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Understanding the Relationship between Trust in Healthcare and Attitudes toward Living Donor Transplant among African Americans with End Stage Renal Disease

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Abstract

Transplantation is the favored therapy for End-Stage Renal Disease (ESRD) patients. Unfortunately, demand for available organs far outpaces the supply. African Americans are disproportionately affected by the ever-widening gap between organ supply and demand. Additionally, structural, biological and social factors contribute to feelings of unease some African Americans may feel regarding living donor transplant (LDT). The present research examines the relationship between trust in healthcare and attitudes towards LDT among African American ESRD patients. We hypothesized that lower trust in healthcare would be significantly associated with negative attitudes toward LDT, and that this relationship would be moderated by patient attitudes toward dialysis. Data were collected from August 2011 to April 2012 as part of a larger study. Measures included trust (of doctors, racial equity of treatment, and hospitals), and attitudes toward both LDT and dialysis. Bivariate analysis revealed that trust in one's doctor, hospital, and in racial equity in healthcare were significantly correlated with attitudes toward LDT ($r=.265$; $r=.131$; and $r=.202$, respectively). Additionally, attitudes towards dialysis moderated the relationships between *Trust in Doctors/Attitudes toward LDT* and *Trust in Racial equity of treatment/Attitudes toward LDT*. Findings suggest a strong relationship between trust in healthcare and attitudes

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Author Contributions

E.M. analyzed data and drafted the manuscript. C.L.P. collected data, assisted in drafting the article, and critically reviewed the article. K.J. was the Principal Investigator of the research, designed the study, and analyzed data. N.T. participated in design of the study, data analysis, critical review, and approval of the article. J.P. participated in study design, critical review of the article, and approval of the article.

toward LDT. These findings also shed light on how dialysis experiences are related to the relationship between trust in healthcare and attitudes toward LDT.

Keywords

Transplant; Trust in Healthcare; Organ Donation; African American

Introduction

Transplantation has become the favored therapy for many individuals with end-stage renal disease (ESRD). While transplants extend lives and improve quality of life for those who receive them, a shortage of available organs has led to far greater demand than supply. Less than 20% of persons on the national transplant waiting list receive a transplant and thousands die while waiting (1). The gap between the number of organs needed and those available continues to widen. The organ donor shortage is one of the foremost concerns in transplantation today, particularly among racial and ethnic minorities (2). Ethnic and racial minorities only account for approximately 36% of the population (3); however, they account for about 55% of the over 124,000 persons awaiting a transplant (1).

African Americans in particular are in dire need of organs, largely because they are disproportionately impacted by certain health conditions such as diabetes and hypertension, which often leads to the need for a transplant (4). In addition, although African Americans make up only 13% of the national population (3), they comprise approximately 35% of the nation's kidney waitlist candidates (1). In the state of Georgia, where the present research was conducted, African Americans represent 31% of the population (5) and 64% of patients awaiting a kidney transplant (1). Further, compared to other racial/ethnic groups, African Americans may spend up to twice the amount of time on the transplant waiting list (6–11).

Although kidney transplants have consistently been shown to be an effective, often preferred, treatment for ESRD, African Americans are less likely than members of other racial/ethnic groups to acknowledge their need for a transplant (12, 13), speak to their families about donation (14–16), or engage in living donation (12, 15, 17). Living donor transplant has numerous advantages over deceased donor transplantation, including better quality of life and increased survival rates (18–21), better organ quality (22), increased short and long term graft survival (23, 24), and reduced healthcare costs (22). Numerous studies have explored barriers to transplantation, including financial concerns (25, 26), fear of surgery (25), and not wanting to be a burden to others (26). These factors, coupled with a lack of knowledge and education about transplantation and other structural barriers, have contributed to limited African American access to transplant (17, 27, 28).

Issues of trust in the healthcare system also pose a significant barrier to living donor transplant (26). Previous researchers have argued that medical abuses of African Americans for research purposes, most notably the Tuskegee Syphilis Study, have occurred since the 18th century, creating a legacy that contributes to African Americans' wariness of the medical system, and have subsequently negatively impacted African American willingness to donate (17, 29–31). In addition, many African Americans perceive the organ allocation system as being biased against poor people and people of color (16, 30, 32–37). Specifically, the long-standing belief is that it is not beneficial for an African American to donate organs, because "doctors will prematurely declare death to procure organs", and that the system is more favorable to the "rich" or "famous" (38). However, in another study, when some African American patients were asked the degree to which they understood the organ allocation process, the majority reported less than "mostly" understanding the process, and

reported believing that the allocation process was either “unfair” or that they were “unsure” about the fairness of the process (39). Therefore, the legacy of historical abuses, coupled with perceived inequalities in the organ allocation system, may contribute to fewer African Americans in the donation pool. Many African American waitlist candidates have expressed this concern in previous studies and believe that the racial bias within the healthcare system would result in their living donor not receiving adequate medical care during and after a transplant (13, 24, 40). Thus, a potential recipient’s level of trust in the healthcare system may impact his or her willingness to pursue living donor transplant.

In addition, African Americans have cited not wanting to burden others as a barrier of transplantation (26). Dialysis allows patients to remain more “private” about treatment, e.g., patients can limit discussions about their ESRD to those directly affected, such as doctors and family members or friends impacted by the patient’s dialysis schedule, which may be one reason African Americans are less likely to pursue living donation. Further, patients who feel less negatively about dialysis may be less likely to actively pursue transplantation, while those with very negative dialysis attitudes may be more willing to seek out other treatment.

Previous research indicates that people with more positive attitudes toward organ donation are more likely to discuss organ donation (41). A greater understanding of the relationship between trust in healthcare and attitudes toward LDT could be vital to improving LDT attitudes among African American ESRD patients. Because LDT often involves donating to a friend or family member, it sidesteps concerns about inequalities in organ allocation. However, trust in healthcare may remain vital in shaping interest in LDT. Although levels of trust in healthcare has been studied, it has often been operationalized as trust for the healthcare system *as a whole* (14, 16, 33, 35, 42–44). However, less clear is if there is a lack of trust in healthcare *in general*, or if patients are more selective of the elements of which he or she trusts (i.e., trusting one’s doctor but being less trusting of the hospital or medical system that employs said doctor). Therefore, the present study seeks to parcel out “trust” by different aspects of healthcare to better understand how trust in healthcare is associated with attitudes toward LDT. In this study, trust in healthcare has been decomposed into three levels: trust in doctors, trust in racial equity of treatment, and trust in hospitals. For purposes of this research, “trust in doctors” refers to the level of trust in one’s doctor or other healthcare provider; “trust in racial equity of treatment” refers to level of one’s trust that healthcare providers would provide the same level of treatment across different races; and “trust in hospitals” refers to level of trust one has in hospitals. Obtaining a better understanding of trust in healthcare from a patient perspective may be crucial in understanding African Americans’ attitudes toward transplantation and why African Americans are less likely to admit need for or discuss LDT than members of other racial/ethnic groups.

The purpose of this research is to examine the relationship between trust in healthcare (of doctors, in racial equity, and in hospitals) and attitudes towards transplant among African American ESRD patients. This research also seeks to examine if attitudes toward dialysis moderate the relationship between trust in healthcare and attitudes toward living donor therapy. We hypothesize that each level of trust will be significantly, positively associated with attitudes toward living donor transplant, and that this relationship will be moderated by attitudes toward dialysis.

Methods

Study Design

The present study is part of a larger study that seeks to test the effectiveness of a culturally sensitive living donation education intervention for African American patients with ESRD. The parent study was a randomized, controlled trial; data from the current study were collected during the baseline assessment (which occurred from August 2011 to April 2012). The current study utilizes a cross-sectional research design, combining baseline data from both treatment groups.

Recruitment and Data Collection

To ensure a sufficient number of recruited, eligible participants, a three-pronged approach was used. Initially, patients meeting eligibility criteria were mailed a letter from the transplant center, describing the study, highlighting the process and incentives for the study, along with the project coordinator's contact information for those interested in participating. Secondly, the project coordinator identified potential study participants through the transplant center's evaluation appointment system. Third, for those patients added to the weekly clinic schedule after the appointment schedule was published, thus not previously identified as eligible participants, the project coordinator would approach those patients for recruitment as they appeared in clinic for their evaluation. Patients were recruited until the desired sample size of 296 was reached.

Measures

Select scales from the parent study were used for the present study. The original baseline measure for the parent study was comprised of 102 items that measured knowledge, attitudes toward living donor transplant, dialysis attitudes, reasons for one's decision about transplant, motivation to share one's need for transplant, attitudes toward talking to family members about LDT, and trust in healthcare. For the purpose of this study, the focus is on the attitudes toward LDT, trust in healthcare, and dialysis attitudes scales, which are detailed below.

Attitudes toward LDT were measured using the *Benefits of Living Donor Transplant* scale (45). This eight-item, Likert-type measure asked participants to think about the impact having a living donor transplant might have on their lives. Response options ranged from one (Strongly Disagree) to five (Strongly Agree), which specified the degree to which the participant agreed with each statement (e.g., "If I got a transplant, my friends and family could have me in their lives longer"). Higher scores indicated more positive views about receiving a living donor transplant. Reliability for this scale was good, with an alpha of .86.

Trust in healthcare was measured using three trust-related scales. Trust in doctors was assessed using Siegel's four-item *Trust in Doctors Scale* (44), and refers to the level of trust the participant has in his or her primary healthcare provider. A sample item of this scale was "I trust my kidney doctor's opinions about my health". Trust in racial equity of treatment was assessed using Siegel's three-item *Trust in Non-Discrimination Scale* (44). The term "trust in racial equity of treatment" refers to the participant's level of trust that he or she would receive equal medical treatment to that of other individuals, regardless of race. The original scale consisted of three-items; however one item was deleted from the *Trust in Non-Discrimination Scale* because the subject was covered by other items. Response options ranged from one (Strongly Disagree) to five (Strongly Agree). The two items of this scale were "People of my ethnic group are treated equal to those of other groups by doctors and medical personnel", and "In most hospitals, people of different ethnic groups receive the same type of assistance." Finally, seven items comprised the trust in hospitals scale, which

were derived from Boulware's *Mistrust Subscale* (24). This scale included items such as "Hospitals often want to know more about your personal affairs or business than they really need to know." For purposes of consistency of terms for this paper, we refer to this scale as *Trust in Hospitals*, as all items were related to treatment at hospitals. For all 3 trust scales, higher scores indicate greater trust. Reliability of each of the scales ranged from acceptable to excellent, with an alpha of .95 for the trust in doctors scale, .73 for the racial equity of treatment scale, and .74 for the trust in hospitals scale.

Dialysis attitudes were operationalized using the *Dialysis Preoccupation* scale (46). This ten-item, Likert-type measure asked respondents about their everyday dialysis experiences. Only participants who had been or were currently on dialysis were directed to answer the items on this scale. Participants who had never been on dialysis were instructed to skip to the next section. Response options ranged from one (Strongly Disagree) to five (Strongly Agree), which indicated the degree to which the participant agreed with each statement (e.g., "I am often worried about the impact that dialysis has on my life"). Higher scores indicated having less positive views towards being on dialysis. Reliability for this scale was good, with an alpha of .85.

Statistical Analysis

Data were analyzed using SPSS 17.0. Frequency distributions were examined for all relevant variables. Normal distributions were observed for all data except attitudes toward LDT. For this variable, the data were skewed right. However, due to our large sample size, sampling distributions of means are normally distributed regardless of the shape of variables, as stated in the central limit theorem (47).

Next, t-tests were examined to determine the relationship between gender, age, marital status, educational attainment, employment, and length of time on dialysis and the independent variable, dependent variable, or moderator. The time on dialysis variable was found to be significantly associated with dialysis attitudes, our moderating factor. Therefore, time on dialysis was entered into each regression model for the study as a covariate.

Third, a series of linear regression models were constructed to test the relationships between the 3 types of trust and attitudes toward LDT. Lastly, a moderation analysis was conducted to examine the effect dialysis attitudes (positive and negative) had on the relationship between attitudes toward LDT and trust. Items from the dialysis preoccupation scale were divided so that total scores less than or equal to 24 were coded as positive and those greater than or equal to 25 were coded as negative. A median split was performed to create positive and negative categories for subsequent moderation testing. An important distinction is that those in the "positive" category do not necessarily have "positive" attitudes towards dialysis; they simply have scores at or above the median. Once data were split into positive or negative dialysis attitudes, moderation was tested using linear regression (48). An alpha of .05 was used to determine statistical significance.

Results

Participant ages ranged from 20 to 76 (Median = 56) years old. Study participants predominantly reported being male (57%), unmarried (59.8%), with "Completed high school or equivalent GED" listed as their highest level of education (60.6%). The majority of participants were also unemployed or retired (80.6%), reported a household income of less than \$30,000 (60.4%), and had been on dialysis between 1 and 4 years (48.6%, see Table 1). Lastly, as aforementioned, individuals who had never been on dialysis were instructed to skip the section on dialysis experiences. Therefore, a sample size of 259 was utilized for these analyses.

Hypothesis 1: Trust will be associated with Attitudes toward Living Donor Transplant

In bivariate analysis, the composite score for trust in doctors was found to be significantly correlated with attitudes toward living donor transplant, $r(267) = .27, p < .001$. Trust in racial equity of treatment was also significantly associated with attitudes toward living donor transplant, $r(261) = .20, p = .001$. A significant correlation between trust in hospitals and LDT attitudes was also observed, $r(257) = .13, p = .04$.

Multivariate analyses were also conducted to determine if the relationships between trust and attitudes toward LDT would remain significant when controlling for time on dialysis. First, we explored the relationship between trust in doctors and attitudes toward living donor transplant and found it to be significant ($\beta = 0.28, p < 0.01$; see Table 2, Step 1). Next, we explored the relationship between trust in racial equity of treatment and attitudes toward living donor transplant and also found it to be significant ($\beta = 0.18, p < 0.01$; see Table 3, Step 1). Lastly, we explored the relationship between trust in hospitals and attitudes toward living donor transplant. However, it was found not to be significant ($\beta = 0.09, p > 0.05$; see Table 4, Step 1).

Hypothesis 2: The relationship between Trust and Attitudes toward Living Donor Transplant will be moderated by attitudes toward dialysis

In the multivariate analyses, we also explored whether dialysis attitudes modified the relationship. Table 2 indicates a significant interaction between trust in doctors and dialysis attitudes. Further analysis (Table 5) indicated there was a significant, positive relationship between trust in doctors and attitudes toward LDT among those with more positive dialysis attitudes ($\beta = .51, p = .00$). However, this was not the case for those with more negative attitudes toward dialysis ($\beta = .10, p = .31$).

We followed a similar procedure for trust in racial equity of treatment. Table 3 indicates a significant interaction between trust in racial equity of treatment and dialysis attitudes. Further analysis, in Table 5, suggests a significant positive association between trust in racial equity of treatment and attitudes toward LDT among those with more positive dialysis attitudes ($\beta = .22, p = .03$), but no significant association among those with more negative dialysis attitudes ($\beta = .12, p = .24$).

Finally, we followed the same procedures for trust in hospitals. Results indicate that there was a significant interaction between trust in hospitals and dialysis attitudes as well (See Table 4). However, as indicated in Table 5, attitude toward dialysis was not a moderating factor for the relationship between trust in hospitals and attitudes toward LDT.

Discussion

This research sought to further understand the relationship between trust in the healthcare system and African American transplant candidates' attitudes toward living donor transplant. Multivariate analysis revealed that both trust in doctors and trust in racial equity of treatment variables were significantly associated with attitudes toward LDT, regardless of how long the person had been on dialysis. The results also suggest that dialysis attitudes can be a moderator of the trust/attitudes toward LDT relationship. We hypothesized that attitudes toward dialysis would moderate the relationship between each trust scale and attitudes toward living donor therapy. However, we found that attitude toward dialysis was only a moderator for the relationship between *Trust in Doctors* and *Trust in Racial equity of treatment* and attitudes toward living donor transplant. This suggests that greater trust in healthcare may be associated with attitudes toward living donor transplant, particularly among those with positive dialysis attitudes. This aligns with previous research that indicates that many African Americans are less trusting of the healthcare system and are,

thus, reluctant to participate in living donor transplant (19, 22, 24, 29, 30). Greater trust in the healthcare system may extend to trust in the organ allocation system and a higher likelihood of pursuing transplant.

These results add to existing literature showing that trust in healthcare is strongly associated with African Americans' willingness to donate. They also indicate that trust is strongly associated with attitudes toward living donation among African American ESRD patients. The strength of the relationship between trust and attitudes toward LDT is particularly important because this may be one reason many potential kidney recipients do not participate in living donor transplant as readily. Interventions designed to address African Americans' lower levels of trust in healthcare may have a significant impact on the attitudes and perceived benefits of LDT, hopefully prompting individuals to seek out this therapy.

The results also suggest that dialysis experiences and attitudes have a significant impact on the relationship between trust and attitudes toward LDT. People with more positive attitudes toward dialysis who trust their doctor and have trust in racial equity of treatment have more favorable attitudes toward LDT. For these individuals, although dialysis itself is not necessarily a "positive" experience, if dialysis has been relatively manageable or with few complications, and if they trust their doctors, and/or believe they will receive medical care comparable to others, they might be more open to seeing the benefits of LDT. They may view it as simply "another treatment option" that may work out in a positive way. Conversely, those with more negative attitudes toward dialysis, while they may trust their doctors and/or have trust in racial equity of treatment, were found to have no more favorable attitudes toward LDT. For these individuals, if dialysis has been a primarily negative experience for them, although they may have trust in their doctors and in how equitably they are being treated, they may be unwilling or unable to look beyond the negativity of their current treatment. In sum, patients with more positive dialysis attitudes may be more influenced by trust in healthcare because they are satisfied with current care, whereas patients with negative dialysis attitudes are not.

The nonsignificant finding in multivariate analysis that trust in hospitals is not significantly associated with attitudes toward LDT when examined independently, and that the relationship was not moderated by dialysis attitudes sheds further light on the relationship between trust and attitudes toward LDT. By measuring several types of trust, we may be better able to understand how dialysis experiences affect certain relationships more than others. It is possible that dialysis attitudes did not moderate the relationship between trust in hospitals and attitudes toward LDT because most study participants received dialysis and other hospital-related care at the same location, which may have resulted in more standardized care than a study conducted at multiple sites.

There are some limitations to this study. First, because recruitment was based on a convenience sampling strategy, it is not possible to generalize beyond the transplant center study site. Future studies might consider expanding this methodology to multiple transplant centers in a variety of regions. Also, the data collected on attitudes toward LDT were skewed in this population, though our large sample size and the robustness of tests used mitigate this limitation. A possible explanation is that since study participants were voluntarily coming to the transplant center to be evaluated for transplant, they might have already made up their minds about the benefits of transplant and, thus, may have held more positive views. Finally, while this research provides valuable information on the relationship between trust in healthcare and attitudes toward LDT, there is no way to determine causation as this is a cross-sectional study.

Despite these limitations, findings of this study expand our understanding of the relationship between different types of trust in healthcare and attitudes toward LDT. Our findings also shed light on the influence of dialysis experiences on the trust-attitudes toward living donor transplant relationship. By deconstructing the concept of “trust in healthcare” and examining its components individually, we were able to determine which trust relationships have the greatest influence on attitudes toward LDT. These findings highlight the importance of addressing African American feelings of lowered trust in healthcare in order to improve African American attitudes toward living donor transplant. Subsequent interventions designed for this community might include messages addressing the varying degrees of trust among levels of medical care in this community to better address this barrier to transplantation. Future studies might be conducted to better understand the complexities of the relationship between these two factors. Studies to determine the pathways through which dialysis attitudes moderate this relationship are also needed.

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Table 1

Demographics

Characteristic	N = 296
Median age in years (range)	53 (20–76)
Female (%)	125 (43.0)
Married (%)	119 (41.2)
Educational Attainment (%)	
<High School	35 (12.2)
High school graduate or GED	174 (60.6)
Completed	61 (21.3)
College Professional degree	17 (5.9)
Employed, full or part-time Household Income Categories (%)	55 (19.4)
Up to \$29,999	157 (60.4)
\$30,000–69,999	86 (33.0)
70,000 or more	17 (6.5)
Length of time on dialysis	
Never been on dialysis	37 (13.5)
1 year or less	104 (38.0)
>1 year but less than 4	72 (26.3)
4 years or more	61 (22.3)

Table 2

Regression model for association between trust in doctors, dialysis attitudes and attitudes toward LDT

	<u>Attitudes toward LDT</u>		
	B	SE	β
Step 1			
Time on Dialysis	0.44	0.19	0.15 [*]
Trust in Doctors	0.54	0.13	0.28 ^{**}
Step 2			
Time on Dialysis	0.41	0.18	0.14 [*]
Trust in Doctors	0.54	0.12	0.28 ^{**}
Dialysis Attitudes	0.31	0.06	0.34 ^{**}
Step 3			
Time on Dialysis	0.31	0.17	0.10
Trust in Doctors	2.20	0.36	1.14 ^{**}
Dialysis Attitudes	1.45	0.24	1.57 ^{**}
Trust (Doctor) x Dialysis	-0.07	0.01	-1.54 ^{**}

Note:

^{*} denotes significance at the .05 level.^{**} denotes significance at the .01 level.

LDT=Living Donor Transplant

Table 3

Regression model for association between trust in racial equity of treatment, dialysis attitudes and attitudes toward LDT

	<u>Attitudes toward LDT</u>		
	B	SE	β
Step 1			
Time on Dialysis	0.47	0.20	0.16 [*]
Trust in Racial equity of treatment	0.60	0.23	0.18 ^{**}
Step 2			
Time on Dialysis	0.44	0.19	0.15 [*]
Trust in Racial equity of treatment	0.56	0.22	0.17 ^{**}
Dialysis Attitudes	0.31	0.06	0.34 ^{**}
Step 3			
Time on Dialysis	0.41	0.19	0.14 [*]
Trust in Racial equity of treatment	2.55	0.79	0.76 ^{**}
Dialysis Attitudes	0.91	0.24	0.99 ^{**}
Trust (Racial equity) x Dialysis	-0.08	0.03	-0.91 ^{**}

Note:

^{*} denotes significance at the .05 level.

^{**} denotes significance at the .01 level.

LDT=Living Donor Transplant

Table 4

Regression model for association between trust in hospitals, dialysis attitudes and attitudes toward LDT

	<u>Attitudes toward LDT</u>		
	B	SE	β
Step 1			
Time on Dialysis	0.43	0.21	0.15 *
Trust in Hospitals	0.12	0.09	0.09
Step 2			
Time on Dialysis	0.42	0.19	0.14 *
Trust in Hospitals	0.20	0.09	0.15 *
Dialysis Attitudes	0.34	0.06	0.37 **
Step 3			
Time on Dialysis	0.41	0.19	0.14 *
Trust in Hospitals	0.89	0.34	0.68 **
Dialysis Attitudes	1.06	0.35	1.14 **
Trust (Hospitals) x Dialysis	-0.03	0.13	-0.88 *

Note:

* denotes significance at the .05 level.

** denotes significance at the .01 level.

LDT=Living Donor Transplant

Table 5
Linear regression testing moderation of the relationship between each trust variable and attitudes toward LDT using median split

	Positive Dialysis Attitudes			
	B	SE	β	t
Trust in Doctors	1.16	0.19	0.51	0.00
Trust in Racial equity of treatment	0.80	0.35	0.22	0.03
Trust in Hospitals	0.17	0.15	0.11	0.25
Negative Dialysis Attitudes				
	B	SE	β	t
Trust in Doctors	1.45	1.41	0.10	0.31
Trust in Racial equity of treatment	0.32	0.27	0.12	0.24
Trust in Hospitals	0.13	0.10	0.13	0.18

LDT=Living Donor Transplant