

African-American Attitudes Toward Kidney Transplant: A Comparative Analysis

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Racial disparities in kidney transplantation continue to persist despite voluminous studies attempting to address this problem. We conducted 26 semi-structured, one-on-one interviews with African-American and Caucasian dialysis patients to analyze whether or not there is a difference in attitudes toward kidney transplantation and whether or not this contributes to these disparities. Pre-dialysis education strongly correlates with a person's willingness to get listed, while fear of surgery and care of the transplanted kidney, and interaction with peers who have gone through a failed kidney transplant, decrease the chances of getting listed. Subjects did not report racial bias in being referred or worked-up for transplant. African Americans were more likely to weigh the pros and cons of transplants while Caucasians were more likely to see dialysis as temporary and viewed transplant as the default treatment for their kidney failure. All dialysis patients, but especially African Americans, may benefit from transplant education tailored to address specific patient concerns.

AFRICAN-AMERICAN ATTITUDES TOWARD KIDNEY TRANSPLANT: A QUALITATIVE STUDY

For at least two decades, much attention has been given to racial disparities in rates of renal transplantation. Renal transplant is considered the optimal renal replacement therapy. Compared to dialysis, transplant generally provides a higher quality of life, better health outcomes, a greater life span, and is less costly (Alexander & Sehgal, 2001; Gordon, 2001; Vamos, Novak, & Mucsi, 2009). Transplant rates overall are lower for non-whites than for Caucasians (Hall, Choi, Xu, O'Hare, & Chertow, 2011). When separated by race, Asians, Pacific Islanders, and Hispanics have similar or even higher rates of transplant listing than Caucasians, but African Americans have disproportionately lower listing rates (Hall, Choi, Xu, O'Hare, & Chertow, 2011). African Americans are also less likely to be referred than Caucasians, even though they represent 29% of the dialysis population (National Kidney Foundation, 2012). When they are referred, studies have shown that this group is less likely to make it through the transplant work-up to take their place on the waiting list (Alexander & Sehgal, 2001; Gillespie et al., 2011; Kucirka, Grams, Balhara, Jaar, & Segev, 2012). Caucasian end-stage renal disease (ESRD) patients are more than twice as likely to have a kidney transplant compared to their African-American counterparts (USRDS, 2008).

Many factors have been identified as to why racial disparities in transplantation continue to persist. Researchers have identified "patient-related barriers," including cultural and religious beliefs, lower socio-economic status, and lower health literacy and education levels (Gillespie et al., 2011; Holley, McCauley, Doherty, Stackiewicz, & Johnson, 1996; Navaneethan & Singh, 2006). Systematic barriers have also been identified and include physician bias based on perceptions of transplant suitability and quality of post-transplant outcomes for African-American patients (Ayanian, 2004). Klassen, Hall, Saksvig, Curbow, and Klassen (2002) reported a history of perceived discrimination led to dis-

trust in the transplant process by African Americans, and decreased their likelihood of completing the transplant work-up. Studies have also shown that African Americans may receive less information about transplantation due to physician bias (Ayanian, 2004).

These barriers aren't necessarily limited to patients being referred for transplant. Alexander and Sehgal (2001) found African Americans, women, and low-income patients less likely to complete the transplant work-up, even though they reported being "definitely interested" in kidney transplants. They may get lost between their initial decision to pursue transplantation and completing the steps to get on the transplant waiting list (Alexander & Sehgal, 2001). Confusion about where they are in the listing process may also keep some patients from completing the workup.

Patient perceptions and attitudes toward transplantation can also play a large role in whether or not patients become listed. Gordon (2001) found "socio- and ethnomedical beliefs and values about the body and transplantation" influenced their desire to pursue transplant. She also found that reasons for not pursuing transplant included: a good quality of life on dialysis, fear of being "cut on" from a transplant, and knowing other patients whose kidney transplants failed. Ayanian et al. (2004) found that African-American men were less likely to believe a transplant would increase their life expectancy, decreasing the likelihood they would pursue transplantation.

Our study used an exploratory approach through in-depth, qualitative interviewing to analyze and understand the underlying causes and identify trends regarding why a patient would not complete a kidney transplant work-up and get listed for transplant. We also investigated differences between African Americans and Caucasians in transplant decision making.

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METHOD

Participants and Data Collection

African-American and Caucasian dialysis patients were recruited from two different dialysis centers in central North Carolina from November 2010 through July 2011. Participants were considered eligible for this study if they were medically eligible for transplantation, self-identified as Caucasian or African-American, English-speaking, and were 18 years of age or older. Patients who were not eligible for transplant due to medical issues (health status or history of substance abuse) were excluded.

Patients participated in one-on-one, semi-structured interviews with one of the two investigators. They were never interviewed by a person who knew their history in order to avoid any bias by the investigator. Each subject was asked to complete a demographic questionnaire at the start of the session.

Three interview guides (see **Appendix A**) were developed by the investigators from a review of the literature. The interview guides addressed the participants' listing status: listed, unlisted, and listing work-up in progress. Subjects who had received a letter from a transplant center stating they were listed at that center for transplant were considered "Listed." Subjects who did not have an active referral in place were considered "Unlisted." Subjects who had been referred for transplant and subjects who had been referred for transplant and who had at least one transplant work-up related appointment were considered "Work-up in Progress." Each participant signed an informed consent form. The study was approved by the University of North Carolina at Chapel Hill's Institutional Review Board. All interviews were digitally recorded and transcribed verbatim.

Recruitment was through flyers given out by the rounding nephrologists, social workers, and dietitians.¹ Names of potential participants were given to the investigators and were screened for eligibility.

A total of 26 dialysis patients were recruited (see **Table 1** for participant demographics). The sample reflected the racial make-up of dialysis patients at these centers and of dialysis patients in North Carolina. Sixty-five percent of participants were African-American, and 42% were female. In 2010, African Americans were 63% of the dialysis population in North Carolina (Southeastern Kidney Council, 2011). Eight patients (30.7%) were listed for transplant at the time of the study, nine (34.6%) were actively being worked-up for transplant, and nine (34.6%) were either not being actively worked-up or did not wish to pursue transplant (see **Table 2**). Participants' ages ranged from 22 to 78 and the average age was 52.2.

¹ Mr. Manton did not recruit participants at the dialysis center where he is employed to avoid any bias.

Table 1.

Race		Annual Income	
African American	17	\$0–\$10,000	10
Caucasian	9	\$10,000–\$20,000	3
		\$20,000–\$30,000	4
Sex		\$30,000–\$40,000	3
Women	11	\$50,000 or above	4
Men	15	Do not wish to disclose	2

Age		Insurance	
20–30	1	Medicare only	2
31–40	5	Medicare & Medicaid	15
41–50	5	Medicare & Medigap	1
51–60	4	Medicare & EGHP	6
61–70	9	Medicare & VA	2
71–80	2		

Education		Time on Dialysis	
Some HS	5	Less than a year	4
HS grad	8	1–5 years	14
Some college	7	6–9 years	4
College grad	3	10 or more years	4
Post-grad	3		

Table 2.

Listing of Subject by Race	AA	Caucasian
Listed (8)	4	4
Work-Up In Progress (9)	7	2
Unlisted (9)	7	2

AA = African Americans

ANALYSIS

Interviews were transcribed by a professional transcriptionist unaffiliated with either of the investigators and then uploaded into Atlas.ti, a computer software program used for qualitative data analysis (Muhr, 1997). Coding categories were developed based on Straus and Corbin's (1990) grounded theory methodology. "Grounded theory uses open coding (free form coding for words, themes, expressions, etc.) followed by axial coding, which seeks to explore categories created through the open coding process" (Jennette, Derebail, Baldwin, & Cameron, 2009). Codes were determined by cross referencing the two author's independent readings of the transcripts and were compared for reliability. The principal investigator continued to code all interviews using this base code list, adding codes as themes developed.

RESULTS

Influence of Pre-dialysis Care

Patients who had received early nephrology care (ENC), and had seen a nephrologist at least three months before initiating dialysis treatment, were more likely to regard dialysis as a "bridge" to transplant and be more informed about treatment options, including transplant prior to starting dialysis. For example, one patient said:

"Before starting dialysis, my nephrologist informed me about transplant and that was immediately what I wanted to do. She made it clear to me that dialysis was a bridge to transplant."

Approximately two-thirds of subjects received ENC (78% of Caucasians and 58% of African Americans). Patients who, at the time of this study, had an employer-group health plan (EGHP) were more likely to receive ENC, compared to those having only Medicaid. All of the subjects who had an EGHP received ENC. Only one subject who did not receive ENC was listed for transplant at the time of this study.

Transplant Education

Transplant education varied greatly among the subjects of this study with regards to source, amount of information, and efficacy. Sources of education included the patient's primary nephrologist, the dialysis center staff or social worker, other dialysis patients, and the media.

There did not seem to be a substantial difference with regard to race and reported level of transplant knowledge. However, there did seem to be a positive difference in the knowledge level of those who received ENC, the majority of whom reported being informed about transplantation prior to starting dialysis.

Surprisingly, there was no correlation between transplant knowledge and listing status (among listed subjects). This was irrespective of race. Just because someone was listed for a transplant does not mean they were well informed about the entire transplant process.

For example, one patient said:

"I don't know. I don't know which list I'm on. I just know I'm on the kidney transplant list. That's all I know... [and] I do not know why someone would be taken off the transplant list."

Other listed subjects reported that they knew what it took to get on the waitlist but were misinformed or uninformed regarding other areas of the transplant process.

Overall, in this patient cohort, African-American subjects were more likely to be less knowledgeable about the transplant listing process. They were less likely to know how one gets on the waitlist, why one would be taken off the list, the average length of time it takes to get a transplant, and the medical regimen needed to avoid graft rejection. Only one patient who was unlisted seemed to be well informed. He reported knowing what was involved in the transplant work-up, knew the average life span of a transplanted kidney, and knew information about the costs and care needed for a successful transplant.

LIVING KIDNEY DONATION

All participants reported that they had been educated about living kidney donation (LKD) or knew from another source (other patients, family, or the media) that it was an option. Only 3 subjects out of 26 (11.5%) reported that LKD was the optimum choice for transplant.

Most subjects expressed unwillingness or ambivalence when questioned about asking a friend or family member to be an LKD. This was true even for those who were planning to accept a kidney from a living donor.

"My son said he would but I'm not gonna take anything from them that might shorten their life. I'm not gonna do that."

"I just think it would be too big a sacrifice because it would alter their health right away. Their kidney life would be in jeopardy, I think, even though they had at least one kidney functioning normally. It doesn't mean they could handle it over the years. As they got older they might end up on dialysis or with a transplant."

Other subjects reported guilt as a reason for not asking to donate:

"And then I guess I just feel kind of guilty asking people."

"I know you can live with one kidney but I feel like... and thank God, I mean this sounds weird but none of my family members qualify anyway. But I just feel that if something happens to them later on and I have their kidney; that could be a factor of why whatever happened to them happened."

More African Americans than Caucasians showed a willingness to discuss LKD, but many family members had been excluded for medical reasons. 53% of African Americans were either unwilling or ambivalent about asking others, versus 100% of Caucasians.

“Most of my family members [are] diabetic so I know they couldn’t [donate]. My daughter offered but she’s diabetic so she couldn’t [donate].”

“Just about all my family, most of them are diabetics. On my father’s side, a lot of them have heart problems. And even with my mother, she had heart problems, and myself. And like I said, a lot of them have other sicknesses themselves. [It] wouldn’t be a problem [asking family or friends to donate a kidney]. That’s if the Lord give me that person to help.”

PREFERENTIAL TREATMENT

Subjects were asked if they thought it was easier for some patients to become listed for transplant than others. Most subjects reported (73%) that they thought there was no preferential treatment given to some individuals over others seeking a transplant. Some reported they did not know if there was a bias in the listing process. We then asked a follow-up question, specifically asking if they thought there was any racial bias in the work-up process and, here again, patients did not seem to perceive any. Some did, however, say preferential treatment was given to those who were more compliant, lived healthier lifestyles, or younger. One patient said:

“Lifestyle factors, whether you smoke or drink. Probably your age.”

There was no distinction in race or listing status among those who reported age as a factor in getting listed.

Several subjects did report that wealth may influence one’s ability get listed. African Americans were more likely to report how wealth had affected the chances of getting listed.

“...you have a certain level of income, or you might have persons who you have influence over who might make it possible for you to get on the list. But I haven’t really researched these things so I can’t be sure about them.”

Or:

“People who have money. You know. More money than I do, I think.”

DECISION-MAKING PROCESS REGARDING WHETHER TO SEEK TRANSPLANT AS A TREATMENT OPTION

Motivations

Caucasian subjects were more likely to see transplant as the default option and dialysis as a temporary treatment. They also had less ambivalence about seeking transplant. One participant stated:

“I think it’s something I knew. You know, intuitively this is the way I wanted to go and this would be easier for all of us. And if it came about, fine. If it didn’t, I’m doing well on dialysis. I knew this was going to happen to me and I knew my life was going to change, so I was ready for it.”

While Caucasian subjects were less likely to cite specific reasons for wanting to be listed, African-American respondents focused on the positive or negative outcomes of a transplant as a motivation (or deterrent) in seeking transplant as a treatment option. For example, African-American subjects were more likely to report an increased quality of life, better health, and getting off of dialysis as motivations to pursue transplant.

“I know it would [be better]. ‘Cause then I wouldn’t have to, you know, go through the filtering and just the process of it [dialysis] ... I can function, like I am supposed to.”

“Well, one thing, I won’t have to come over here [dialysis unit]. Another, I want to go back to work. That’s one of the main reasons— I want to go back to work.”

Barriers

Participants were asked if they encountered any barriers to getting listed for transplant. Responses to this question varied greatly and many patients stated that they had encountered no barriers to getting listed for transplant. African-American subjects were more likely to report listing barriers.

Financial issues were the most commonly cited, and there was not a racial difference in the rates of this reporting. While some subjects reported worrying about costs associated with time lost from work or the costs of surgery, the overwhelming concern was the cost of immunosuppressive medications.

“...I don’t know anything about transplant or anything like that, but a girl [I know], she had one, [and] she was telling me they let you stay on it [Medicare] for five years and after that you had to do your own thing. I don’t have money for that. I don’t have money for this medicine and stuff like that...[without Medicare], I would be totally lost.”

The next most commonly cited listing barriers were fear of surgery, and fear or guilt related to the possibility of losing a transplanted kidney and returning to dialysis. African Americans were more likely to talk about knowing someone who had received a kidney transplant that had failed. In fact, only one Caucasian subject reported knowing someone who received a transplant that was unsuccessful; that subject stated that he did not wish to pursue transplant. Knowledge of someone who has lost their transplanted kidney may increase the fear of a patient receiving a transplant, of it failing, and having to return to dialysis. This seemed to have a particular impact on African-American subjects who had been on dialysis longer. These patients were more likely to say they feared getting a transplant and then having to return to dialysis.

“...When I first got on dialysis you know, I seen people, where they had a transplant but they be right back in there [dialysis unit].”

“...I see people come back down here that have already had a transplant and that kind of scares me.”

“...if I have a transplant and everything went well, I’m scared about getting sick again and having to come back. I wouldn’t want that.”

“Well, I have another friend who had been on it and back and she was just sick all of the time, you know, and, just different things. I see them [patients with failed transplants] and I hear them talk and I just don’t want to do it right now.”

“It’s just the emotional things you have to deal with... I mean, knowing that you have to have a surgery and then just having to live with somebody else’s body part in you. That’s hard to grasp sometimes.”

DISCUSSION

This study highlights several issues important to consider when looking at patients’ motivations for pursuing transplant. Pre-dialysis education and the perception that dialysis is a bridge to transplant may increase a person’s willingness to get listed, while fear of surgery and fear of losing the transplant decrease the chances of getting listed. Additional barriers include lack of education about transplant and interaction with peers who have gone through a failed transplant. In this study, race also seemed to be a factor in terms of getting listed, but there were no differences in attitudes about preferential treatment.

Subjects who received ENC were much more likely to be either listed for a transplant or in the process of a work-up. Among the 9 listed subjects in this study, 78% received ENC. They were more likely to have no reluctance or ambivalence about seeking a transplant with a common theme of viewing dialysis as a “bridge” to transplant. This is consistent with earlier studies showing that those receiving ENC were more likely to be referred for transplant pre-dialysis or within

the first few months of starting dialysis and more likely to be listed for transplant in general (Vamos et al., 2009). And the longer it takes to be referred for transplant, the less likely one is to ever be listed and receive a transplant (Klassen et al., 2002).

The importance of ENC and access to transplant is also reflected in national data. Kucirka et al (2012) found that almost a third of patients who started dialysis between 2005 and 2007 had not been informed of transplant by the time they started dialysis. Those who were not assessed reflect those previously reported in the literature as more likely to not to have access to transplant: African Americans, the uninsured/publicly insured, women, and older patients (Alexander & Sehgal, 2001; Ayania et al., 2004; Vamos et al., 2009).

It is important to note that, nationally, almost half of newly diagnosed patients had not seen a nephrologist prior to dialysis initiation, which makes ENC difficult for a large cohort of patients (USRDS, 2011).

There may also be a selection bias in that patients who receive ENC may be more likely to be listed for transplant because they are more invested in their health, more self-efficacious, and/or more proactive in general about their health. They may also be, in general, healthier and thus more likely to be candidates for transplant. While subjects who received ENC overall were more likely to see dialysis as temporary until they are able to receive a transplant, African Americans who received ENC were still less likely to complete the transplant work-up and be actively listed.

Differences in socioeconomic status (SES) and insurance coverage have been identified as factors exacerbating disparities in transplant rates (Ayanian, Cleary, Weisman, & Epstein, 1999; Kutner, Johansen, Zhang, Huang, & Amaral, 2012; Vamos et al., 2009). In our study, subjects having an employer group health plan (EGHP) were more likely to receive ENC. Caucasians were more likely to have both a relatively higher SES and to have received ENC, increasing their likelihood to be listed and receive a transplant.

Related to SES and insurance coverage were financial concerns regarding getting a transplant. A common barrier identified was the cost of immunosuppressant therapy. This was mentioned by subjects who were listed and not listed alike. However, for the patients who were not listed, those who said this was a barrier were more likely to not know how insurance covers these medications or how much medications would actually cost. Other financial concerns included the cost of the surgery and financial losses from time missed at work. Based on the literature, these concerns are well founded (Evans et al., 2010; Gordon, Prohaska, & Sehgal, 2008; Rodrigue, Cornell, Kaplan, & Howard, 2008). In Gordon et al.’s (2008) qualitative study, she found a third of subjects reported financial strain post-transplant due to costs associated with transplant, and another third anticipated financial strain.

Subjects in our cohort reported a wide range of knowledge of kidney transplant. Some patients who had been on dialysis for years reported having no knowledge of transplant. Even patients who were listed for kidney transplant at the time of this study had relative deficits in their overall knowledge of kidney transplant. African Americans, overall, had less knowledge about transplant. This reflects others who have found a deficit of knowledge among dialysis patients about the option of transplant. Gillespie et al. (2011) in a single dialysis center study, found approximately half of patients who were in the work-up process thought they were already listed for transplant.

These results may be because dialysis centers, in general, may be ill-suited to provide education about transplant. The Centers for Medicare & Medicaid Services Conditions for Coverage (Federal Register, 2008) mandate dialysis centers to provide this education annually. Waterman, Goalby, Herrington, and Hyland (2012), in a 500-center survey, found staff at these centers felt they did not have adequate knowledge to answer questions about kidney transplant, they rarely discussed living kidney donation, and while they were informing patients that transplant is an option, few were providing "true transplant education." The examples of transplant education provided in the centers reviewed consisted mainly of referrals of patients to education programs at transplant centers.

Another issue regarding transplant education at the dialysis center may be the relative cognitive decline of dialysis patients and the fact that cognitive function may decline while a patient is on dialysis. Studies have suggested cognitive impairment among dialysis population ranges from 22% to over 60% (Tamura et al, 2010; Murray et al., 2006; Sorenson et al., 2012). Other studies have suggested that cognitive function can decline acutely during the dialysis session (Murray, 2008). This may indicate that education provided at the dialysis center is less fruitful than in other settings and could be another reason patients in this study and others have reported relative ignorance of kidney transplant. It also underscores the benefits of pre-dialysis nephrology care.

We also attempted to better understand why some patients were more motivated to seek the option of transplant, and whether or not race played a role in their decision-making process. We found that Caucasians were more likely to see transplant as the default therapy for ESRD and, interestingly, this was irrespective of their knowledge of transplant or of the fact that transplant is considered the best renal replacement therapy in terms of health outcomes and quality of life. African American subjects, on the other hand, were more likely to weigh the costs and benefits of transplant, and reported them as an influencing factor of their pursuit of transplant. This reflects Ayanian (1999), who found African Americans less likely than Caucasians to be very certain about wanting to get a transplant, and less likely to report that kidney transplant would improve their quality of life.

African Americans' personal experiences with transplantation seem to have a strong influence on their attitudes towards potential transplant. Because ESRD is more prevalent in African Americans in general, and a larger proportion of dialysis patients tend to be African-American, especially in the southern United States, knowing an African American peer who received a transplant was common in our study population. Negative experiences (unsuccessful transplants) seemed to overwhelmingly exert greater influence than positive ones. This reflects Holley et al. (1996), who found that patients who reported seeing transplant recipient return to dialysis after a failure were *more* likely to not want to seek this option for themselves. Coupling this with African Americans being more likely to be referred later and take longer to become listed, these experiences seem to greatly reduce the chances for African Americans to become listed.

While all subjects reported being familiar with LKD, most, regardless of race, were either unwilling or ambivalent about asking others for a living kidney donation. This issue was related to concerns for the health of the donor, guilt, or other emotions. Even though the data suggest that donation does not affect future chance of kidney disease in the donor, this fear persists (Fehrman-Ekholm, Elinder, Stenbeck, Tydén, & Groth, 1997). Our study reflects Rodrigue et al. (2008), who also found over half of patients were either unwilling to discuss LKD with potential donors or were ambivalent about doing so. The literature suggests patients do not consider living donation due to a fear of jeopardizing the kidney donor's health in the future, fear of inconveniencing the donor, not wanting to be indebted to the donor, and guilt associated with the potential of the transplant failing and the kidney being wasted (Gordon, 2001; Waterman et al., 2006; Zimmerman, Albert, Llewellyn-Thomas, & Hawker, 2006). Many of the participants in our study reflected these same feelings towards transplant, regardless of their level of knowledge about the transplant process. However, the literature shows potential donors are very willing to donate when *asked* (Robinson, Borba, Thompson, Perryman, & Arriola, 2009) and have a much greater risk tolerance regarding future health problems than potential recipients (Young, et al., 2008). While there have been gains in transplant rates for African Americans, these gains will be limited by the dearth of organs available for transplantation (Hall, 2011) so addressing recipient fears and hesitations towards LKD is of vital importance.

Approximately three-quarters of subjects, regardless of race and listing status, thought the process of getting listed was not biased, or said they did not know if there was any bias. The researchers did not know if this was because the interviewers were both Caucasian and African-American and the subjects did not feel comfortable admitting to perceived racial bias. However, African Americans were more likely than Caucasian subjects to suggest that wealthy individuals have an advantage in the transplant process. This may indicate that African Americans think there is an economic bias in the work-up process, which is partially true. Most

transplant centers take into account the ability of a person to pay for immunosuppressive medications long-term in their work-up for transplant eligibility. There was no direct correlation between the perception of economic bias and a person's motivation toward seeking a transplant, but financial concerns were often mentioned as a general barrier to getting listed.

Subjects also reported preferential treatment given to patients based on their age, health status, compliance or, conversely, lifestyle factors (such as substance abuse and smoking). While age was mentioned by several participants as a barrier to getting listed, it is less of an issue than it has been in the past, signaling an area where education may be warranted (Danovitch & Savransky, 2006; Schaeffner, Rose, & Gill, 2010; Stratta et al., 2006).

Limitations

There are also some limitations to this study. The sample size was relatively small and was limited to two dialysis centers in central North Carolina. With smaller sample size, and qualitative data, results may not be generalizable. The research was also based on self-reported information, and the patients' answers were not checked against their actual medical records (in order to confirm their listing status, for example).

CONCLUSION

Our study highlights differences between African-American and Caucasian views on the transplant process, and how these different perceptions may contribute to racial disparities in listing rates. African Americans were more likely to weigh the pros and cons of transplants, while Caucasians were more likely to see dialysis as temporary and viewed transplant as the default treatment for their kidney failure. African Americans also were more likely than their Caucasian counterparts to be influenced by knowing someone who has had a failed transplant. Because of this difference, African Americans, especially, would benefit from transplant education tailored to address their specific concerns. General information, while important, is not enough to allow many patients to make an informed decision about kidney transplant and LKD. An assessment of one's health literacy and providing patients with "concern-specific" (Rodrique et al., 2008) kidney transplant information will help achieve this goal.

Our findings lead to many implications for practice. Social workers are an integral part of the treatment team; they lead in providing education about transplant. For those who practice in dialysis units, renal social workers can use this study to recognize differences between how African American and Caucasian patients view transplant, and how these backgrounds can lead to different treatment options. Social workers have the expertise to recognize these differences, the role one's background plays in their decision-making process, and how to individualize patient education to optimize their treatment.

For transplant social workers, this highlights the need to be more cognizant of the education that is being provided to patients prior to transplant work-up and how this affects their reactions to work-ups. It also is a call to recognize that ambivalence or hesitation may be manifestations of fears based on cultural perceptions or history and this should be recognized in the assessment process.

The results of this study raise further questions that could be investigated. An interventional study to see if *patient-specific* education, especially with African Americans, would be effective in reducing transplant disparities. This study also could be expanded to include other regions of the country to see if the results are generalizable and include other racial categories to see if there are further differences among racial groups. Our study also raises questions about living kidney donation. Because of the hesitancy of many patients to ask others to participate in living kidney donation, research could address how this barrier could be eliminated.

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Appendix A.*Interview Guide: Unlisted*

1. a. When did you find out you needed to be on dialysis?
 - b. Can you tell me how you found out you needed dialysis? Did you know prior to starting dialysis that you had kidney disease?
2. Prior to starting dialysis (or when you started on dialysis), what was your understanding of the kind of treatment you would need?
3. Were you given information about kidney transplant when you started dialysis?
 - a) What information was given to you?
 - b) Was this information useful?
 - c) Who has given you the most information about transplant?

If NO, have you been given information about it since your initial diagnosis?
4. What is your understanding of how getting a transplant works?
 - a) How do you get on the transplant waitlist?
 - b) Do you know why a person may be taken off the waitlist?
5. What have you been told about using a living kidney donor instead of being waitlisted for a deceased donor?
6. Have you ever talked to your family members about being an organ donor? Why or why not?
7. If you are currently not on the waitlist for a kidney transplant, why did you decide not to get listed?
8. Earlier, I asked how you get on the transplant waitlist. Have you been listed before?
 - a) If yes, what made you not complete the process?
9. Are there any specific financial barriers to you getting on the waitlist?
10. Is there anything that would make you change your mind about getting on the waitlist now?
11. What kind of information would help you make a decision? In what format?
12. Do you think it's easier for some people to get listed and get a transplant or is access to the waiting list about equal for everyone?
 - a) For whom is it easier to get listed?
 - b) Why?

Interview Guide: Listed

1. a. When did you learn you needed to be on dialysis?
 - b. Can you tell me how you found out you needed dialysis? Did you know prior to starting dialysis that you had kidney disease?
2. Prior to starting dialysis (or when you started on dialysis), what was your understanding of the kind of treatment you would need?
3. Were you given information about kidney transplant when you started dialysis?
 - a) What information was given to you?
 - b) What this information useful?
 - c) Who has given you the most information about transplant?

If NO, when were you given information about it since your initial diagnosis?
4. What is your understanding of how the transplant waitlist works?
 - a) How do you get on the transplant list?
 - b) Do you know why a person may be taken off the waitlist?

5. What have you been told about using a living kidney donor instead of being waitlisted for a deceased donor?
6. Have you ever talked to your family members about being an organ donor? Why or why not?
7. What was the hardest thing about making it through the steps to get onto the waitlist? What was the easiest thing?
8. Were there any specific financial barriers to you getting on the transplant waitlist?
9. Do you think it's easier for some people to get listed and get access to the transplant waitlist, or is it about equal for everyone?
 - a) For whom is it easier to get listed?
 - b) Why?

Interview Guide: Listing Work-Up in Progress

1.
 - a. When did you find out you needed to be on dialysis?
 - b. Can you tell me how you found out you needed dialysis? Did you know, prior to starting dialysis, that you had kidney disease?
2. Prior to starting dialysis (or when you started on dialysis), what was your understanding of the kind of treatment you would need?
3. Were you given information about kidney transplant when you started dialysis?
 - a) What information was given to you?
 - b) Was this information useful?
 - c) Who has given you the most information about transplant?If NO, have you been given information about it since your initial diagnosis?
4. What is your understanding of how getting a transplant works?
 - a) How do you get on the transplant waitlist?
 - b) Do you know why a person may be taken off the waitlist?
5. What have you been told about using a living kidney donor instead of being waitlisted for a deceased donor?
6. Have you ever talked to your family members about being an organ donor? Why or why not?
7. You are currently going through the waitlist process. What kind of information would help you make a decision? In what format?
8. Can you tell me what the process has been like? What's been the hardest thing about? What has been the easiest thing about it?
9. Are there barriers to completing the process for you? Any specific financial barriers?
10. Do you think it's easier for some people to get listed and get access to the transplant waitlist, or is it about equal for everyone?
 - a) For whom is it easier to get listed?
 - b) Why?