37%) of facilities reported that >75% of their patients are ineligible for transplantation; however, previous literature from single-center studies estimate ineligibility for kidney transplantation to be <15% (13, 14). The majority of respondents (61.05%) report that they refer <50% of their patients for KTx. While the actual proportion of patients referred for KTx within dialysis facilities is unknown, a recent study by Patzer et al (2) found that the median within-facility referral for transplantation among GA dialysis facilities was 24.4% (IQR, 16.7%–33.3%). Our results suggest that while these staff may correctly identify the proportion of patients referred for transplantation, overall referral for transplant is low. Based on recommendations from the CMS Technical Expert Panel (TEP) convened to develop kidney transplant referral clinical performance measures (15), all interested patients without permanent contraindications to KTx should be referred to transplant centers for evaluation. The TEP concluded that there are very few permanent contraindications to KTx and that the transplant center, not the dialysis facility, is the appropriate party to evaluate patients interested in a KTx when they do not have an absolute contraindication to transplant.

Nearly one-third (30%) of respondents in our study indicated that 25% of their patients have completed the transplant evaluation process and are waitlisted for transplant. However, this is in discordance with the actual proportion of dialysis patients served by the

Southeastern Kidney Council who are on the waiting list for a KTx (mean= $18.36\%\pm9.28$). This suggests that staff may not have an accurate understanding of where their patients are on the transplant pathway, and interventions related to helping patients navigate this pathway may be most important. This is also needed so that dialysis facilities are in compliance with the CMS recommendation that 24.3% of all patients younger than age 70 be on a KTx waitlist (16).

While offering promising insight into the KTx referral practices in this region and areas for improvement, this study has its limitations. The state of GA has more dialysis units than NC and SC, therefore the majority of participant responses came from GA and there may be unique attributes about GA staff that are biasing the findings. However, we found no significant difference across the three states regarding dialysis facilities receiving waiting listing criteria and information on the kidney transplantation referral process, or facilities having a transplant education protocol in place.

This survey relied on the self-reported information from one dialysis professional at each unit and may not represent an accurate reflection of KTx practices occurring in dialysis facilities, and we are unable to validate the findings. It is likely that dialysis team members other than the respondents provided KTx education and assistance that are not accounted for in these results (particularly from physicians). Unfortunately, there are no standardized measures for KTx eligibility or KTx referral processes (17) in dialysis centers at this time therefore we chose survey questions that asked for the opinion of the respondents for this information. A recent study in this region suggests that self-reported dialysis facility transplant philosophy influences actual access to the transplant waitlist (5), suggesting that the self-reported questions used in this study may be useful to predict actual KTx referral practices.

To address these limitations, the Southeastern Kidney Transplant Coalition plans to examine the actual behaviors related to KTx referral in dialysis facilities. However, querying dialysis professionals is also necessary to capture their attitudes and beliefs about KTx, and cannot be done analyzing clinical outcomes available for the total environment of the Network. Dialysis facility factors are also just one attribute contributing to KTx rates, in addition to patient, geographical factors, and transplant center factors. Accordingly, the Coalition has sought the insight from patients about their perception of KTx barriers and continues to conceptualize KTx referral success as dependent on multiple factors. Although the majority of respondents indicated the medical director or nephrologist was the primary decision maker about a patient's candidacy for tx, the majority of the surveys were actually completed by non-physicians. Future research is needed to examine the attitudes and roles of all dialysis center staff about KTx and how that may impact patient outcomes given physicians' roles in promoting KTx, and elaborate on the roles of medical directors and physicians related to KTx.

Adopting an approach which significantly increases the rates of referrals for KTx may place a burden on transplant centers, and the United States already has a shortage of kidneys available for transplant. However, the southeastern United States actually has a relatively higher organ supply per million population compared to other areas in the country, with SC

having a "high" kidney donation rate and GA and NC having a "medium" kidney donation rate (18). The low KTx rate in this region despite higher organ supply may due to patient and dialysis system factors, as well as the fact that this ESRD Network has the fewest transplant centers out of any networks in the country (2.2 transplant centers per 10,000 ESRD patients; 19). Efforts that help dialysis patients get kidney transplants should also include promotion of living donor transplantation that are not dependent on the availability of the country's overall low number of deceased donor organs (18). Regardless of donor organ supply or transplant center capacity, all dialysis patients must be informed about all of their treatment options including KTx (4,13).

This survey is one method used by an ESRD Network to help identify potential barriers to KTx. These results can help to create multifactorial interventions that can help patients seek KTx as an ESRD treatment option. Given our very high (93%) response rate, other regions in the United States could consider ESRD Network / Coalition collaborations as one approach to inform KTx needs assessments. Overall, our study suggests that dialysis facility staff-reported barriers may be important to consider when developing potential quality improvement interventions at the dialysis facility level in order to improve the rates of kidney transplantation in the Southeast and beyond.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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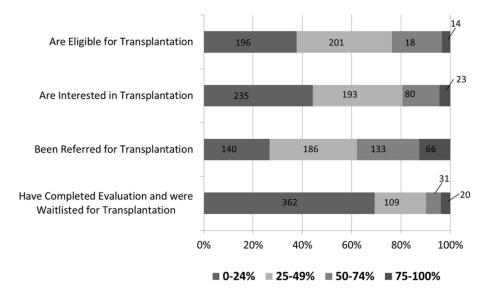


Figure 1. Staff reported perceptions of the proportion of patients that are <u>interested</u> in transplant, <u>eligible</u> for transplant, <u>referred</u> for a transplant, or have <u>completed the evaluation process</u> and been listed for a transplant. A total of 23% of dialysis facility staff perceive that > 50% of their patients are eligible for KTx; 19% of staff perceive that >50% of their patients are interested in KTx; 68% report they perceived <25% of their dialysis patients had completed the evaluation process and been waitlisted for a kidney transplant. The numbers presented in the bar graph represent the number of reporting dialysis facilities.

Table 1

Descriptive characteristics of the ESRD Network 6 dialysis facilities that completed the survey for the total population and stratified by Georgia, North Carolina, and South Carolina, 2012.

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FACILITY & PATIENTS	Total Facility Population (n=545)	Georgia (n=259)	North Carolina (n=174)	North Carolina (n=174) South Carolina (n=112)	Kruskal-Wallis Chi-Square test statistic for comparing the 3 states	uare test statistic he 3 states
CHANACIENSIICS	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	test statistic	p-value
# Patients per Facility	43.00 (30.00, 67.00)	40.00 (28.00, 63.00)	50.00 (30.00, 79.00)	45.00 (33.00, 60.00)	9.65	<.001
Number of Staff	11.00 (7.00, 15.00)	9.00 (7.00, 14.00)	12.00 (8.00, 17.00)	12.00 (8.00, 16.00)	11.91	0.0059
For Profit, %	87.11	88.40	84.57	87.74	1.36	0.003
Average Age within facility	61.71 (58.45, 65.00)	61.53 (58.09, 65.24)	62.04 (59.29, 65.09)	61.39 (58.60, 64.03)	1.62	0.49
% Female, Mean (SD) $^{\!$	46.60 (7.70)	46.75 (8.26)	45.61 (6.82)	47.71 (7.53)	2.53	0.08
% White	37.84 (21.05, 57.14)	36.36 (20.00, 59.26)	40.83 (22.73, 57.14)	37.50 (21.05, 55.56)	2.88	0.50
% African American	60.00 (38.46, 75.00)	61.54 (35.71, 76.92)	57.14 (36.36, 71.43)	62.50 (42.86, 78.95)	5.28	0.24
% Uninsured	8.70 (0.00, 16.67)	8.33 (0.00, 17.65)	7.69 (0.00, 13.79)	10.00 (0.00, 18.18)	4.05	0.28
% Unemployed	71.43 (53.85, 100.00)	66.67 (50.00, 91.67)	71.43 (57.14, 91.67)	75.00 (60.00, 100.00)	10.45	0.05
Time on Dialysis (Years), Mean, IQR (Avg yrs of prior ESRD therapy)	4.79 (4.23, 5.44)	4.86 (4.19, 5.55)	4.64 (4.19, 5.12)	4.88 (4.41, 5.63)	5.84	0.05
% Waitlisted (Age $< 70 \text{ yrs only}$)	17.96 (11.54, 23.81)	17.57 (10.91, 24.56)	19.23 (13.89, 24.14)	15.15 (10.53, 21.43)	9.15	0.01
Standardized Transplant Ratio (4 year rate) \sharp	0.61 (0.33, 0.94)	0.50 (0.24, 0.82)	0.85 (0.48, 1.19)	0.65 (0.43, 0.91)	36.13	<.001

Fased on the Kolmogorov-Smirnov's test for normal distribution, %Female was determined as normally distributed, therefore the means (SD) are presented and the values from the F-test for statistically significant difference are reported

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^{*}The Standardized Transplant Ratio was calculated by the University of Michigan Kidney Epidemiology and Cost Center and was included in the 2008–2011 Dialysis Facility Report. The ratio was calculated by dividing the number of expected transplant by the number of observed transplants, and then standardized against the national average.

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Table 2

The prevalence of ESRD Network 6 dialysis facilities with updated staff information on kidney transplantation and availability of patient education protocols and education modes, stratified by Georgia, North Carolina, and South Carolina, 2012.

	Total Populatio	Total Facility Population (n=545)	Georgia	Georgia (n=259)	North Caro	North Carolina (n=174)	South Car	South Carolina (n=112)	Chi-Square test statistic for comparing the 3 states	statistic for e 3 states
STAFF INFORMATION	u	%	u	%	u	%	u	%	test statistic	p-value
Dialysis facility received written listing criteria for kidney transplantation:									14.72	0.06
In the Past Year	354	64.84	171	66.02	116	29.99	99	58.93		
In the Last Two Years	57	10.44	27	10.42	20	11.49	10	8.93		
In the Last Three Years	13	2.38	7	2.7	5	2.87	-	0.89		
Upon Request	94	17.22	36	13.9	27	15.52	31	27.68		
Never	28	5.13	18	6.95	9	3.45	4	3.57		
Dialysis facility received written information on the kidney transplantation referral process:									13.68	0.09
In the Past Year	357	65.38	180	69.5	1111	63.79	65	58.04		
In the Last Two Years	54	68.6	26	10.04	19	10.92	6	8.04		
In the Last Three Years	12	2.2	4	1.54	5	2.87	3	2.68		
Upon Request	91	16.67	33	12.74	34	19.54	24	21.43		
Never	32	5.86	16	6.18	5	2.87	Ξ	9.82		
PATIENT EDUCATION										
Dialysis facility has an protocol in place for educating patients about kidney transplantation	457	83.7	220	84.94	145	83.33	91	81.25	0.80	0.67
Dialysis facility offers video education to patients										
In Treatment Area	316	58.52	135	52.94	114	66.28	99	58.93	7.54	0.02
In Lobby	164	32.6	75	32.05	61	36.97	28	26.92	2.99	0.22
Dialysis facility offers computer and internet access to patients										
In Treatment Area	316	58.52	131	50.58	75	44.12	40	62.5	9.17	0.01
In Lobby	172	33.53	87	36.1	48	28.24	37	36.27	3.20	0.20

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Table 3

The percentage of ESRD Network 6 dialysis facilities that utilized the listed education materials and the languages the education material is offered, 2012. Unknown 12.09 1.83 5.68 6.78 4.76 4.76 6.78 0.18 1.47 96.9 Do Not Use This Method 13.74 49.27 10.62 42.67 14.47 32.05 63.37 37.73 57.88 0.37 Language of educational material English and Other Languages 1.83 0.92 0.18 3.85 0.37 0.73 4.03 1.83 1.28 5.68 **English and Spanish** 55.13 48.72 24.18 20.15 12.09 13.92 23.81 68.6 2.2 English only 85.16 30.95 33.88 26.56 22.53 52.75 38.64 27.29 39.38 16.3 Transplant recipients return to facility to talk with dialysis patients Brochures given to patient/family and reviewed with facility staff Videos/DVDs for patients/family reviewed with facility staff Staff helps talk to patient's family about living donation Scheduled discussions with facility staff/nephrologist Brochures given to patient to review on their own Videos/DVDs for patients to review on their own Any education materials Posters Internet