



# VCU

Virginia Commonwealth University  
VCU Scholars Compass

---

Theses and Dissertations

Graduate School


---

2016

## FACTORS PREDICTING AFRICAN AMERICAN RENAL PATIENTS' COMPLETION OF THE MEDICAL EVALUATION PROCESS FOR KIDNEY TRANSPLANTATION

Camilla W. Nonterah  
*Virginia Commonwealth University*

Follow this and additional works at: <https://scholarscompass.vcu.edu/etd>

 Part of the [Community Psychology Commons](#), [Counseling Psychology Commons](#), and the [Health Psychology Commons](#)

© The Author

---

Downloaded from

<https://scholarscompass.vcu.edu/etd/5045>

This Dissertation is brought to you for free and open access by the Graduate School at VCU Scholars Compass. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of VCU Scholars Compass. For more information, please contact [libcompass@vcu.edu](mailto:libcompass@vcu.edu).

FACTORS PREDICTING AFRICAN AMERICAN RENAL PATIENTS'  
COMPLETION OF THE MEDICAL EVALUATION PROCESS FOR KIDNEY  
TRANSPLANTATION

A dissertation submitted in partial fulfillment of the requirements for the  
degree of Doctor of Philosophy at Virginia Commonwealth  
University

By: CAMILLA WEPIAH NONTERAH  
Masters of Arts, Central Connecticut State University, August 2009  
Bachelor of Arts, Concordia College, May 2005

Directors:

Shawn O. Utsey, Ph.D.  
Title: Professor  
Department of Psychology  
Virginia Commonwealth University

Heather M. Traino, Ph.D.  
Title: Associate Professor  
Department of Public Health  
Temple University  
Faculty Affiliate, Department of Health Behavior and Policy  
Virginia Commonwealth University

Virginia Commonwealth University  
Richmond, Virginia  
April, 2016

## Acknowledgements

I believe it takes a village to successfully complete a doctorate program, so I would like to thank all the people in my village. First, I owe a tremendous amount of gratitude to my family for encouraging me to pursue my dreams and supporting me throughout the years. I am particularly grateful to my mother, Sophia Mate-Kole who has always been my biggest cheerleader, and my brothers, Benedict Nonterah and Frederick Nonterah for their encouragement, support and spiritual guidance.

Second, I would like to acknowledge the mentors who supported me and helped shape my professional identity. Specifically, I would like to thank my advisor, Dr. Shawn Utsey for supporting me through five years of the program, and for helping to shape me as a researcher. I am grateful to Dr. Heather Traino for sharing her knowledge of kidney transplantation with me and for assisting me in the development of various aspects of the study. I would also like to extend my gratitude to my committee members, Dr. Faye Belgrave, Dr. Micah McCreary and Dr. Gaurav Gupta for their mentorship and support, and for serving on my committee. I am grateful to Dr. Lisa Abrams for her qualitative analysis training and for providing feedback on my analyses. Additionally, I appreciate the support of my research mentor, Dr. Everett Worthington.

Third, I am fortunate to have an amazing group of colleagues and friends who reminded me to practice self-care, and helped me navigate various challenges. I greatly value the support and experiences with my cohort, namely, Jennifer Coleman, Nathasha Hahn, Brooke Green, Caroline Lavelock, Gillian Leibach, and Janette Hamilton. I also appreciate the support and memories shared with Anh-Thuy Le, Annie Bays, Amma Agyemang, and Jennifer St. Clair Russell. My special thanks to the rest of my close friends, Laura Lamptey, Abenaa Asiama, Jaclyn Owusu-Mensah, Rachel Atchley, Kevin Dzakpasu, Matthew Dennis, and Derek Owusu-Mensah who have supported me in different ways throughout my PhD journey.

Fourth, I would like to thank the undergraduate research assistants who worked on this project for their assistance with data collection and coding. Finally, I appreciate the financial support from the American Psychological Association Graduate Student Ellin Bloch and Pierre Ritchie Diversity Dissertation Grant.

## TABLE OF CONTENTS

	Page
Acknowledgements. . . . .	ii
List of Tables. . . . .	iv
List of Figures. . . . .	v
Abstract. . . . .	vi
Introduction. . . . .	1
Literature Review . . . . .	4
African Americans and Kidney Transplantation. . . . .	9
Factors that positively impact completion of the medical evaluation for kidney transplantation. . . . .	15
Factors that negatively impact completion of the medical evaluation for kidney transplantation. . . . .	18
Theoretical Framework . . . . .	23
Statement of Problem . . . . .	25
Study Aims . . . . .	27
Method. . . . .	28
Phase I. . . . .	28
Phase I. . . . .	31
Data Analysis. . . . .	37
Results. . . . .	41
Thematic Analyses. . . . .	42
Rankings for Barriers to Completing the Medical Evaluation. . . . .	58
Rankings for Motivators to Completing the Medical Evaluation. . . . .	62
Summary of Top Barriers, Motivators and Possible Solutions. . . . .	69
Correlations. . . . .	70
Test of Independence. . . . .	76
Discussion. . . . .	76
List of References. . . . .	88
Appendices. . . . .	101
A Transplant Professional Interview Protocol. . . . .	101
B Transplant Professional Survey. . . . .	107
C ESRD Patients Nominal Focus group (Status 1 & 2) Protocol. . . . .	110
D ESRD Patients Nominal Focus group (Status 7) Protocol. . . . .	113
E Nominal Focus Group Survey. . . . .	116
Vita. . . . .	120

## List of Tables

	Page
Table 1. Facilitators of Medical Evaluation Completion. . . . .	17
Table 2. Impediments to Medical Evaluation Completion . . . . .	22
Table 3. Sample characteristics. . . . .	41
Table 4. Transplant Professionals' Rankings of Barriers to Completing the Medical Evaluation. . . . .	59
Table 5. Patients' Rankings of Barriers to Completing the Medical Evaluation. . . . .	60
Table 6. Transplant Professionals' Rankings of Motivators to Completing the Medical Evaluation. . . . .	62
Table 7. Patients' Rankings of Motivators to Completing the Medical Evaluation . . . . .	63
Table 8. Patient Group Rankings of Barriers to Completing the Medical Evaluation . . . . .	68
Table 9. Patient Group Rankings of Motivators to Completing the Medical Evaluation. . . . .	68
Table 10. Summary of Top Barriers, Motivators and Possible Solutions . . . . .	70
Table 11. Pearson's Product Moment Correlations for Perceived Barriers and Motivators for Transplant Professionals . . . . .	73
Table 12. Pearson's Product Moment Correlations for Perceived Barriers and Motivators for Patients. . . . .	74
Table 13. Pearson's Product Moment Correlations for Perceived Barriers and Motivators for all participants . . . . .	75

**List of Figures**

	Page
Figure 1. Hypothetical demonstration of the Health Beliefs Model .....	25
Figure 2. Data Collection Methods by Phase .....	34
Figure 3. Differences and Similarities between participant rankings of the top five barriers to completing the medical evaluation process. ....	66
Figure 4. Differences and Similarities between participant rankings of the top five motivators to completing the medical evaluation process. ....	67

**Abstract****FACTORS PREDICTING AFRICAN AMERICAN RENAL PATIENTS' COMPLETION OF  
THE MEDICAL EVALUATION PROCESS FOR KIDNEY TRANSPLANTATION**

By CAMILLA WEPIAH NONTERAH

A dissertation submitted in partial fulfillment of the requirements for the  
degree of Doctor of Philosophy at Virginia Commonwealth  
University

Virginia Commonwealth University, 2016

## Major Directors:

Shawn O. Utsey, Ph.D.  
Title: Professor  
Department of Psychology  
Virginia Commonwealth University

Heather M. Traino, Ph.D.  
Title: Associate Professor  
Department of Public Health  
Temple University  
Faculty Affiliate, Department of Health Behavior and Policy  
Virginia Commonwealth University

African Americans (AA) are more susceptible to end-stage renal disease (ESRD) for several reasons. Treatment options for patients with ESRD include dialysis therapy and transplantation, with the latter typically producing better outcomes. AA are less likely to complete the medical evaluation process, which requires patients to consult with doctors and undergo a series of tests and examinations. This study sought to determine the factors that predict completion of the medical evaluation for AA ESRD patients using a mixed methods design. Participants consisted of transplant professionals ( $N=23$ ) recruited from nine transplant centers in the Mid-Atlantic, Mid-Western and Southeastern parts of the United States, and kidney patients ( $N=30$  patients)

recruited from one transplant center in the Mid-Atlantic region. Semi-structured interviews and nominal focus groups were conducted to gather qualitative data; quantitative survey data were also collected. The results revealed factors classified as impacting patients at the individual-level and systemic level, and others classified as health-related and informational/educational.

Participants ranked insurances issues, limited income, lack of a personal means of transportation, lack of patient motivation, the number of procedures required to complete the evaluation, scheduling difficulties and time constraints as top barriers to completing the medical evaluation process. Top motivators consisted of informational support, social support, religious beliefs, patients' desire to get off dialysis, support from the transplant staff, center-based education, patient's knowledge of the benefits of transplantation and patient navigators. These findings provide valuable information on factors that impact AA renal patients' completion of the medical evaluation.



## Factors Predicting African American Renal Patients' Completion of the Medical Evaluation Process for Kidney Transplantation

African Americans are more susceptible to end-stage renal disease (ESRD) as a result of genetic characteristics and socioeconomic factors such as higher rates of hypertension and diabetes, both leading causes of kidney disease, differences in antigens (substances which activate the production of antibodies), income differences and health behaviors (Andrews et al., 2012; Churak, 2005; Ladin, Rodrigue & Hanto, 2009). According to the United States Renal Data System (USRDS, 2015), the incidence rate of ESRD was 3 times higher among African Americans relative to Caucasians in 2013. The prevalence rate of ESRD continues to be highest among African Americans at 5,584 per million population compared to Whites and Asians at 1,499 and 2,196 per million population respectively (USRDS, 2015). According to the Organ Procurement and Transplantation Network (OPTN) there are 108, 258 patients in the US on the waitlist in the hopes of receiving a kidney as of April 1, 2016 (OPTN, 2016). Of the total number of patients on the waitlist, 36, 456 (33.68%) are African Americans, although they consist of about 13.3% of the US population (OPTN, 2016; United States Census Bureau, 2016). This disparity in incidence is also mirrored in the treatment options pursued by African American patients relative to Caucasians and patients from other racial and ethnic groups.

Treatment options for patients with ESRD include dialysis therapy (i.e., hemodialysis, peritoneal dialysis) and transplantation, with the latter typically producing better outcomes. ESRD patients who receive transplants experience less mortality and morbidity and have a better quality of life in comparison to those who remain on dialysis (Christensen & Ehlers, 2002). USRDS (2013) data shows that adjusted rates for all-cause mortality for dialysis patients are 6.5 to 6.9 times greater than the general population. In contrast, transplant patients' adjusted rates

for all-cause mortality are 1.0 to 1.5 times higher than the general population, indicating significant benefits of transplantation (USRDS, 2013).

Yet, research comparing African Americans to other ethnic groups indicate lower rates of transplantation. One explanation is that African Americans are less likely to donate organs than are individuals of other races/ethnicities (Lunsford et al., 2006) which causes a disparity in the number of African Americans receiving kidneys relative to other groups. Although there is an increased need within the African American community, African Americans are less likely to seek kidney transplantation or complete the medical evaluation for placement on a waitlist for a transplantable kidney. Alexander and Sehgal (2001) noted that 84% of Blacks expressed a lack of interest in transplantation and/or were medically unsuitable for kidney transplantation relative to 74% of Whites. Garg, Diener-West and Powe (2001) also reported lower rates of waitlist placement for Blacks relative to White renal patients. This disparity in placement on the waitlist appeared to be greatest among younger African Americans and African Americans with fewer health concerns, who were 50% and 40% less likely to be waitlisted, a finding contrary to previous findings. However, access to kidney transplantation involves the completion of several procedural steps not the least of which is a medical evaluation.

The medical evaluation or pre-transplant work up, which requires patients to consult with doctors and undergo a series of tests and examinations (e.g., chest x-ray, dental exam, cancer screenings, etc.), is a tedious process and one that often impedes a patient's ability to be placed on the waitlist. For some patients, the medical evaluation process may be the first time they learn about transplantation (Gaston et al., 2003). Successful completion of the medical evaluation generally leads to transplant candidacy status and placement on the waitlist for a deceased donor transplant or a living donor transplant in cases where the patient has identified a living donor

(Weng, Joffe, Feldman, & Mange, 2005). Low rates of completion of the medical evaluation could contribute to reduced access to transplantation among African American patients with ESRD (Weng et al., 2005). As a result, these patients must endure sustained dialysis treatments, which are associated with decreased quality of life, greater dependence on health care providers, diet restrictions and depression (Christensen & Ehlers, 2002). Alexander and Sehgal (2001) advocate for reducing barriers during the early steps in the transplant process such as referral and evaluation in an effort to reduce racial disparities in access to transplantation. An exploration of the factors that promote and/ or impede the completion of the medical evaluation process is central to diminishing disparities in access to transplantation between African Americans and other racial groups such as Whites and Asians.

Several studies have been conducted in an effort to understand why some African American ESRD patients complete the medical evaluation process, while the majority are unable to do so. Past research attributes patient and healthcare related factors including physician recommendation, socioeconomic status (SES), social support and physician beliefs to racial and ethnic differences in completion of the medical evaluation for transplantation (see Dageforde, Box, Feurer & Cavanaugh, 2015; Joshi, Gaynor, & Ciancio, 2012; Navaneethn & Singh, 2006). Given that an examination of the past literature indicates a myriad of factors contributing to racial differences in executing a pre-transplant work up, the current study examined the factors that impact medical evaluation completion specifically, the barriers and motivators to completing the medical evaluation. This study sought to address this phenomenon by examining the perceptions of transplant center professionals and ESRD patients regarding the factors that promote and/or hinder completion of the medical evaluation for kidney transplantation among African American renal patients.

## **Literature Review**

### **End stage renal disease (ESRD)**

Chronic kidney disease (CKD) occurs when the kidneys fail to filter the blood properly, allowing waste products such as excess water and ammonium to build up in the body; the result is a multitude of health problems including high blood pressure, fluid in the lungs and kidney failure (Centers for Disease Control and Prevention (CDC), 2014). Risk factors for CKD include high blood pressure, diabetes, cardiovascular disease, high cholesterol, lupus and a family history of CKD. People with CKD are susceptible to kidney failure or ESRD (also referred to as Stage 5 CKD), a life-threatening disease (CDC, 2014). Some of the symptoms associated with this disease include appetite loss, nausea, weight loss, muscle cramps, problems urinating, difficulties concentrating, and sleep problems (CDC, 2014). The leading causes of kidney failure are diabetes and hypertension, accounting for 7 of the 10 new cases of ESRD (CDC, 2014). African Americans are more likely to develop ESRD than Whites which can be accounted for in part by the higher prevalence of hypertension and diabetes in this population (Klag, et al., 1997; Martins, Tareen & Norris, 2002). Blacks are also more likely to receive an HIV/AIDS diagnosis which could cause kidney disease, increasing a person's likelihood of developing ESRD (Martins et al., 2002). Black patients tend to develop ESRD at a younger age and incidence rates increase by age, every ten years of life. They also have the highest rate of hypertension-related ESRD, surpassing any other racial or ethnic group (Martins et al., 2002). Nonetheless, there are effective treatments for ESRD with good outcomes.

### **Treatments for ESRD**

Dialysis therapy and kidney transplantation are necessary for survival when diagnosed with ESRD (CDC, 2014). Dialysis therapy involves the use of an artificial replacement where

blood is pumped from the body into a filtration device. This device cleans the blood by removing waste, excess fluid and toxins (USRDS, 1999). Hemodialysis is one form of dialysis treatment where the patient is connected to a machine which filters waste and water through the circulation of blood, through an artificial dialyzer also referred to as an “artificial kidney.” The cleaned blood is then pumped back into the patient’s body (Center for Medicare & Medicare Services (CMS), 2016; USRDS, 1999). Treatments are typically scheduled three times a week and could last for three to four hours (USRDS, 1999). Peritoneal dialysis is another form of dialysis treatment which requires the placement of a catheter into the abdominal cavity and is accompanied with repeated instillation and drainage of sterile dialysate (cleansing fluid which removes toxins from the bloodstream) (USRDS, 1999). Both peritoneal and hemodialysis may be performed at home after a patient and an assistant undergo weeks of training. However, hemodialysis is typically carried out in dialysis centers (USRDS, 1999). Finally, hemofiltration which is synonymous to hemodialysis, is used for emergency purposes (Ledebro, 1998). Past literature indicates that dialysis patients are more likely to be in danger of five-year mortality and tend to have a poorer quality of life as compared to patients who undergo transplantation (Waterman et al, 2006; USRDS, 2015).

Kidney transplantation is the preferred treatment option for ESRD given that it is associated with reduced mortality and morbidity relative to dialysis treatments (Patzner et al., 2009; Waterman Rodrigue, Purnell, Ladin & Boulware, 2010). The United Network for Organ Sharing (UNOS) 2012 annual data report for kidneys show ongoing improvements for transplant recipients over the last 15 years (OPTN/SRTR, 2014), including a decrease in graft failure and an increase the number of people living after receiving a transplant. As of June 2011, 164, 200 adults in the US survived with a functioning kidney graft which is about twice the rate of

survival rate ten years ago (OPTN/SRTR, 2014). There are two forms of kidney transplantation: live donor kidney transplantation and deceased donor kidney transplantation. Regardless of the route to transplantation chosen, patients risk organ rejection, lifetime use of immunosuppressant medications and surgical complications (Serur et al., 2011).

Live donor kidney transplantation (LDKT) occurs when a kidney is donated from a healthy person, usually a living family member, friend or another altruistic person (Waterman et al., 2010). LDKT is associated with higher organ survival, better renal function and shorter wait times, especially since a live donor transplantation can be arranged in three to four months (Gruessner & Benedetti, 2008; Waterman et al., 2010). Patients are less knowledgeable of LDKT, hesitant to discuss this option of transplantation with potential donors, and have concerns about the risks associated with donation, limiting the number of living donor transplants performed each year (Pradel, Mullins, Bartlett, 2003; Cabrer et al., 2003; Lunsford et al., 2006; Traino 2014).

Deceased donor transplantation, also referred to as cadaveric or posthumous transplantation, occurs after a donor's organs are procured and evaluated for transplantation, after the person is pronounced brain dead or after the person's heart is no longer beating (MacPhee & Fronek, 2012). The benefits of deceased donor transplantation include better quality of life without having to depend on a machine for survival, and it does not involve the use of a live donor.

Deceased donor transplantation requires access to a transplant wait list (Gaston et al., 2003). There has been a historic scarcity of deceased donor organs including kidneys, due to high demands and limited organs made available for transplantation. The median time for patients who were enrolled on the waitlist in 2009 was 3.6 years. In 2008, 51% of African

Americans remained on the waitlist after three years in comparison to 36% of Caucasians (USRDS, 2013, 2015). Although there are about 108, 258 renal patients on the waitlist in hopes of receiving a transplantable kidney, only 1,447 transplants have been performed this year. African American transplant recipients make up a small fraction of this number given that only 390 (26.95%) African American patients have received transplantable kidneys (OPTN, 2016).

### **Pre-transplant Medical Evaluation**

Placement on the transplant waitlist requires patients to meet certain criteria and complete numerous tests to assess transplant suitability. The medical evaluation for transplantation aims to identify contraindications that would preclude transplantation and to make rectifications where necessary in order to maximize a patient's odds of a successful transplant (Gruessner & Benedetti, 2008). The pre-transplant work up also provides an opportunity to educate the patient about the transplantation process given that the potential recipient meets and interacts with several members of the transplant team (Gruessner & Benedetti, 2008). The first part of the medical evaluation begins with consultations and interviews with a number of transplant professionals such as nephrologists, transplant coordinators, social workers although there may be a few variations depending on the transplant center (Gruessner & Benedetti, 2008; Ortiz, Manzarbeitia & Zaki 2002).

The purpose of the consultation is to gather a comprehensive history and provide a physical examination. An emphasis is placed on the etiology of the progression of the disease, the amount of time spent on dialysis, vascular access history and problems, urine production, and the occurrence of urologic issues such as neurogenic bladder (a condition which causes a person to lose control of their bladder). Additional emphasis is placed on medications and an examination of systems to detect unique extrarenal organ system complications (Ortiz et al.,

2002). Furthermore, the patient's ability to tolerate exercise as well as discussions about how previous infections may compromise the transplantation are addressed (MacPhee & Fronek, 2012). Laboratory testing, x-rays and other procedures are also performed. Some of the required tests include human leukocyte antigen (HLA; proteins found on white blood cells that help a person's immune system detect differences between healthy body tissues and foreign substances); blood typing to match a kidney to the transplant candidate; chest x-rays; coagulation screens; mammograms for women over 40 years old; and, electrocardiograms (EKG) (Gruessner & Benedetti, 2008; MacPhee & Fronek, 2012). Immunizations for Hepatitis B, influenza, and among others are updated as needed (Gruessner & Benedetti, 2008).

Psychosocial evaluations are performed where a social worker evaluates prospective candidates who are then referred to a psychologist or psychiatrist if significant psychological concerns come to light (McGrath & Rubin, 2012). Additionally, extensive laboratory, radiologic and specialty tests (e.g., endoscopy, colectomy, and liver biopsy) are performed (McGrath & Rubin, 2012). Elderly patients are presented with separate challenges since they are more likely to develop infections and malignancy may be prevalent, reducing their overall life expectancy (MacPhee & Fronek, 2012). Patients with comorbidities face additional challenges since this increases the number of tests needed to complete the evaluation (Danovitch, Cohen & Smits, 2004). After completing this process, the patient's information and tests are reviewed by a multidisciplinary team who determine whether the patient is suitable for placement on the national waitlist. The patient must also be financially cleared (Ortiz et al., 2002). The pre-transplant process could take up to a year to complete with recent studies indicating that patients have a median referral to listing time anywhere from 46 days to 226 days (Norris, 2014). Racial differences in completing the medical evaluation process are evident indicating Blacks are less



likely to complete the process or take longer to complete the process in comparison to Whites (Alexander, Ashwini & Sehgal, 1998; Patzer et al., 2012).

### **African Americans and Kidney Transplantation**

Several studies have investigated African American beliefs and health behaviors surrounding kidney transplantation. A plethora of reasons account for the problems this racial group faces in accessing renal transplantation. One major reason for the inequality in the pursuit of kidney transplantation is lower rates of organ donation among Blacks which could be influenced by several factors such as a lack of awareness, attitudes towards donation and medical mistrust (Churak, 2005; Moore, 2007; Whaley, 2001). Immunological incompatibility of deceased donor kidneys, lower rates of referral, limited access to healthcare, less desire for kidney transplantation, and socioeconomic factors such as health insurance, (see Boulware et al., 2005; Hall, Choi, Xu, O'Hare & Chertow, 2011; Held, Pualy, Bovbjerg, Newmann & Salvatierra, 1988) also influence patients' desire to seek or attain transplantation. These barriers may occur during different components of the transplantation process including the medical evaluation.

### **Organ donation among Blacks**

Blacks display lower rates of organ donation relative to other racial groups (Ariola, Perryman & Doldren, 2005; Ariola, Perryman, Doldren, Warren & Robinson, 2007; Held et al., 1988). Moore (2007) reported that when families are approached to donate organs or tissues of their death relatives, African American families are less likely to respond. OPTN data indicates that of the 767 deceased donor kidneys donated in 2016, 126 were from African Americans in comparison to 511 from Whites. Similarly, fewer living donor kidney organs were donated from African Americans (32 of 425 total organs) relative to Whites (310 out of 425) (OPTN, 2016). At

first glance these statistics may lead one to believe that African Americans are less altruistic than other racial groups, particularly Whites. However, past studies indicated that African Americans are very charitable and contribute a larger percentage of their income to charities and churches in comparison to Caucasians (Moore, 2007). This suggests that other factors may account for the low organ donation rates among Blacks. The difference in organ donation could be attributed to lack of knowledge about the need for organs, attitudes and distrust of the medical system, concerns about the fairness of the allocation system, religious beliefs including certain misconceptions and socioeconomic factors such as problems with insurance. These reduced donation rates could contribute to the health disparities in obtaining kidney transplants (Ariola et al., 2005).

Many Blacks are unaware of the growing need for renal organs in the African American community. Blacks are also less likely to know someone who has donated an organ or signed up to become a donor (see Churak, 2005; Joshi et al., 2012). Moore (2007) highlighted the importance of increasing awareness of the need for organs in the African American community given that the lack of awareness places African Americans at a disadvantage for life saving treatments. Results from study of 311 African American adults whose attitudes towards organ donation were examined indicated that people who engaged in family discussions about donation were more knowledgeable of organ donation and had more favorable attitudes towards donation (Morgan, 2004). This suggests that one reason for the low rates of donation among African Americans is a lack of awareness of the need. Therefore, increasing awareness among this population could result in better donation rates.

A number of common misconceptions about donation could also account for the disparities in donation among Blacks and Whites. For example, many Blacks believe that signing the donor

card would result in reduced medical care and an early declaration of death without provision of all the medical help available (Ariola et al., 2005). This could be a result of a general distrust of the medical community. Mistrust of the medical system and health care professionals by Blacks may be attributed to the historical exploitation of Blacks such as the sterilization of African American women and abuse during hospitalization (Churak, 2005). One of the most popular examples of the exploitation of Blacks is during the Tuskegee Syphilis study in which researchers funded by the federal government withheld treatment from the African American male participants (Boulware, Cooper, Ratner, Laveist & Powe, 2003). Consequently, African Americans who are aware of historic events of discrimination and/or have personal accounts of exploitation in the healthcare system are more likely to be wary of the medical community (Corbie-Smith, Thomas, Williams & Moody-Ayers, 1997). Previous studies found out that Blacks who are suspicious of Whites may terminate psychotherapy because they think they will be seen by a White counselor, and they perceive the healthcare facility to be governed by Whites (Terrell & Terrell, 1984). Many Blacks do not trust that doctors have their best interests in mind and as a result avoid routine checkups (Churak 2005; Moore, 2007). Terrell and colleagues (2004) found that Blacks who are suspicious of Whites are less willing to consent to either donating their own organs or agreeing to the recovery of organs from relatives (Terrell, Mosley, Terrell & Nickerson, 2004). An analogous study found that Blacks who were distrustful of hospitals and had concerns about discrimination explained some of the variability in willingness to donate (Boulware et al., 2002). This distrust of the medical system is likely to impede access to kidney transplantation since African Americans may believe doctors do not have their best interest in mind. Hence, they may be hesitant to complete the pre-transplant work up since this

would mean more interactions with doctors and with an increasingly complex and confusing healthcare system.

### **Factors that impact access to kidney donation**

Organ allocation and matching also have roles in African American views on kidney transplantation. Some African Americans are skeptical about donation due to apprehensions about race and class-based inequalities in the distribution of organs (Ariola et al., 2005) which could be a result of the uncertainty that the health care system is working in their favor. The current allocation system gives priority to people in the same geographic region versus those most in need. Posthumous transplantation generally favors patients living in closest proximity to the transplant center, which suggests that waitlisted candidates living farthest from transplant centers are less likely to receive a transplant (Axelrod et al., 2010). Universal criteria for candidate selection have yet to be established hence, individual transplant centers create their own medical criteria. This increases the chances that a patient who is listed at one center may be regarded as less critical at another center with more rigorous medical criteria (Moore, 2007).

Biological factors such as immunological incompatibility also result in lower rates of kidney transplantation among Blacks (Boulware et al., 2005). Organ allocation practices take into consideration certain biological characteristics of both the recipient and the donor to enhance graft survival. Differences in the expression of HLA antigens are more likely to occur among people with different racial backgrounds. Therefore, the organ allocation system attempts to match patient recipients to donors with similar expressions of HLA antigens (i.e., the same racial and ethnic background). Although this practice is less emphasized in recent years due to the introduction of improved immunosuppressants, recipients and donors must still possess significant biological similarities. Therefore, since most of the transplantable kidneys available

are from White donors, this reduces matching rates for Blacks (Churak, 2005; Joshi et al., 2012). Racial differences in ABO blood type indicate that African Americans are more likely to have blood type O which places them at a disadvantage since this blood type has a reduced likelihood of kidney transplantation according to UNOS requirements for ABO identity between donor and recipient (Churak, 2005), resulting in longer wait times. OPTN data shows that between 2003-2004, the median wait time for African Americans waiting for a kidney was about 1831 days (5 years). This varied for Whites who had a median wait time of 1310 days (3.5years) (OPTN, 2016). Arguably, knowledge of the potential drawbacks to procuring a transplantable organ based on an individual's racial status may prevent Blacks from pursuing transplantation as a treatment option, and prevent people from donating their kidneys.

Religious beliefs regarding the desecration of the body and a desire to keep the human body in good condition for the afterlife also impact African Americans' attitudes toward organ donation (Ariola et al., 2005; Held et al., 1988). This belief system could be attributed to Judeo-Christian religious attitudes which state that the body must be kept whole on judgment day (Moore, 2007). Boulware and colleagues (2002) found that spirituality and religion accounted for most of the difference observed in willingness to donate for Black men and women relative to Whites (Boulware et al., 2002). A qualitative study by Thompson (1993) revealed that many African Americans believe they need their organs for resurrection in order to bring their death to completion, although participants noted that religious beliefs did not have an impact on their decision to donate. Some African Americans continue to hold certain religious misconceptions about donation although all major religions such as Christians, Amish, Buddhism and Hinduism support and encourage organ donation (Gallagher, 1998). Some researchers advocate for the inclusion of the clergy and utilization of altruistic values in Christian beliefs to promote donation

(Ariola et al., 2005; Boulware et al., 2002). The impact of religious beliefs is substantial to Blacks' ability to pursue transplantation and serves as another barrier to organ donation and the procurement of transplantable kidneys.

Socioeconomic factors such as income, education and insurance status affect transplantation accessibility. These factors impact the distribution of wealth, power and opportunities among people (see Churak, 2005; Joshi et al., 2012), making it difficult for some people to access the best services and treatment. Patients who are listed on the transplant waitlist tend to be well-educated, employed and have health insurance particularly private insurance (Churak 2005; Coorey, Paykin, Singleton & Gaston 2009; Joshi et al., 2012; Soucie, Neylan & McClean, 1992). Income alters treatments choices given that patients with more money can seek superior treatments including specialty services, and have better access to transportation (Axelrod et al., 2010; Held et al., 1988). People from low socioeconomic backgrounds, many of whom are Black, tend to be less educated and thus have less awareness of the benefits of renal transplantation (Naveneethn & Singh, 2006). Subsequently, these patients may exhibit poor medical compliance (Naveneethn & Singh, 2006), further reducing their likelihood of seeking transplantation. ESRD patients without insurance or with limited insurance show a reduced likelihood of maintaining doctors' appointments since they may have concerns about costs and payments (Churak, 2005). Some research suggests that African Americans are in favor of financial reimbursement for deceased donor's funeral expenses, cash payments to deceased donor's families or estates, cash payments to deceased donor's charity of choice, tax breaks for deceased donor's families, and reimbursement of deceased medical expenses after adjustments, among other compensations. Nonetheless, these public incentives have been debated with strongly voiced objections to such compensations (Boulware, Troll, Wang & Powe, 2006).

It is apparent that kidney transplantation for African Americans is influenced by a myriad of factors which may affect their beliefs about donation, their knowledge of transplantation and their ability to obtain transplantable organs. Nonetheless, should ESRD patients decide to seek a medical evaluation, it is necessary to understand the factors that may facilitate or impede their success.

### **Factors that positively impact completion of the medical evaluation for kidney transplantation**

Weng and colleagues (2005) proposed that social networks could improve pre-transplant work up completion rates since patients with previous knowledge about transplantation facilitated by their family and/or friends, may be prone to perceive transplantation as a viable treatment option. In a study of both patient attendees and non-attendees of the initial visit for a medical evaluation, Dageforde and colleagues (2015) found a relationship between attendance and patient's reported knowledge of transplantation. Churak (2005) advocated for increasing patient social networks among African Americans to become more heterogeneous since this could increase access to information about the benefits of kidney transplantation. Consequently, this could propel Black ESRD patients to complete the evaluation process.

According to Clark, Hicks, Keogh, Epstein and Ayanian (2008), the medical evaluation can be difficult to finish when a patient has clinical and social problems. As their study revealed, increases in levels of instrumental support networks was connected to better completion rates among Black women, after examining Black and White ESRD patients who had started dialysis in four regional networks. The authors recommend the use of instrumental social support to assist with tasks such as cooking, cleaning, scheduling appointments, navigating health care systems, and child care in order to help patients pursue and complete diagnostic evaluations

(Clark et al., 2008). Supplemental private insurance was noted as a possible motivator for completing pre-transplant work ups among Black men (Clark et al., 2008). Garg and colleagues (2001) further advocated for an intervention which targets young Black men to reduce the disparity in transplant activation. This is because young Black men are less likely to be listed for a transplantable organ although they have a better chance of survival because they may have fewer health problems aside from renal disease (Garg, Diener-West & Powe, 2001).

Support from physicians and healthcare professionals can be advantageous to Blacks completing the medical evaluation. Black patients were more likely to complete the medical evaluation when their physicians appeared to be invested in their care and expressed a preference for transplantation (Clark et al., 2008). Other recommendations for improving kidney transplantation access include minority education about renal disease, post-secondary education, media promotion, emotional support and counseling, more diverse clinicians, and ongoing encouragement during the transplant process (Churak, 2005; Moore, 2007).

Navigators, health care providers who educate patients and guide them through the medical system, can also be helpful in assisting ESRD patients through the medical evaluation process (Sullivan et al., 2012). A study which implemented an intervention with navigators reported that patients completed the transplant steps faster than the control group without navigators (Sullivan et al., 2012). This shows the potential of faster pre-transplant work up completion when patients are educated and supported throughout the process. Additionally, social networking websites have been found to be useful for helping kidney patients provide information about transplantation and solicit living donors (Chang, Anderson, Turner, Shoham, Hou & Grams, 2013). The literature provides some suggestions and presents minimal study findings regarding the factors which facilitate the completion of the medical evaluation



suggesting that this is an area for more research. See Table 1 for a compiled list of proposed factors that positively impact patients' completion of the medical evaluation for transplantation.

Table 1  
*Facilitators of Medical Evaluation Completion*

<b>Factor</b>	<b>Study</b>
Accessible or free transportation	Churak, 2005
Diverse clinicians	Churak, 2005
Education of minority groups about renal disease	Churak, 2005
Emotional support and counseling	Churak, 2005
Knowledge about transplantation	Dageforde et al., 2015
Instrumental support with tasks such as cooking and cleaning	Clark et al., 2008
Interventions targeted towards Black men	Garg et al., 2001
Media promotion	Moore, 2007
Navigators	Sullivan et al., 2012
Physician investment	Clark et al., 2008
Private insurance	Clark et al., 2008
Post-secondary education	Moore, 2007
Social networks to facilitate knowledge about transplantation	Churak, 2005; Weng et al., 2005
Social networking websites	Chang et al., 2013

## **Factors that negatively impact completion of the medical evaluation for kidney transplantation**

Patient-related elements like socioeconomic status (i.e.; unemployment, lack of health insurance, poverty), comorbid illnesses which in turn increase the number of tests a person has to undergo during the evaluation, and beliefs about transplantation delay the completion of the pre-transplant workup (Danovitch et al., 2004; Navaneethn & Singh, 2006; Weng et al., 2005). A study by Weng and colleagues (2005) examined rates of completion of 175 patients who were undergoing the pre-transplant work up for a kidney transplantation. Findings indicated that Blacks were less likely to complete the medical evaluation; failure to complete the process was associated with more comorbidities, which likely slowed the process due to the additional medical tests needed to confirm candidacy. Synonymous findings were reported by Danovich and colleagues (2004) who found that patients with more complex illnesses had prolonged or incomplete workups. Patients who first heard about transplantation from their nurses or doctors reported a reduced likelihood in completion of their pre-transplant work up. Weng and colleagues (2005) attributed this to patients' lack of close relations to educate them about transplantation (Weng et al., 2005). Thus, the lack of prior knowledge about the medical evaluation for transplantation serves as a barrier to completing the process.

Another study examining 2,291 patients referred for medical evaluation (1,486 Blacks and 805 Whites) reported higher rates of incompleteness of the requirements for evaluation among Blacks relative to Whites (45.7 vs 17.9) (Patzner et al. 2012). Blacks in this study were less likely to have health insurance and more likely to live in poor neighborhoods. Socioeconomic factors such as insurance, education, employment, distance, neighborhood poverty and degree of rurality accounted for some of the variability in completing several transplant steps such as starting

evaluation, completing evaluation and being waitlisted. Indeed, patients with higher socioeconomic status progressed faster through the transplant steps (Patzner et al. 2012). In contrast, patients with low SES often delay seeking medical care and specialty services which results in delayed referrals to regional transplant centers, evaluations, and enrollment on the waitlist (Axelrod et al., 2010). Patients who initiate the medical evaluation for kidney transplantation report concerns related to finding a living donor, and concerns about the cost of the medical evaluation, transplant operation, transportation and medications. Furthermore, those who are listed at other transplant centers may be less compelled to complete their evaluation due to transportation difficulties (Dageforde et al., 2015). These findings provide support for the impact of socioeconomic factors in the completion of the pre-transplant work up.

Other patient-related factors also affect the completion of the medical evaluation. Distance from the transplant center is another factor that has been discussed in the literature and shown to delay the medical evaluation process. Blacks living in rural areas are inclined to experience transportation problems in their attempts to get to the transplant center, impeding placement on the waitlist (Danovich et al. 2004; O'Hare, Johansen & Rodriguez, 2006). Dialysis status could also reduce a patient's ability to complete the pre-transplant work up since dialysis patients may be less motivated to seek transplantation. This could be attributed to a number of reasons such as feeling sick after using the dialysis machine and patient's perception that he or she is functioning well on dialysis. Hospitalizations and the navigation of complications associated with dialysis therapy could also hinder progression through the medical evaluation (Weng et al., 2005). Furthermore, extended dialysis use makes it harder to have a successful transplant given that it increases the patient's susceptibility to other illnesses and poor physical health, reducing the chances of receiving a transplantable kidney. Consequently, since the

majority of Black ESRD patients are on dialysis, this reduces their ability to finish the pre-transplant work (Weng et al., 2005). Also, findings from Clark and colleagues (2008) show that renal patients who perceive the dialysis and patient support staff as important to their treatment are less likely to complete pre-transplant workup (Clark et al., 2008). It is possible that these patients wish to maintain the relationship they have with the dialysis staff and are thus reluctant to pursue transplantation since dialysis becomes a part of their socialization. Blacks are less likely to recognize potential benefits of transplantation, less likely to be referred, and are referred later than Whites, increasing the likelihood that they have already initiated dialysis therapy before considering transplantation as a treatment option (Alexander et al., 1998; Rodrigue, Cornell, Kaplan & Howard, 2008). Therefore, it is critically important that the patients who present at a transplant center for evaluation complete the pre-transplant work up to get listed.

Healthcare-related barriers linked to medical evaluation completion revolve around racial discrimination and difficulties in the physician-patient relationship. Reports of racial discrimination by African American patients reduces their desire to seek transplantation given that they have to go to unfamiliar healthcare settings (Klassen, Hall, Saksvig, Curbow & Klassen, 2002). Victims of discrimination anticipate poorer outcomes and expect to be treated poorly which makes them reluctant to access new treatment settings. According to Klassen et al., (2002), most African Americans report more positive racial relationships in dialysis centers which reduces their desire to seek new treatment facilities.

The role of the physician is very important in motivating patients to pursue transplantation. Doctors are less likely to provide Blacks with information about transplantation relative to White patients (Kasiske, London & Ellison, 1998; Joshi et al., 2012). Healthcare professionals may consciously or unconsciously discriminate against disadvantaged people,

many of whom are African American and turn out to be medically non-adherent, resulting in barriers to placement on the waitlist (Kasiske, London & Ellison, 1998). Blacks are prone to remain on the waitlist for long periods of time and have a reduced likelihood of receiving an organ in comparison to Whites (Callender & Miles, 2004). Hence, Black patients with an awareness of their reduced chances of obtaining a kidney transplant could be deterred from completing the medical evaluation.

Lower referral rates impact the initiation of the pre-transplant work up, creating problems for African Americans seeking renal transplantation (Alexander & Sehgal, 1999; Joshi et al., 2012). This could be attributed to factors such as less interest in transplantation and physicians' beliefs about transplantation (Alexander & Sehgal, 1999; Ayanian et al., 2004). Doctors may be less likely to view transplantation as a superior treatment for Black ESRD patients in comparison to Whites, although they perceive transplantation to improve the quality of life for ESRD patients over dialysis therapy (Ayanian et al., 2004). In cases where nephrologists practiced in two or more dialysis facilities, Blacks reported receiving less information or no information about transplantation than Whites (Ayanian et al., 2004). Reports indicate that Blacks have better outcomes on dialysis, which could lead to the misconception that kidney transplantation may not be appropriate or not needed for them (Churak, 2005). Health literacy, a concept used to explain a patient's capacity to navigate the health care system either by understanding medical terminology or services in order to make informed decisions about one's health, has been linked to the accessibility of kidney transplantation (Grubbs, Gregorich, Perez-Stable & Hsu, 2009). Low health literacy has been shown to produce poorer health outcomes and health care consumption. A study by Grubbs and colleagues (2009) indicated that inadequate health literacy was associated with lower rates of referrals among 45 Black patients and 17 White patients

receiving hemodialysis (Grubbs et al., 2009). Taken together, past research indicates several barriers in accessing transplantation among African Americans. Refer to Table 2 for a compiled list of factors that negatively impact the completion of the medical evaluation.

Table 2  
*Impediments to Medical Evaluation Completion*

<b>Factor</b>	<b>Study</b>
Being listed at different transplant centers	Dageforde et al., 2015
Comorbidity which results in additional testing	Danovich et al., 2004; Weng et al., 2005
Concerns about finding a living donor	Dageforde et al., 2015
Dialysis status	Weng et al., 2005
Dialysis center as main form of social support	Clark et al., 2008
Distance from the transplant center	Danovich et al., 2004; O'Hare et al., 2006
First knowledge of transplantation from nurses or doctors	Weng et al., 2005
Lack of health insurance	Patzer et al., 2012
Late referrals or fewer referrals from doctors	Alexander & Sehgal, 1999; Joshi et al., 2012; Rodrigue et al., 2008
Less knowledge about the potential benefits of transplantation	Alexander & Sehgal, 1999
Limited health literacy	Grubbs et al., 2009
Low SES	Axelrod et al., 2010; Navaneethn & Singh, 2006; Patzer et al. 2012

Physician beliefs about transplantation	Ayanian et al., 2004
Reports of racial discrimination	Kassike et al., 1998; Klassen et al., 2002

**Theoretical Framework**

The Health Beliefs Model was used as a guide in understanding factors that impact kidney patients’ completion of the medical evaluation process. Developed in the 1950s, the Health Beliefs Model was used to explain the utilization of health services. The model proposes that an individual would be more likely to use health promotion strategies to avoid or manage a disease based on the person’s perception of their susceptibility and the severity of the disease. Additionally, the individual is more likely to engage in efforts to avoid or reduce the severity of the disease assuming these strategies are useful and not accompanied with barriers such as costs, convenience and pain (Rosenstock, 1974). Variations in perceived susceptibility of a disease or illness may range from complete denial to perceiving the illness as a serious threat to the individual’s physical health. An individual’s perception of the severity of an illness may be determined by both psychological and physical consequences of the illness. For example, concerns that the illness may be deadly and/or cause psychological impairment or negatively impact the individual’s social functioning. Accepting one’s susceptibility to an illness may promote taking action to prevent or manage the disease which is in turn influenced by the individual’s perception of the costs and benefits associated with taking that action. Hence, the individual is more likely to engage in preventive health behaviors or treatment when susceptibility or the severity of the illness can be reduced. Psychosocial and economic factors such as the impact on the family unit, personal motivation, level of psychological distress, and expenses also play a role in whether the individual chooses to engage in the health behavior.

Internal or external cues to action (e.g., personal realization of the individual's health status, education about the illness, family encouragement to engage in health behavior) may further propel the person to engage in the health behavior (Rosenstock, 1974). Specific to kidney transplantation, patients' decision to complete the medical evaluation may be influenced by perceptions of susceptibility to more adverse outcomes such as death, either from stay on prolonged dialysis or from the surgical procedure for transplantation, and the severity of their illness (e.g., some patients' health may have significantly deteriorated due to prolonged dialysis use or due to other comorbidities). Additionally, patients may base their decision to complete the evaluation process on the costs and benefits of transplantation. For example, patients who rely on dialysis centers as their main source of support may be less inclined to complete the medical evaluation process; whereas those who see the adverse effects of prolonged dialysis use may be more inclined to finish the process. Further, cues to action such as education about the benefits of kidney transplantation may encourage some patients to complete their evaluation. Figure 1 provides a representation of how this model may be used to understand factors that impact completion of the medical evaluation.



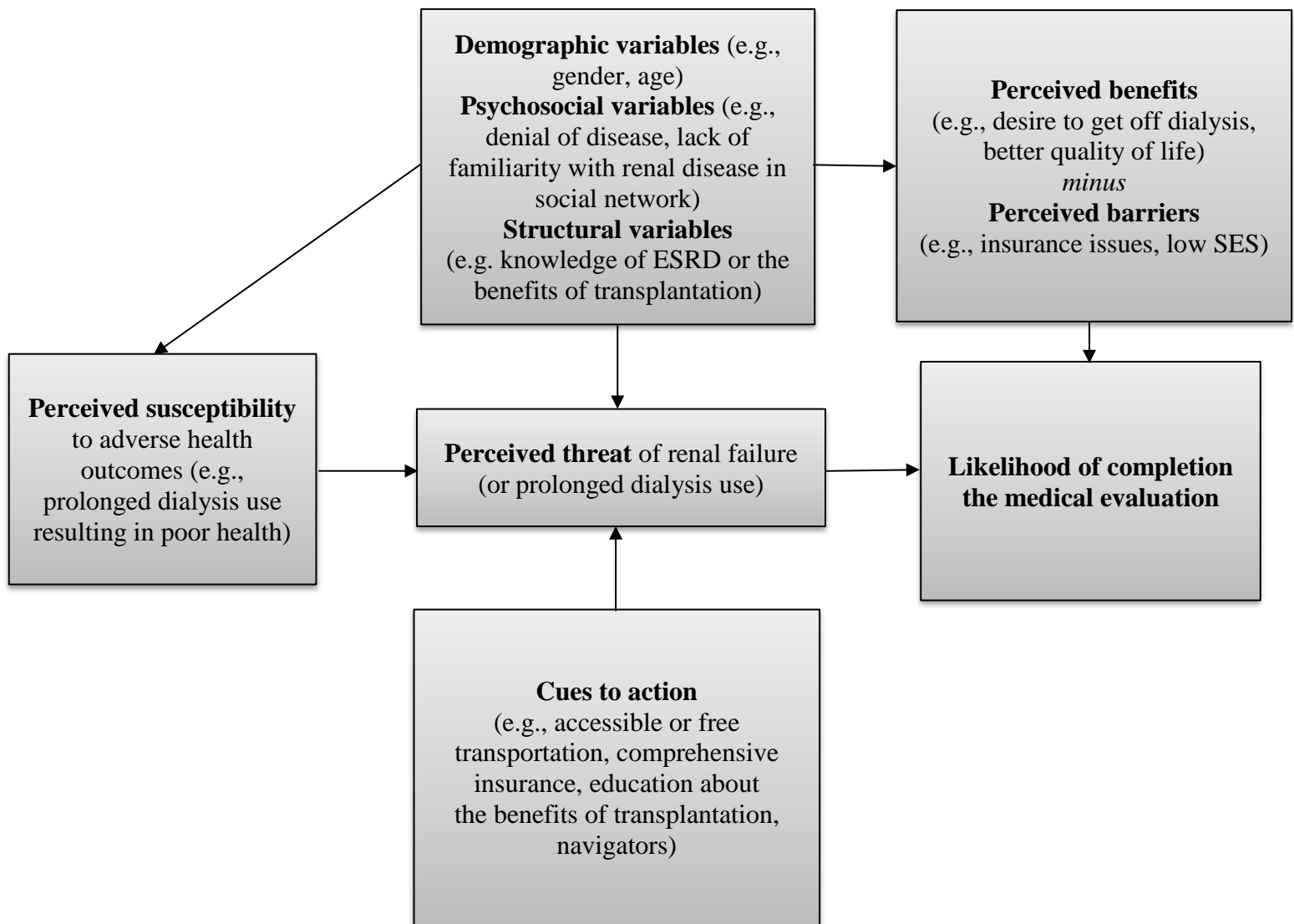


Figure 1. Hypothetical demonstration of the Health Beliefs Model to understand factors that are likely to impact completion of the medical evaluation for kidney transplantation.

### Statement of Problem

As revealed in the discussion above, past research highlights a variety of factors that impact African American ESRD patients’ ability to access kidney transplantation. However, there is no clear consensus as to which factors facilitate and hinder the pre-transplant work up in order to have patients registered on the transplant waitlist. Thus, further investigation is

warranted regarding the pre-transplant work up process in order to help reduce disparities in access to transplantation.

This study explored the views of transplant professionals and ESRD patients regarding barriers and facilitators to completion of the medical evaluation for kidney transplantation. The purpose of this study was to determine specific factors that predict completion of the medical evaluation by identifying the most significant barriers and motivators. The findings may provide insight that could lead to systemic changes to improve rates of completion of the medical evaluation process for African Americans. Subsequently, understanding barriers and motivators to completing the medical evaluation will serve to fulfil the needs of patients, in order to reduce health disparities between African Americans and other racial groups. Recent studies have assessed physician beliefs about transplantation accessibility but no study to date has assessed transplant professionals' views of the factors that impact the completion of the medical evaluation. This study sought to extend the literature by providing a comprehensive view on the medical evaluation process by examining African American ESRD patients and different transplant professionals such as nephrologists, transplant coordinators and social workers, all of whom are integral to the completion of the pre-transplant work up. This will provide a thorough understanding of the facilitators and barriers to initiating and completing the pre-transplant work up. The use of a mixed methods approach serves to shed light on this phenomenon as the qualitative and quantitative approaches complement each other, and provide a detailed portrait of the most important factors impacting completion of the medical evaluation for Black ESRD patients.

## **Study Aims**

The present study sought to identify the factors that impact the completion of the medical evaluation process for kidney transplantation among African American ESRD patients. It is guided by the following overarching questions:

1. What factors facilitate and impede the initiation and completion of the medical evaluation process for kidney transplantation?
2. What are the most significant factors to initiating and completing the medical evaluation process?

**Aim 1:** To identify barriers and motivators to completing the evaluation process as perceived by transplant professionals.

Research Question (RQ) 1: What are the barriers to renal patients' completion of transplant evaluations as perceived by transplant professionals (e.g., nephrologists, coordinators, social workers)?

RQ 2: What factors motivate patients to complete the transplant evaluation process as perceived by transplant professionals (e.g., nephrologists, coordinators, social workers)?

RQ3: Are there differences in perceptions of the motivators and barriers by transplant professionals (e.g. differences between nephrologists, coordinators and social workers)?

**Aim 2:** To identify the most significant barriers and motivators to completing the transplant evaluation process as perceived by ESRD patients by incorporating the list of barriers and motivators solicited by the transplant professionals

RQ 4: What barriers do patients cite as impediments to completing the evaluation for transplantation?

RQ 5: What factors facilitate patients' completion of transplantation evaluations?

RQ 6: How do patients rank the barriers to completing the medical evaluation for transplantation?

RQ 7: How do patients rank the motivators to completing the medical evaluation for transplantation?

**Aim 3:** To identify differences in perceptions of the factors that impact the completion of the medical evaluation process as determined by patients and transplant professionals.

RQ 8: How do rankings differ between patients who have completed the process (Status 1 and/or 2) and patients who have not (Status 7)?

RQ 9: How do rankings differ between patients and transplant professionals?

### **Method**

This study applied a mixed-methods design to examine factors associated with completion of the medical evaluation process for kidney transplantation. The two phases of the proposed study utilize both qualitative and quantitative data collection methods through the use of focus groups with a nominal group technique (NGT) and semi-structured interviews, as well as survey data with participant ratings. All phases of the study were approved by the Institutional Review Board (IRB) at Virginia Commonwealth University (# HM20001313).

### **Phase I**

#### **Participants**

The first phase of the study consisted of semi-structured interviews with a stratified purposeful sample of transplant professionals ( $N = 23$ ). Purposeful sampling aims to gather information rich cases for a thorough examination of a phenomenon (Patton, 1990). Specifically, stratified purposeful sampling helps illustrate the characteristics of particular subgroups and creates an avenue for making group comparisons (Patton, 1990). Participants consisted of

nephrologists ( $n = 6$ ), transplant coordinators ( $n = 8$ ), social workers ( $n = 6$ ), psychologists ( $n = 2$ ), and a transplant nurse practitioner ( $n = 1$ ). The majority of transplant professionals were female ( $n=16$ ; 69.6%) self-identifying as Asian (8.7%), Black/African American (13.0%), and the majority as White (78.3%). On average, these professionals had 10.24 ( $SD = 8.65$ ) years' experience working with transplant patients undergoing the medical evaluation process. The majority of these professionals had a medical degree (34.8%) or master's degree (34.8%), and the rest had some graduate training (4.3%) or a bachelor's degree (26.1%).

### **Procedure**

Participants were recruited from nine transplant centers in the Mid-Atlantic, Mid-Western and Southeastern regions of the United States. They were invited to participate in the study via phone or email correspondence, listservs, letters and through word of mouth or snowballing techniques (e.g., other transplant professionals informing potential participants about the study). Data collection took place over a five-month period from September 2014 to January 2015. Semi-structured interviews were used for data collection. The interviews were digitally audio-recorded and lasted approximately 60 minutes; all interviews were conducted by the principal investigator, a middle-age Black woman in a private room. At the beginning of each interview, participants were provided with information about the structure of the interview and verbal informed consent was obtained from all participants before recording the interview. Nine interviews were conducted in person and 14 were held via telephone to maximize enrollment in the study. Additionally, participants were asked to complete a survey capturing demographic information and questions assessing participants' ratings of factors that impact the medical evaluation process. Participants were compensated with a \$5 Starbucks gift card as gratitude for participating in the study.

## **Semi-structured Interviews**

Semi-structured interviews allow for the collection of comprehensive information about participants' perceptions of the factors associated with completion of the medical evaluation process. This form of data collection facilitates the expression of thoughts, feelings and attitudes in a private setting. Semi-structured interviews usually consist of observations of behavioral patterns, casual and unstructured interviewing. Open-ended questions provide some structure and also allow for gathering different ways of perceiving the topic discussed (Cohen & Crabtree, 2006). Some of the questions included in interview are: 1) How long does it take the average patient to complete the evaluation process? 2) What individual-level factors impede patients' completion of the evaluation process? 3) What would you recommend to help African American patients, specifically, complete the medical evaluation process and reduce disparities in this aspect of transplantation? (Refer to Appendix A for a complete description of the questions). The semi-structured interview was initially pilot tested by the principal investigator and her supervisor (HMT) prior to recruitment. The structure of the protocol and some of the initial questions were edited after the pilot test and feedback received from the first four participants. The addition of several open-ended questions and probes helped ensure a thorough examination of the issue. The information gathered on barriers and motivators to completing the medical evaluation process was incorporated into the second phase of the study.

## **Quantitative Measures**

In addition to the interviews, participants were asked to complete a brief quantitative survey (paper or online version via SurveyMonkey.com). The survey was designed to elicit ratings of the potential barriers and motivators to patients' completion of the medical evaluation

process as identified in the extant literature. A copy of the survey is provided in Appendix B and the specific measures included are described below.

**Perceived barriers.** Ten 7-point Likert-type questions were used to assess perceived barriers to completing the medical evaluation process. Specifically, respondents were asked to indicate the extent to which each potential barrier impacted patients' completion of the medical evaluation along a 7-point scale (1-*Not at all* /7-*Strongly impacts*). These questions were developed for this study and informed by the past literature on proposed barriers to completing the medical evaluation process. Individual items were summed to create a global measure of perceived barriers (Cronbach's alpha ( $\alpha$ ) = 0.84).

**Perceived motivators.** Two 7-point Likert-type questions, informed by the past literature on proposed motivators to completing the medical evaluation process were used to assess transplant professionals' perceptions of their impact on the medical evaluation process (1-*Not at all*/7-*Extremely positive impact*). The first question measured *navigators* as a motivator for completing the medical evaluation process (i.e. how much would navigators impact an African American patient's ability to complete the medical evaluation process?) and the second question measured *instrumental support* (i.e. how much would instrumental support impact an African American patient's ability to complete the medical evaluation process?).

**Demographic information.** Demographic information was also collected (e.g., years of education, racial/ethnic background and type of occupation).

## Phase II

### Participants

The second phase of the study consisted of purposeful sample of African American renal patients ( $N = 30$ ). Patients who have completed the medical evaluation process are assigned a

status of 1 or 2. Status 1 patients have been cleared for a transplant, and could receive a call for a transplantable kidney at any time. Status 2 patients have also been cleared but their need for an organ may not be as urgent as a Status 1 patient. Status 7 patients are those who have not completed the pre-transplant work up or those who have been added to the transplant list but are not yet cleared due to medical, financial or psychosocial reasons (Pham, Pham, Pham, Pham & Pam, 2011). To secure a full understanding of the motivators and barriers, ESRD patients with a Status 1 assignment ( $n = 10$ ) and Status 7 patients ( $n = 20$ ) who had not completed the pre-transplant workup at the time of enrollment were recruited. The study sought to recruit equal numbers of patients who had completed the medical evaluation and those who had not. However, recruitment yielded more Status 7 patients, which is preferred given that one of the main goals of the study is to identify barriers to completing the medical evaluation process.

Participants consisted of Black/African Americans (100%) with 21 (70%) men and 9 women (30%) and a mean age of 49.79 ( $SD = 8.57$ ). The majority of patients were single (33.3%) or married/cohabited (33.3%) and the remaining were divorced (23.3%), separated (3.3%) or widowed (6.7%). Participants' identified their religious affiliation as Protestant (60%), Catholic (13.3%), Other (13.3%, including people who identified as non-denominational and Jehovah's witness), and four patients did not report a religious affiliation (13.3%). Twelve patients (40%) had a high school education or less and another twelve patients (40%) had an Associate's degree or some college. Six patients had a Bachelor's degree (10%) or some graduate training/Master's degree (10%). Most of the patients (53.3%) had an annual household income of less than \$20,000, eight patients had an annual household income of less than \$40,000, two reported that their household income was less than \$60,000 and the rest (10%) had an income of \$60,000 or more. One person did not report their income.



## Procedure

Participants were recruited from one Mid-Atlantic transplant center in the United States from which the principal investigator obtained a list of African American patients who had either completed the medical evaluation or were in the process of doing so. Potential participants were mailed a letter inviting participation in the study. They were then contacted via telephone to solicit questions and invite participation; patients expressing interest were scheduled to attend one 90-minute focus group interview. Data collection took place over a ten-month period from March 2015 to December 2015. Refer to Figure 1 for a complete description of the data collection methods by study phase.

Due to the high no-show rate, both in-person semi-structured interviews ( $n = 8$ ) and focus groups ( $n = 22$ ) were used for data collection. For example, five patients would be scheduled for a focus group and one patient would show up. Consequently, semi-structured interviews were conducted in place of a focus group when there was only one patient present. The focus group moderator's guide was initially pilot tested by the principal investigator and research assistants prior to recruitment. The focus groups (or semi-structured interviews) were conducted in a private room conference (with a whiteboard) located in an office building of a local university. The focus groups were digitally audio-recorded and lasted between one to two hours (semi-structured interviews last about thirty); all interviews were moderated by the principal investigator (PI), a middle-age Black woman and co-moderated by a research assistant, who made observations and took notes. The racial/ ethnic backgrounds of the co-moderators (research assistants) included Asian ( $n = 1$ ), Black/African American ( $n = 3$ ), Hispanic ( $n = 1$ ) and White ( $n = 2$ ). At the beginning of each focus group interview, participants were provided with focus group guidelines (e.g. confidentiality and use of first names only or pseudonyms; Appendices C & D).

A total of nine focus groups were conducted that ranged in size from two to four participants; three ( $n = 2$ ), two ( $n = 3$ ), one ( $n = 4$ ) Status 7, and three ( $n = 2$ ) Status 1.

The last two questions of the focus group applied a nominal group technique which required participants to rate the most significant barriers and motivators to completing the medical evaluation individually and together as a group. Patients were given the option to incorporate information gathered from transplant professionals from phase I (i.e. a list of barriers and motivators) before finalizing their group rankings. At the end of each focus group or semi-structured interview, participants were asked to complete a paper survey which included demographic information and questions assessing participants' ratings of factors that impact the medical evaluation process (See Appendix E). Light refreshments were provided during each session, and participants were compensated with a \$20 visa gift card as gratitude for their participation.

<b>Phase One</b> (Transplant professionals)	<b>Phase Two</b> (ESRD patients)	
Semi-structured interviews ( $N = 23$ )	Focus groups with ESRD patients ( $N = 30$ )	
Nephrologists, Coordinators, Social workers ( $n = 6$ )                      ( $n = 8$ )                      ( $n = 6$ )  Psychologists, Transplant Nurse Practitioner ( $n = 2$ )    ( $n = 1$ )	Status 1 / 2 ( $n = 10$ )	Status 7 ( $n = 20$ )

Figure 2. Data Collection by Phase

### **Focus group with Nominal group technique (NGT)**

Focus groups are a data collection technique that facilitate group interaction (Ashbury, 1995). A highly structured focus group with a nominal group technique (NGT) was used to gather information about the phenomenon under investigation (Morton, Tong, Webster, Snelling & Howard, 2011). Focus groups with an application of a nominal group technique (NGT) employ a group process in which members work independently within the presence of others to yield quantitative data that are then explained by the qualitative component (Delp, Thesen, Motiwalla & Seshardi, 1977). Subsequently, group members interact with each other to discuss ideas generated throughout the process. Finally, participants weigh the ideas generated against others, and rank-order the items on a scale of importance (Delp et al., 1977). NGTs allow for the solicitation of views from interviewees, and provide a means of gathering information from each group member on predetermined questions. Additionally, it provides two forms of output; a list of items relevant to the topic (for this study the output will be factors that are associated with the completion of the medical evaluation), and quantified individual and collective measures of the items identified (Delamere, Wankel & Hinch, 2001). The qualitative data generated provides a rationale for why participants rank certain items as being most and least important (Corner et al., 2007). Developed by Van de Vaen and Delbecq (1972), NGTs prevent interviewees from tailoring their answers to the interviewer's nonverbal responses (Porter, 2013). This technique facilitates the prioritization of ideas (Harvey & Holmes, 2012) which in this study would be ranking the factors with the greatest impact on patients' completion of the medical evaluation process.

In a typical focus group with NGT, the moderator poses a question to the group and each member writes down as many ideas as possible. The moderator asks each group to share the

ideas generated, which is written on a flip chart for all group members to see. Discussions do not occur until each member has shared their ideas. The ideas generated are then discussed together and as a group. Finally, group members prioritize the most important items or ideas. The outcome is a mathematical cumulative of individual member preferences to provide group rankings (Delp et al., 1977). Modified from the NGT used by Corner and colleagues (2007), the focus group interviews conducted in the current study began with introductory questions and transition questions, before key questions were asked using the nominal group technique (Corner et al., 2007).

NGTs have been applied in health research and have been used to identify areas of priority in research (Corner et al., 2007). This technique has been used in several studies by the National Institutes of Health (NIH) since 1977 to gather information on different health related topics (Fink, Kosecoff, Chassin & Brook, 1984). NGTs have also been applied to research in educational settings, social service and government organizations (Fink et al., 1984). Morton and colleagues (2011) used the NGT as a mixed methods approach to gather characteristics of dialysis important to patients and family caregivers (Morton et al., 2011).

For example, Status 1 patients were asked: 1) What are some things that made it easier to complete the medical evaluation process for kidney transplantation? 2) What are some things which made it difficult to complete the medical evaluation process? Questions posed to Status 7 were modified as appropriate and included: 1) What are some things which have made it difficult to complete the medical evaluation process? 2) What do you think will help you complete the medical evaluation process for kidney transplantation? Open-ended questions and the use of probes were used to prompt participants to elaborate on or provide more detail about their responses. The full moderator's guides are provided in Appendices C & D.

## **Quantitative Measures**

The same questionnaire administered to the transplant professionals in phase I was administered to patients in Phase II. The patient version of the demographic questions had additional patient-specific questions such as health insurance status and distance from the patient's house to the transplant center (see Appendix E).

## **Data Analysis**

### **Qualitative analysis**

Information from the semi-structured interviews and focus groups were audio-recorded, de-identified, and transcribed verbatim by a research assistant. The transcripts were then reviewed by another research assistant and edited as needed, to ensure that the information had been accurately transcribed. Consequently, the transcripts were uploaded into MAXQDA 11, a qualitative and mixed-methods software for data analysis.

**Grounded theory.** Grounded theory was used as a theoretical paradigm for assessing the qualitative data gathered in Phases I and II. This theory is particularly advantageous for analyzing qualitative data since it has the potential to lead to the development of a theory (Creswell, 2007) , which would to explain relationships between and among factors that facilitate or impede the completion of the pre-transplant work up. According to Strauss and Corbin (1998), grounded theory brings awareness to and offers a meaningful guide to action which enhances understanding of a phenomenon (Strauss & Corbin, 1998). This theory uses constant comparative analysis where the data is coded into categories and then recoded to develop themes, leading to the development a theory (Birks & Mills, 2011; Glaser & Strass, 2012). Rigorous coding procedures such as open coding, axial coding and selective coding guide the analyses to derive meaning from the data (Strauss & Corbin, 1998).

Open coding utilizes an analytic process to generate concepts in relation to their properties and dimensions. During open coding, data is broken down into discrete parts, closely examined, and compared for similarities and differences (Strauss & Corbin, 1998). Events, happenings and/or actions which are conceptually synonymous are grouped under more abstract concepts called categories (Strauss & Corbin, 1998). Specifically, this study reviewed the responses from each discussion topic generated from the semi-structured and focus group interviews to assign code names. These codes were then used to produce major categories and subcategories. A preliminary coding scheme was developed by the PI through open coding in MAXQDA 11. Consequently, a coding manual was developed with clear definitions for each code. New codes were included under an *Other* category for further examination, discussion and categorization. Three research assistants also coded the data to facilitate inter-coder reliability (i.e. transcriptions were divided among research assistants for coding whereas the PI coded all transcriptions). All team members created their own projects in MAXQDA.

Axial coding was used as the next step in the coding process, wherein categories are related to their subcategories along the lines of their properties and dimensions. This process aims to determine how categories crosscut and link (Strauss & Corbin, 1998). During this stage of the coding process, the data is assessed in new ways and responses generated are compared to each other. Finally, selective coding was performed to integrate the categories and refine them (Strauss & Corbin, 1998). This whole process involved a constant comparative analysis, as transcribed responses were compared to each other and themes emerged from the data. Information gathered from the interviewer/moderator notes during the semi-structured interviews and focus groups were also incorporated into the analyses. Data saturation was achieved when no new themes emerged from participants' responses.

**Trustworthiness.** Trustworthiness is a way to increase rigor in qualitative studies and to assess the value of findings (Krefting, 1991). Specific strategies must be implemented to avoid possible threats and to test the validity (credibility) and reliability (dependability) of findings (Krefting, 1991; Maxwell, 2013). Verbatim transcripts of the semi-structured interviews and focus groups facilitated the collection of rich, detailed data, and provide a complete portrait of the phenomenon under investigation (Maxwell, 2013). Credibility and dependability was demonstrated through triangulation, which involves the use of a diverse sample and different data collection methods (Krefting, 1991; Maxwell, 2013). To facilitate triangulation, this study utilized semi-structured interviews and focus group interviews and recruited different transplant professionals, as well as patients at different points in the pre-transplant work-up. Further, the interviewer/moderator notes were also incorporated into the data analysis. Reflexivity, which is an assessment of the influence of a researcher's background and perceptions of the research process (Krefting, 1991), is another strategy used to demonstrate credibility and was implemented in the current study. The PI kept a log to reflect on her experiences and methodological issues that arose during the research process. The PI and RAs also processed their experience of the focus group interviews and discussed group dynamics. As indicated by Maxwell (2013), these memos helped the PI develop a more thorough understanding of the topic, study and setting. Furthermore, dependability was established through peer examination where the PI discussed the findings with impartial colleagues specifically, other graduate students and faculty with expertise in qualitative research design. These colleagues checked the categories as developed and assessed disconfirming cases (Krefting, 1991).

## Quantitative Analysis

The quantitative data gathered from the surveys were entered into the statistical program, SPSS Version 23 (IBM Corporation, 2015), by the PI. Descriptive statistics such as means and standard deviations were calculated to characterize the transplant professional and patient samples. Given the small sample size of the study, and that the data did not meet the stringent assumptions of its parametric equivalent (Pallant, 2010; Rovai, Baker & Ponton, 2013), the Students t-test for independent samples (Levene's test  $p > .05$ ), the Mann-Whitney  $U$  was the preferred analytic approach for examining differences in perceived barriers and motivators to completing the medical evaluation process.

Priority scores were calculated from the top five barriers and motivators (first = 5 points, second = 4 points, third = 3 points etc.) to completing the medical evaluation generated through NGT and summed across all focus groups and semi-structured interviews. The data was then presented as a percentage of the maximum possible priority score (number of participants completing rankings multiplied by 5 points) (Sanderson, Morris, Calnan, Richards, Hewlett, 2010; Morton et al., 2011). The data for the group consensus of the top barriers and motivators was displayed as a percentage of the weighted total score (Locke et al., 2015).

**Power Calculation.** The G\*Power statistical software (Faul, Erdfelder, Lang, & Buchner, 2007) was used to develop a priori power analyses to determine the most appropriate sample size for analyzing associations between perceived barriers and motivators. Power analysis for correlations using  $\alpha = .05$  criterion for achieving an 80% chance of detecting a large-sized effect yielded the most conservative sample size estimate ( $N = 13$ ). The total number of participants ( $N = 53$ ) recruited for the study was above sample estimates for conducting the chi-square tests and correlations. Given that the total sample size was small, A Mann  $U$  Whitney test



was used to examine differences in perceived barriers and motivators between transplant professionals in place of the parametric equivalent, an independent groups *t* test.

## Results

### Descriptive Statistics

Means, standard deviations, and counts were calculated for transplant professional and patient characteristics (see Table 3). Certain demographic data was not gathered given that not all questions were applicable to both subpopulations.

Table 3  
*Sample characteristics*

<b>Variable Name</b>	<b>Total (N=53)</b>	<b>Transplant Professionals (n=23)</b>	<b>Patients (n=30)</b>
<b>Age</b>		*	49.79 ( <i>SD</i> =8.57)
<b>Gender</b>			
Male		7 (30.4)	21(70)
<b>Race</b>			
Asian		2 (8.7)	*
African American		3 (13)	30 (100)
White		18(78.3)	*
<b>Occupation</b>			
Nephrologists		6 (26.1)	*
Transplant Coordinators		8 (34.8)	*
Social Workers		6 (26.1)	*
Psychologists		2 (8.7)	*
Transplant Nurse Practitioner		1 (4.3)	*
<b>Education</b>			
High or less		*	12(40)
Associate's degree/Some college		*	12(40)
Bachelor's degree		6 (26.1)	3 (10)
Some graduate/Master's degree		9 (39.1)	3 (10)
Doctorate/Medical degree		8 (34.8)	*
<b>Years of Experience</b>		10.24 ( <i>SD</i> =8.65)	*
<b>Marital Status</b>			
Single/Never married		*	10(33.3)
Married/Cohabit		*	10(33.3)
Divorced		*	7 (23.3)
Separated		*	1 (3.3)
Widowed		*	2 (6.7)

<b>Religious Affiliation</b>		
Protestant	*	18(60)
Catholic	*	4 (13.3)
Other	*	4 (13.3)
Not reported	*	4 (13.3)
<b>Annual Household Income</b>		
\$0 - \$19,000	*	16(53.3)
\$20,000-39,999	*	8 (26.7)
\$40,000-59,999	*	2 (6.7)
\$60,000+	*	3 (10)
Not reported	*	1 (3.3)
<b>Patient Perception of Completion<sup>1</sup></b>		
Yes	*	18 (60)
No	*	12 (40)
<b>Patient Health Insurance Status</b>		
Yes	*	29(96.7)
No	*	1 (3.3)
<b>Distance to transplant Center (miles)</b>	*	12.54 ( <i>SD</i> =8.15)
<b>Transportation</b>		
Yes	*	29(96.7)
Car Share	*	1 (3.3)

*Note.* <sup>1</sup>Patient perception of completion indicates patient's perception of whether they have completed the medical evaluation or not. Values are expressed as count (percentage) unless noted otherwise.

### Thematic Analyses

#### Transplant Professionals' Identified Barriers to Completion of the Medical Evaluation

Thematic analyses were conducted to address RQ1, namely, identifying transplant professionals' perceptions of barriers to patients completing the medical evaluation. These themes are presented here, in descending order, beginning with most frequently reported barriers.

**Theme 1: Individual-level barriers.** Transplant professionals most often reported barriers that impact the patient at the individual level. The majority of these barriers consisted of socioeconomic impediments such as limited income, insurance issues and limited social support, personality characteristics such as personal motivation and fears, and belief systems such as medical mistrust or religious beliefs.

*Subtheme (a): Socioeconomic barriers.* Patients with limited income have a difficult time covering the costs associated with medication (e.g., immunosuppressants and steroids) and transportation. Insurance issues such as difficulty covering the necessary co-pays and frustrations with navigating insurance paperwork fall into this category. Additionally, those with limited social support experience barriers in completing the medical evaluation, resulting from lack of emotional support as well as difficulties with transportation and childcare. Examples of socioeconomic barriers are reflected in the following quotes from participating transplant professionals:

Transplant Nephrologist: “Uh, biggest one is poorness. I mean that's it. I mean that's... Whether you're white or black, it doesn't really matter. But if you're poor, you're not going to, you have a less likelihood of having support, and having, you know, transportation, having all that stuff that you need to have to, uh, to complete the evaluation.”

Transplant Coordinator: “Um, lower socioeconomic patients who don't have the Medicaid full, the full Medicaid for transportation, and medications. Um, they're going to take a while to get things done. Just because they don't have the resources they need.”

Transplant Coordinator: “Um, transportation can sometimes be a problem because a lot of the people who are on dialysis do not drive and they are reliant on other people to drive them so those people have to take time off work to do that.”

*Subtheme (b): Beliefs systems.* Patients who do not believe that healthcare professionals have their best interest in mind or those with concerns about discrimination are less likely to

complete the pre-transplant workup. This is exacerbated by the fact that patients are asked to provide a thorough medical, psychosocial and financial history, consequently increasing their interactions with healthcare professionals. Transplant professionals noted that some patients with religious beliefs perceive the outcome of their illness to be in “God’s hands” or are cautious about seeking living donation. The following quotes reflect this subtheme:

Social Worker: “Um, I think sometimes male patients in particular, um, and certainly middle-aged African-American men often, um, I think are a little bit tougher to, um, connect with, or in the sense that, in the way that I work with them as a social worker, I think sometimes they’re a bit distrusting with me and the questions that I have to ask and the things we have to go over.”

Transplant Coordinator: “I think that sometimes people that are African American or even Hispanic if they’re hearing the message that we can’t move forward with transplant or there’s a barrier, occasionally, not very often, we will be told by that recipient, “well you don’t want to do this because I’m Black or because I’m Mexican.”

Psychologist: “Actually, the times that that has come up it has been in African American patients. The times that either has been a belief that they will get healed; that they don’t need a transplant because a miracle will happen and they will get healed; um, or that they’ve stopped taking their medicine because they believed that God was going, that you know, God would protect them and they didn’t need to take their medication ‘cause God would heal them and make that kidney work. Um, those, those specific cases, and it’s only been a handful, have been in African American patients.”

*Subtheme (c): Other individual-level barriers.* Professionals also viewed patients who are unmotivated or passive as being less likely to complete the pre-transplant workup. According to the professionals interviewed, patients may be overwhelmed by the process, have fears about losing their benefits or making several hospital visits, and/or be afraid of the surgical procedure for transplant. Other patients may be less prepared for their appointments and may not have the appropriate paperwork. For example, a nephrologist reported, "... Some people are just afraid of coming to a major hospital and navigating the corridors the hallways, uh, it's the feeling of the unknown that they have to go through a surgery, uh, which might be a problem if they think, 'Okay, I'm on dialysis why do I need this big surgery....'"

**Theme 2: Informational/educational barriers:** Barriers related to a patient's lack of knowledge of the medical evaluation process, transplantation, and/or kidney disease were also cited by transplant professionals. Additionally, gaps in information provided to patients or gaps in patients' formal education may impede comprehension of said information. These informational/educational barriers were the second most commonly identified type of barrier to completing the medical evaluation.

*Subtheme (a): Limitations in formal education.* Several professionals reported that patients with limited formal education display challenges with literacy or comprehension of reading materials. For example, a transplant coordinator stated, "...If they're not able to read all the information that we give them in the booklets or they don't look it up on their own, I think that does play a factor into whether or not they complete their evaluation because they may not understand the importance of it." Another transplant coordinator shared:

"Um, that seems to be an issue sometimes, they just, some people just don't seem to really get it, you know, understand why it's important or why they're going to benefit

from it. Um, and I guess you do see that kind of more often in people that don't have as, as high of an education level.”

*Subtheme (b): Access to information about transplantation.* Transplant professionals reported that some patients do not have access to information about transplantation. They may not have access to the Internet to read about transplantation or they are unable to access information about transplantation from their social networks. Other patients may not know how to obtain information about transplantation or kidney disease. A transplant coordinator reported:

“Um, possibly more so with the older ones I guess because, you know, they don't have the computer skills that younger people do. You know, younger people it doesn't matter what ethnicity, you know what I'm trying to say. Um, you know, they know about computers and how to look for information if they wanted and I guess maybe because we do have a higher, uh, percentage of African Americans that you do see that more commonly with them, especially in the older ones that don't surf the web and, you know, look up information.”

*Subtheme (c): Transplant education.* Many transplant professionals discussed the fact that patients are presented with high volumes of information during their evaluation and the information is not always catered to their understanding. An example of this can be seen in this excerpt from a transplant coordinator: “...They receive a lot of education on their first visit and no one could humanly really retain all of that so as coordinators we do kind of follow up.”

*Subtheme (d): Limited knowledge of the medical evaluation and/or transplantation.* Patients without knowledge of the benefits of transplantation over sustained dialysis or those who do not know the purpose of the medical evaluation process face barriers in completing their evaluation. This is reflected by the following quote from a nephrologist: “... Yeah, I think

understanding the importance of the test and understanding where they are in the transplant process and why they have to complete the tests, and the benefits of transplants.”

**Theme 3: Systemic barriers.** Systemic barriers, or barriers at the hospital level, were the third most frequently identified barrier to patients’ completion of the medical evaluation for transplantation. Transplant professionals reported that patients experience these barriers because of referral processes and scheduling difficulties, and struggle to navigate their way around a large hospital.

*Subtheme (a): Healthcare logistics.* Patients have a difficult time navigating the healthcare system including finding a doctor’s office or trying to find their way around large, complex hospital campuses. One social worker speculated that navigating unfamiliar hospital settings may be intimidating for patients: “. . .um, the hospital, uh, a large university hospital in the inner city can be very intimidating for them.”

*Subtheme (b): Transplant-specific problems.* Some patients are not referred for transplant or there is a delayed referral by their general nephrologist. Since there is no central testing location, patients must attend several doctors’ appointments, sometimes at different locations. Scheduling multiple appointments around ongoing dialysis treatments presents additional difficulties. Further confusion arises when breakdowns in communication between the transplant professionals and patients occurs. A nephrologist stated, “. . .Uh they’ll see different providers even in their own facilities, different nephrologists. . .they might not get referred early so they might develop a lot more disease by the time they get to see us. . .”

**Theme 4: Health-related barriers.** Health-related barriers were the fourth most named barrier to completion of the medical evaluation process. Barriers that fall under this category

include the patient presenting with multiple health conditions or comorbidities; prolonged dialysis use, which may make the patient more ill; and weight issues.

*Subtheme (a) Comorbidities.* Patients with multiple health conditions, in addition to ESRD (e.g., cardiovascular disease), experience delays because considerably more tests are required to progress through the evaluation process. In some instances, patients must also be deemed clear of the condition before being allowed to complete the evaluation process. A transplant coordinator stated:

“Um, heart disease, if they have, um, severe heart disease. Um, calcification in the vessels where the kidney would attach that could prevent someone from being able to receive a transplant. Um, you know we just have to make sure that in general they’re going to become better, not worse, from the transplant. So if they have multiple comorbidities it may not be a good idea for them. So, a lot of times it’s heart disease.”

*Subtheme (b) Health status.* Dialysis is a physically demanding therapy leaving many patients exhausted and physically ill, limiting the ability to keep appointments as scheduled. Further, prolonged dialysis is associated with both physical and psychological problems such as fatigue, depression, decreased quality of life and heart disease (Christensen & Ehlers, 2002, Heerspink et al., 2009; Jhamb, Weisbord, Steel & Unruh, 2008). In general, most ESRD patients have poor health because of their disease. This excerpt from a transplant coordinator exemplifies this subtheme:

“So, because if somebody isn’t feeling well then that, that person might just say, you know, I can’t go to (transplant center) today and sit there for, like, three hours. That’s health status, and it can, but it can mean a lot of different things, as much as, you know, not feeling well. But there could also be complications, um, with dialysis. You know



maybe they have, they're planning to do dialysis early in the morning and something went wrong."

*Subtheme (c): Health requirements.* Patients with BMI above 30 are required to lose weight before being released to complete the medical evaluation. Similarly, patients with severe mental illness and substance use may be required to seek treatment, be medically stable, or be drug free before they can complete the evaluation. A nephrologist reported:

"Um, I think if people aren't being properly treated for their mental health issues they don't... I think mental health, you have to come back and meet with a psychiatrist as well too, with an extra layer to it. Um, and if someone's depressed, then they don't want to go to their test. And so, I think it's untreated mental health, let me re-phrase that. Um, and then the other thing is substance abuse you know. I think that's a major impediment. You have these functional drug abusers as well. People who use cocaine but are still functional, to the sense that, I mean, functional in a sense that they have End Stage Renal Disease and cocaine probably contributed to it but they're not, you know, they're still married, they still live in a house, they have kids who want to donate kidneys to them but keep coming back positive for cocaine. Well, you know, they're the model dialysis patients, that all their labs are perfect, they never miss a dialysis treatment, but they keep getting disqualified because of their positive drug, and even marijuana as well too, and a lot of patients use marijuana to help them with the nausea associated with the dialysis, so that becomes it, but those are really the major two things..."

## **Patient-identified Barriers to Completion of the Medical Evaluation**

Thematic analyses were conducted to address RQ4: identifying patients' perceptions of barriers to completing the medical evaluation process. These themes are presented here, in descending order, beginning with most frequently reported barriers.

**Theme 1: Individual-level barriers.** Similar to transplant professionals, patients were most likely to report individual-level barriers. The majority of these barriers were socioeconomic in nature, such as limited income, impacting the cost of medications and access to transportation. Additionally, insurance issues and limited social support were indicated as contributing to socioeconomic difficulties. Some patients also mentioned time constraints in trying to fit their medical appointments in with their dialysis schedule and other activities such as work and childcare. Further, difficulties finding a living donor also served as a barrier. Some patients reported that lack of motivation or fears (e.g., about losing benefits after transplant, undergoing the transplant surgery) impede completion of the medical evaluation process. A few patients attributed difficulties in completing the evaluation process to medical mistrust. The following excerpts reflect this theme:

Male patient: "...That's one things I have a problem with, if I go through with the transplant, that's the only things I'm going to have problem with all my appointments because my mother doesn't drive, my two sisters refuse to drive in the city because they two country girls. They will not drive in (city), and I don't think I'm going to be able to drive so I have to find somebody to bring me back and forth."

Male patient: "...As far as with you, man, when I get my transplant I don't got nobody to take care of me. Um, how can I get some assistance with this, you know what I'm saying? Because I'm by myself ..."

Female patient: "...You know there's, um, the financial aspect of it, um, of getting a transplant, the funding of it, um, you know because even with insurance you still, um well, sometimes if you have insurance and social security or Medicare then usually you're pretty good but there's a copay if you just have insurance so it's still a big financial responsibility that you end up..."

Female patient: "...Well, you have to make sure the donor is a match obviously. Um, and it's hard to get a donor. No one wants to go through it and, um, uh it's just a hard process..."

Male patient: "... like you get a kidney and you're off disability but what if I'm just not ready. Ok, and then nobody says ok, and I know how things work because they'll say, well, you got a kidney and you're fine, well, ok you're saying I'm fine but what if I'm not fine you know who's to make that judgment to say your finances should be cut off..."

**Theme 2: Systemic barriers:** In contrast to transplant professionals, systemic barriers were the second most commonly identified barrier among patients. The barriers were mostly transplant-specific problems that related to poor communication between the patients and transplant staff; scheduling difficulties; having to work with several doctors; long wait times for doctor's appointments and test results; and, not having access to transplant coordinators. Further, some patients also reported systemic barriers related to healthcare logistics such as difficulty finding their way around the hospital, parking issues, and construction. The following examples illustrate this theme:

Female patient: "It takes a long time for some of them, some people have to have sleep studies, it could take you up to four months to get an appointment for a sleep study, so it's a lot of stuff and there is a check list, so you have to get this done."

Male patient: "...The transplant coordinators, they aren't very communicative, that's the one part I would probably say could use some improving. I mean, I've called them sometimes just to find out where things are and, um, many times I haven't got a call back, um, from them...I know they are probably busy but they could do a little more communicating..."

Female patient: "It's a lengthy process to actually get onto the transplant list."

Male patient: "...uh, the only thing I, it was just hard finding my way around (hospital). They had a parking deck that I end up going backward..."

**Theme 3: Health-related barriers:** Health-related barriers were the third most identified barriers to completing the medication evaluation by patients. Patients reported subthemes related to having health conditions other than kidney disease, health status, and health requirements. Some patients also reported being fatigued, while others mentioned that they had not been cleared from psychiatry. The quotations below reflect this theme:

Female patient: "Well mine's is not just a kidney, uh, disease. Um, I guess you could kinda say I have another illness. Um, my illness is, I don't know if you ever heard of it, it's called tubular sclerosis. And I think I got the complex, which means like the tumors that's on my face, it grows on my kidney. And that's what the doctor, uh, was sayin' and that the tumors had grew on my kidney where was messing with the function of my kidney. So, you know, those two is kinda, you know, together."

Female patient: "I would say I am really tired all the time, like never before. I just don't have energy to do too much of anything. Tired and also with all the medication I take 'cause I have a chronic hypertension problem so I am on, like, five different blood

pressure meds... But I just don't feel like doing anything anymore. That's the worst part of all of this. I lay down a lot."

Male patient: "Mine is fatigue, my energy level is not what it used to be, you know, um, and I guess, like, from a mental stand point one of the things that, uh, kind of messed with me is, you know..."

Female patient: "Um, my problem was with the psychiatry because I've been under stress and not only from that but other stuff and I had to go every week, every Tuesday. I got a lot of problems from fibromyalgia so I don't sleep at night, I take a lot of medication for it but I be in a lot of pain so ...9'oclock every Tuesday, they had me going to psychiatry and I just stopped going."

**Theme 4: Informational/educational barriers.** Limited information/education was the fourth most reported barrier to completing the medical evaluation. Patients expressed that they would have liked more information about transplantation, especially the medical evaluation process, the number of tests and medical procedures required, and the financial aspects of getting a transplant. The following quotes exemplify this theme:

Male patient: "Um, well, I wish they would have, um, or somebody would have told me a little bit more 'cause, be honest, I didn't know nothing about tests and stuff. All they just told me is that I am on the list, and um, be ready when they call me, you know. If I get a transplant. And you know, that was it. They didn't really give me much information and, you know, they should have told me that I had to go through tests and stuff."

Female participant: "We don't know all of the procedures that need to be done so we can't make that call as to, okay, what needs to be done? You know, it's ever changing. You know. If you need more blood work, let us know. You know, because the worse

thing is you come up here for an appointment, procedure or whatever, and they say, ‘Oh, Ms. X, you haven’t had this done. Why weren’t you here for this appointment?’ And you had no idea it was there. You know. You don’t want to be surprised.”

### **Transplant Professionals’ Identified Motivators to Completion of the Medical evaluation**

RQ2 was addressed by identifying transplant professionals’ perceptions of motivators, encompassed by the following themes:

**Theme 1: System-level motivators.** The majority of the motivators identified were system-level. Transplant professionals indicated that specific structural changes in the hospital and transplantation system could impact African Americans’ completion positively. The facilitators include: greater referrals from local nephrologists; patient navigators and/or case management staff; physician repertoire (i.e., the physician’s ability to build rapport with the patient); compressed time frame for medical testing; and comprehensive insurance for patients. A nephrologist commented that, “I think removing the intimidation aspect of things that comes with the medical system. Trying to work, and I think this goes across racial barriers, trying to work with their schedule rather than imposing, this must be done by this day and stuff like that...”

**Theme 2: Informational/educational motivators.** The second most identified motivator reported by transplant professionals were informational/educational factors. These include center-based education about the evaluation process, formal education, presenting information in lay terms, education of nephrologists, promotion of transplantation, and continued education about transplantation. One nephrologist stated, “Constant education of the patient so far as the patient’s education and comprehension level, you want the patient to be able to comprehend

really quickly as to why they're not taking their medication and sometimes if they don't but as long as you lay out the guidelines, they'll still be okay as long as they follow your instructions.”

**Theme 3: Individual-level motivators.** The third most reported type of motivator identified by transplant professionals impacted patients at the individual level. These include patients' desire to get off dialysis and have a better quality of life, patients' religious beliefs or faith, and knowledge of a successful transplant recipient. The following excerpt from a transplant professional reflects this theme:

“...they also see that in their dialysis unit, you know, people are dying or getting their limbs amputated and they don't want to be in that situation. They also see patients in the dialysis unit getting a kidney transplant coming back to dialysis unit doing well after a kidney transplant, so that is a big motivating factor for a lot of patients. I think the number one motivation is, the number one answer I get is that I can't deal with dialysis anymore, but I think they do realize though because it just drains you so much, they can't do anything else the rest of the day. But they also realize the health benefits to that...”

**Solutions identified by transplant professionals.** Solutions proposed by transplant professionals include: removing intimidating factors in transplantation, better case management, comprehensive insurance, improving access to primary care, pre-dialysis treatment, working with the patients to problem solve, creating programs to motivate or empower patients, and more education about transplantation and the evaluation process.

### **Patient-identified Motivators to Completion of the Medical Evaluation**

To address RQ5, themes representing patient-identified motivators to completing the medical evaluation were grouped into the categories below.

**Theme 1: Individual-level motivators.** The majority of the motivators identified were individual-level facilitators to transplant completion. Included in this category was family support, such as financial support from family members, support from the transplant staff, patients' desire to get off dialysis, and belief systems such as spiritual or religious beliefs. The following quotes illustrate this theme:

Female patient: "... My co-pay was \$853 a month, and at the end, the last six months it was almost \$900 a month, however, because God is good, and I have a good brother, he actually paid my co-pay for me for a total of a little over \$10,000 over a 18-month period because I was unemployed, no income..."

Male patient: "...I mean, if it wasn't for my wife, I give her all the praise for, uh, pushing me to go to my appointments and, you know, doing everything I was supposed to, it makes the process a lot easier...you need somebody."

Male patient: "Maybe providing transportation..."

**Theme 2: Systemic motivators.** The second most identified type of motivator to completing the medical evaluation was systemic. These included good communication with the transplant coordinators, updates on the patient's position on the waitlist, appointment reminders, decreasing the intervals between doctor's appointments, and rehabilitation support for patients without social support. This theme is evident in the following quote given by a female patient:

"... I mean, the coordinators have folks to help them (patients) too. They have financial coordinator and a social worker. Their own staff that works for the transplant office. You know, and both of those folks can help you if you have financial issues to get your medication or to get your transplant. And it's a good thing to do to talk to them before to see what your financial outlook looks like as far as, you know, even with insurance."



**Theme 3: Informational/educational motivators.** Patients reported informational/educational motivators least frequently. These include education about transplantation, specifically the medical evaluation, providing information that is easy to understand, and knowing a successful transplant recipient. This lack of information is embodied in the response of one male patient, “Yeah, yeah, I guess if they expect you...why these number of tests are being done in order to get on the list...you know, why do you need to test that many to get on the list...um, I guess.”

### **Group Differences in Identified Barriers**

**Group differences among transplant professionals’ identified barriers.** To help address RQ3, differences in transplant professionals’ perceptions of barriers were examined. Specific to barriers, nephrologists reported the most barriers to completing the medical evaluation process in comparison to transplant coordinators, social workers, and psychologists. Social workers and psychologists were more likely to address the psychosocial factors associated with completion of the medical evaluation, such as problems with social support, financial barriers and problems with substance use or severe mental illness. Nephrologists and transplant coordinators were also more likely to report individual-level barriers relative to transplant coordinators, social workers, and psychologists.

**Status differences among patients’ identified barriers.** To help address RQ8, Status 1 and Status 7 patients’ reports of barriers were compared. Status 1 patients reported fewer barriers to completing their evaluation and at times had difficulty identifying any roadblocks as compared to Status 7 patients.

## **Group Differences in Identified Motivators**

**Group differences among transplant professionals' identified motivators.** To help address RQ3, group differences in perception of motivators by the different types of transplant professionals were examined. Nephrologists were more likely to report systemic and individual-level motivators relative to transplant coordinators, social workers, and psychologists. In contrast, transplant coordinators were more likely to propose information/educational-related solutions whereas nephrologists proposed systemic solutions. Social workers and psychologists reported more socioeconomic solutions to completing the medical evaluation process in comparison to the other professionals.

**Status differences among patients' identified motivators.** To help address RQ8, differences between Status 1 and Status 7 patients' reports of motivators were examined. Status 1 patients reported more social support, no transportation difficulties, and minor insurance issues. Both groups reported support from the transplant staff.

## **Rankings for Barriers to Completing the Medical Evaluation**

Twenty-one barriers reported by transplant professionals were prioritized as impeding completion of the medical evaluation process to help address RQ1. These barriers were further categorized into individual-level, systemic, health-related and informational/educational barriers. The majority of the barriers (42.86%) prioritized impact the patient at the individual level and consisted primarily of socioeconomic difficulties. Six informational/education level barriers (28.57%), four systemic barriers (19.05%), one health-related barrier (4.76%), and another was categorized as both a health and systemic barrier (4.76%). The top five barriers identified were: limited income/low SES, lack of a personal means of transportation, limited/lack of patient

motivation, insurance issues, and the number of procedures and/or tests required to complete the evaluation (see Table 4).

To address RQ6, for patients, 36 barriers were ranked and assigned priority scores, with individual-level barriers (44.44%), systemic barriers (33.33%) and health-related barriers (11.11%), informational/educational barriers (5.56%), one classified as both a health and systemic barrier (2.78%), and another as both an individual-level and systemic barrier (2.78%). The highest ranked barriers were insurance issues, scheduling difficulties, lack of a personal means of transportation, time constraints that make it difficult to complete several medical procedures/tests, and limited income/low SES (see Table 5).

Table 4  
*Transplant Professionals' Rankings of Barriers to Completing the Medical Evaluation*

Top Barriers	Total Score	Max Priority Score (%)	<i>n</i> of participants ranking this their Top 5
1. Limited income/Low SES <sup>a</sup>	52	45.22	15
2. Lack of personal means of transportation <sup>a</sup>	40	34.78	11
3. Limited/ lack of patient motivation <sup>a</sup>	38	33.04	11
4. Insurance issues <sup>a</sup>	33	28.70	11
5. Number of procedures and/tests required to complete the evaluation <sup>cd</sup>	32	27.83	12
6. Multiple health conditions <sup>d</sup>	31	26.96	11
7. Lack of understanding of the information <sup>b</sup> provided during the medical evaluation	27	23.48	10
8. Limited knowledge of the benefits <sup>b</sup> of transplantation	24	20.87	7
9. Inability to pay for out-of-pocket costs associated with the evaluation <sup>a</sup>	21	18.26	7
10. Limited health literacy <sup>b</sup>	17	14.78	7
11. Distance to transplant from patient's house <sup>a</sup>	12	10.43	6
12. Limited information about the medical evaluation process <sup>b</sup>	9	7.83	3
13. Religious beliefs <sup>a</sup>	4	3.48	1

14. Racial discrimination <sup>c</sup>	3	2.61	1
15. Medical mistrust <sup>a</sup>	2	1.74	2
<b>Other barriers</b>			<b>Count</b>
16. Lack of care partner support <sup>c</sup>	*	*	1
17. Limited formal education	*	*	1
18. Limited/lack of social support <sup>a</sup> (especially lack of family support)	*	*	2
19. No localized testing <sup>c</sup>	*	*	1
20. No primary care physician <sup>c</sup>	*	*	1
21. Poor comprehension of reading materials <sup>b</sup>	*	*	1

*Note.*  $N=23$ . The maximum possible priority score was 115. Priority scores were not calculated for other barriers (not in the top 5) indicated by transplant professionals. <sup>a</sup>Individual-level barrier, <sup>b</sup>Informational/educational barrier, <sup>c</sup>Systemic barrier and <sup>d</sup>Health-related barrier.

Table 5  
*Patients' Rankings of Barriers to Completing the Medical Evaluation*

Top Barriers	Total Score	Max Priority Score (%)	<i>n</i> of participants ranking this in their Top 5
1. Insurance issues <sup>a</sup>	32	24.62	9
2. Scheduling difficulties (e.g., getting <sup>c</sup> an appointment for some tests takes a while)	19	14.62	5
3. Time constraints that make it difficult to <sup>a</sup> complete several medical procedures/tests	19	14.62	4
4. Lack of a personal means of transportation <sup>a</sup>	16	12.31	4
5. Limited income/Low SES (including difficulty <sup>a</sup> covering the cost of medications)	11	8.46	3
5. Finding a living donor <sup>a</sup>	11	8.46	3
6. Length of time to complete the medical <sup>c</sup> evaluation (e.g., time spent waiting for tests)	9	6.92	2
6. Medical complications (e.g., infections, health problems) <sup>d</sup>	9	6.92	2
7. Poor communication with the transplant center <sup>c</sup>	8	6.15	2
8. Length of time spend at the transplant center (i.e., long appointment days) <sup>c</sup>	7	5.38	2
8. Limited/lack of social support (i.e., from <sup>a</sup> family and friends)	7	5.38	2
8. Number of procedures and/tests required to	7	5.38	2

complete the evaluation <sup>cd</sup>			
9. Difficulties with the stress test <sup>c</sup>	7	5.38	2
10. Limited/lack of patient of motivation <sup>a</sup>	6	4.62	2
10. Multiple health conditions <sup>d</sup>	6	4.62	2
11. Concerns about kidney rejection after transplantation <sup>a</sup>	5	3.85	1
11. Concerns about losing financial support after transplantation <sup>a</sup>	5	3.85	1
11. Poor physician rapport <sup>c</sup>	5	3.85	1
11. Having to complete medical procedures/tests at another facility <sup>c</sup>	5	3.85	1
11. Limited/lack of family involvement in the evaluation process <sup>ac</sup>	5	3.85	1
11. Issues with medical compliance <sup>a</sup>	5	3.85	1
11. Medical readjustments <sup>d</sup>	5	3.85	1
11. Multiple medical procedures/tests in one day <sup>c</sup>	5	3.85	1
11. Not knowing whether the medical procedures/tests would disqualify patient from being placed on the waitlist <sup>a</sup>	5	3.85	1
11. Poor physical health (i.e. feeling sick) <sup>d</sup>	5	3.85	1
11. Smoking cessation <sup>a</sup>	5	3.85	1
11. Wait time for a deceased organ <sup>c</sup>	5	3.85	1
11. Waiting for information about the evaluation <sup>b</sup>	5	3.85	1
12. Concerns about taking medicine for the rest of the patient's life <sup>a</sup>	4	3.08	1
12. Medical mistrust <sup>a</sup>	4	3.08	1
12. Navigating a large hospital (e.g. parking difficulties, construction) <sup>c</sup>	4	3.08	1
13. Fear of going to the dentist <sup>a</sup>	3	2.31	1
13. Lack of communication between the dialysis unit and transplant center <sup>c</sup>	3	2.31	1
13. Length of time it takes for tests results to get to the transplant center <sup>c</sup>	3	2.31	1
14. Limited information about financial aspects of the evaluation <sup>b</sup>	1	0.77	1
14. Difficulty maintaining social support throughout process <sup>a</sup>	1	0.77	1

*Note.*  $N = 26$ , four participants did not provide rankings. The maximum possible priority score was 130. Priority scores were not calculated for other barriers (not in the top 5) indicated by patients. <sup>a</sup>Individual-level barrier, <sup>b</sup>Informational/educational barrier, <sup>c</sup>Systemic barrier and <sup>d</sup>Health-related barrier.

## Rankings for Motivators to Completing the Medical Evaluation

To help address RQ2, thirteen motivators identified by transplant professionals were ranked and assigned priority scores. The majority of the motivators prioritized were systemic in nature (38.46%), four were informational/educational motivators (30.77%), two were individual-level (15.38%), and the remainder were a combination of both individual-level and systemic motivators (15.38%). The top five motivators were center-based education about the evaluation process, instrumental support (e.g. help with childcare and transportation), patients’ knowledge of the benefits of kidney transplantation over sustained dialysis, the availability of patient navigators, and informational support about kidney transplantation (see Table 6).

To address R7, fifty-four motivators identified by patients were prioritized as facilitating completion of the medical evaluation process. These motivators were classified into individual-level motivators (38.89%), informational/educational motivators (25.93%), systemic motivators (29.63%), and combinations of individual-level, systemic and informational/educational motivators (5.55%). Patients ranked their top five motivators as social support, religious beliefs, more information about the medical evaluation process, support from the transplant staff, and a desire to get off dialysis (see Table 7).

Table 6  
*Transplant Professionals’ Rankings of Motivators to Completing the Medical Evaluation*

Top Motivators	Total Score	Max Priority Score (%)	<i>n</i> of participants ranking this in their Top 5
1. Center-based education about the evaluation process <sup>b</sup>	59	53.64	18
2. Instrumental support (e.g. having assistance with childcare and transportation) <sup>ac</sup>	56	50.91	17
3. Knowledge of the benefits of kidney	49	44.55	14

transplantation over sustained dialysis <sup>b</sup>			
4. Patient navigators <sup>c</sup>	46	41.82	15
5. Informational support (i.e. having people who are knowledgeable of transplantation in one's social network) <sup>ac</sup>	40	36.36	15
6. Physician investment <sup>c</sup>	25	22.73	9
7. Emotional support and counseling <sup>ac</sup>	19	17.27	8
8. Comprehensive insurance <sup>c</sup>	19	17.27	7
9. Formal education <sup>b</sup>	11	10	4
10. Exposure to diverse clinicians <sup>c</sup>	5	4.55	2
11. Exposure to media promotion of the benefits of kidney transplantation	1	0.91	1
<b>Other motivators</b>			<b>Count</b>
12. Ability to cover out-of-pocket costs <sup>a</sup>	*	*	1
13. Motivation to return to work <sup>a</sup>	*	*	1

*Note.*  $N = 22$ , one participant did not provide motivator rankings. The maximum possible priority score was 110. Priority scores were not calculated for other motivators (not in the top 5) indicated by transplant professionals. <sup>a</sup>Individual-level motivator, <sup>b</sup>Informational/educational motivator, <sup>c</sup>Systemic motivator and <sup>d</sup>Health-related motivator.

Table 7  
*Patients' Rankings of Motivators to Completing the Medical Evaluation*

Top Motivators	Total Score	Max Priority Score (%)	<i>n</i> of participants ranking this in their Top 5
1. Social support (i.e., support from family and friends) <sup>a</sup>	34	27.2	10
2. Religious beliefs <sup>a</sup>	21	16.8	5
3. More information on the evaluation (e.g., what to expect, why it could take about a year to complete) <sup>b</sup>	19	15.2	4
4. Support from transplant staff (e.g., doctors, coordinators, social workers) <sup>c</sup>	14	11.2	5
5. Desire to get off dialysis <sup>a</sup>	13	10.4	3
6. Knowing a successful transplant recipient <sup>b</sup>	10	8	4
7. Good communication with transplant staff (especially pre-transplant coordinators) <sup>bc</sup>	10	8	2
8. Follow up by transplant staff (including	9	7.2	2

calls notifications/reminders for upcoming appointments, what to expect, what's next) <sup>c</sup>			
9. Motivation to return to work <sup>a</sup>	7	5.6	2
10. Knowing the medical procedures/tests involved in the evaluation process <sup>b</sup>	6	4.8	2
11. Explaining information in manner that facilitates understanding <sup>b</sup>	5	4	2
11. Financial assistance (e.g., to help with the cost of medications) <sup>c</sup>	5	4	2
12. Decreasing the intervals between doctors' appointments <sup>c</sup>	5	4	1
12. Desire to live because of family (e.g. desire to live for children) <sup>a</sup>	5	4	1
12. Follow up appointments after medical procedures/tests are completed <sup>c</sup>	5	4	1
12. Knowledge of transplantation <sup>b</sup>	5	4	1
12. Hearing stories from former kidney patients <sup>a</sup>	5	4	1
12. Patient motivation <sup>a</sup>	5	4	1
12. Personal means of transportation without relying on others <sup>a</sup>	5	4	1
12. Providing reading information about kidney transplantation for the patient to take home <sup>b</sup>	5	4	1
12. Rehabilitation support for patients without social support after transplantation <sup>c</sup>	5	4	1
12. Support from dialysis center <sup>c</sup>	5	4	1
13. Education about how to maintain contact with pre-transplant coordinators <sup>b</sup>	4	3.2	1
13. Comprehension of the evaluation process <sup>a</sup>	4	3.2	1
13. Increased information sharing (between patients) <sup>b</sup>	4	3.2	1
13. Kidney support groups <sup>c</sup>	4	3.2	1
13. Knowing social workers <sup>a</sup>	4	3.2	1
13. Patient's desire to live longer <sup>a</sup>	4	3.2	1
13. Support from primary care physician <sup>c</sup>	4	3.2	1
14. Support from specialists <sup>c</sup>	4	3.2	1
15. Communication between dialysis and transplant centers <sup>c</sup>	3	2.4	2
15. Education about the benefits of transplantation <sup>b</sup>	3	2.4	2
15. Improved scheduling of medical appointments <sup>c</sup>	3	2.4	2
15. Being able to ask questions <sup>a</sup>	3	2.4	2
15. Continuous education as patients go through the medical evaluation process <sup>b</sup>	3	2.4	2
15. Desire for better health <sup>a</sup>	3	2.4	2
15. Knowing that kidney transplant is near <sup>ab</sup>	3	2.4	2
15. Meeting doctors and nurses <sup>a</sup>	3	2.4	2

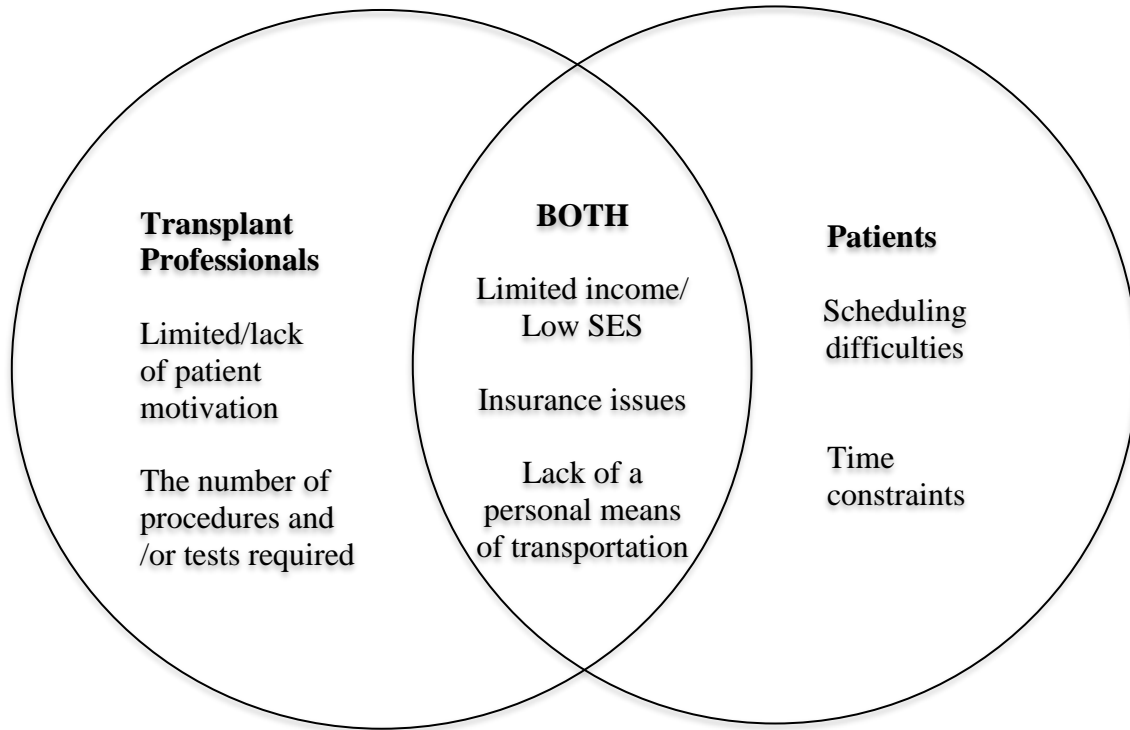


15. More Information about the transplant surgery <sup>b</sup>	3	2.4	2
15. Physician repertoire <sup>c</sup>	3	2.4	2
15. Support from primary nephrologist <sup>c</sup>	3	2.4	2
15. Updates on position on the waitlist <sup>b</sup>	3	2.4	2
16. Desire to resume recreational activities (e.g. travel) <sup>a</sup>	2	1.6	1
16. Improved access to social workers and financial coordinators <sup>c</sup>	2	1.6	1
16. Information on how to raise funds to help with financial costs associated with evaluation <sup>b</sup>	2	1.6	1
16. Patience (from patient) <sup>a</sup>	2	1.6	1
16. Seeing other peers (i.e. patients in the same age group) in bad health <sup>a</sup>	2	1.6	1
16. Support and information groups <sup>bc</sup>	2	1.6	1
17. Change in patient's perspective of disease <sup>a</sup>	1	0.8	1
17. Focus group (from the current study) <sup>a</sup>	1	0.8	1
17. Patient navigators <sup>c</sup>	1	0.8	1
17. Occupational support <sup>a</sup>	1	0.8	1
<b>Other motivators</b>			<b>Count</b>
17. Having a living donor <sup>a</sup>	*	*	1
18. Knowledge of patient expectations <sup>b</sup>	*	*	1

*Note.*  $N = 25$ , five participants did not provide motivator rankings. The maximum possible priority score was 125. Priority scores were not calculated for other motivators (not in the top 5) indicated by patients. <sup>a</sup>Individual-level motivator, <sup>b</sup>Informational/educational motivator, <sup>c</sup>Systemic motivator and <sup>d</sup>Health-related motivator.

### Between-Group Differences and Similarities in Top Barriers in Rankings

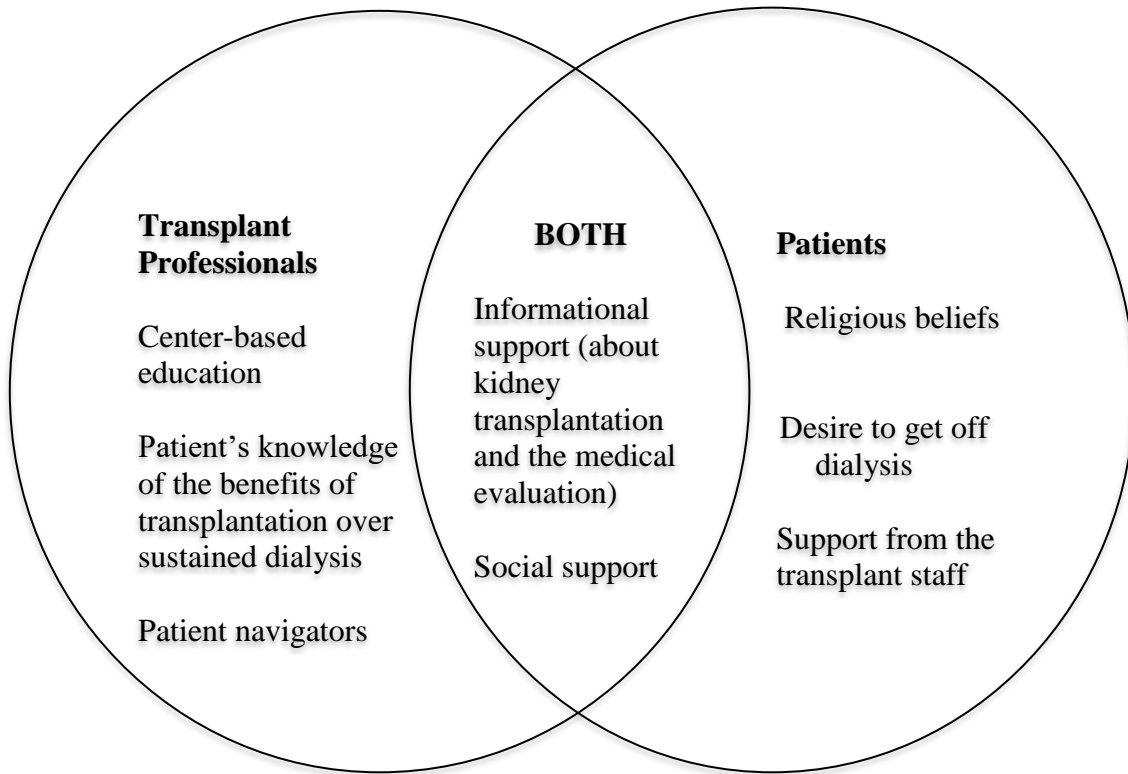
Transplant professionals and patients similarly rated limited income/low SES, insurance issues and lack of a personal means of transportation in their list of top five barriers. From the perspective of transplant professionals, limited or lack of patient motivation and the number of procedures and/or tests required during the pre-transplant evaluation are among the top five barriers. Alternatively, patients listed scheduling difficulties and time constraints. Synonymous rankings and differences between transplant professionals and patients in top five barriers are depicted in Figure 3.



*Figure 3.* Differences and Similarities between participant rankings of the top five barriers to completing the medical evaluation process.

### **Between-Group Differences and Similarities in Top Motivators in Rankings**

Transplant professionals listed center-based education, patients' knowledge of the benefits of transplantation over sustained dialysis and patient navigators as top motivators to completing the evaluation process. In contrast, patients listed scheduling difficulties and time constraints. Synonymous rankings and differences between transplant professionals and patients in the top five motivators are depicted in Figure 4.



*Figure 4.* Differences and Similarities between participant rankings of the top five motivators to completing the medical evaluation process.

### **Group Rankings of Top Five Barriers**

Patients who participated in the focus groups included poor communication with the transplant center and difficulty finding a living donor in their top five rankings. The top five group rankings of barriers by focus group patients are displayed in Table 8.

Table 8  
*Patient Group Rankings of Barriers to Completing the Medical Evaluation*

Top	Barriers	Total Score	Number of Focus Groups/ n of participants	Weighted Total (%)
1.	Insurance issues	20	6 (13)	36.36
2.	Limited income/low SES	12	3 (8)	21.82
3.	Poor communication with the transplant center	9	2 (6)	16.36
4.	Length of time to complete the medical evaluation (e.g., for appointments, for results)	8	3 (9)	14.55
5.	Finding a living donor	6	2 (5)	10.91

*Note.*  $N = 22$ . Priority scores were calculated based on group consensus of the five top barriers elicited during the NGT focus groups (i.e., 1<sup>st</sup> = 5 points, 2<sup>nd</sup> = 4 points, 3<sup>rd</sup> = 3 points etc.) and expressed as a percentage of the weighted total of scores (55).

### Group Rankings of Top Five Motivators

Focus group participants counted financial assistance throughout the evaluation process and information about the medical evaluation process (e.g., financial and psychosocial information). The top five group rankings of motivators are displayed in Table 9.

Table 9  
*Patient Group Rankings of Motivators to Completing the Medical Evaluation*

Top Motivators	Total Score	Number of Focus groups/ n of participants	Weighted Total (%)
1. Social support	18	5 (11)	32.14
2. Information about the medical evaluation process (including financial and psychosocial-related information)	10	2 (6)	17.86
3. Religious Beliefs	10	2 (4)	17.86
4. Financial assistance throughout the evaluation process	9	3 (9)	16.07
5. Support from dialysis center	9	2 (6)	16.07

---

*Note.*  $N = 22$ . Priority scores were calculated based on group consensus of the five top motivators elicited during the NGT focus groups (i.e., 1<sup>st</sup> = 5 points, 2<sup>nd</sup> = 4 points, 3<sup>rd</sup> = 3 points etc.) and expressed as a percentage of the weighted total of scores (56).

**Differences in focus group rankings of barriers based on patient status.** To help address RQ8, Status 1 and Status 7 patients' group rankings were compared. Both Status 1 and 7 patients reported insurance issues in top five barriers. Status 1 patients also reported scheduling difficulties, medical complications, multiple health conditions, and navigating a large hospital. In contrast, Status 7 patients reported limited income/low SES, poor communication with the transplant center, difficulties finding a living donor, and lack of social support.

**Differences in focus group rankings of motivators based on patient status.** To help address RQ8, Status 1 and Status 7 patients' group rankings were compared. Both Status 1 and 7 patients reported social support in top motivators. Status 1 patients also religious beliefs, support from transplant staff, motivation to return to work and a personal means of transportation without relying on others. In contrast, Status 7 patients reported financial assistance throughout the evaluation, information about the medical evaluation process, knowing a successful recipient, and support from the dialysis center.

### **Summary of Barriers and Motivators and Possible Solutions**

A summary of the top barriers, motivators and possible solutions to improve completion rates of the medical evaluation project was developed in an attempt to combine the qualitative and quantitative elements of this project. Table 10 provides a snapshot of the findings from both transplant professionals and patients.

Table 10  
*Summary of Top Barriers, Motivators and Possible Solutions*

<b>Top Barriers</b>	<b>Motivators/Possible Solutions</b>
Insurance issues	<ul style="list-style-type: none"> <li>• Comprehensive Insurance</li> <li>• Information about financial aspects of the evaluation (e.g., insurance paperwork)</li> <li>• Support from the transplant staff especially financial coordinators</li> </ul>
Limited income/low SES	<ul style="list-style-type: none"> <li>• Financial assistance</li> <li>• Information on how to raise funds to help with financial costs</li> <li>• Support from social workers and financial coordinators</li> <li>• Family member assistance with costs of completing the evaluation</li> </ul>
Lack of a personal means of transportation	<ul style="list-style-type: none"> <li>• Instrumental social support</li> <li>• Comprehensive insurance that includes transportation</li> </ul>
Limited/lack of patient motivation	<ul style="list-style-type: none"> <li>• Creating programs to motivate or empower patients</li> <li>• Kidney support groups</li> <li>• Hearing the stories of kidney recipients</li> <li>• Patient navigators</li> </ul>
The number of procedures and/ tests required	<ul style="list-style-type: none"> <li>• Informational support</li> <li>• Center-based education about the medical evaluation process and kidney transplantation</li> <li>• Education catered to patient's understanding</li> <li>• Centralized testing</li> </ul>
Scheduling difficulties/Time constraints	<ul style="list-style-type: none"> <li>• Case management</li> <li>• Good communication between patients and transplant center</li> <li>• Liaisons between transplant center and dialysis center</li> </ul>

## Correlations

Transplant professionals' ratings of perceived barriers and motivators indicated a number of positive associations (see Table 11). This analysis was performed to determine whether certain

barriers and motivators were related to each other. Based on Cohen's (1998) interpretations, the strength of these relationships ranged from moderate to large ( $r$  values ranged from .44 to .68). For example, there was a positive relationship between income and knowledge of treatment options, knowledge of the medical evaluation, health literacy and navigators, with strengths ranging from moderate to large. Similarly, patient ratings of barriers and motivators revealed several positive associations (moderate to large;  $r$  values ranged from .37 to .72) (see Table 11). There was a positive relationship between income and distance to the center, comorbidities, being on dialysis, health literacy and instrumental support. The strength of these relationships were moderate to large.

Ratings for both transplant professionals' and patients' perceived barriers and motivators to completing the medical evaluation process were also examined for associations (see Table 12). There was a positive relationship between distance from the patient's house to the transplant center, and income, comorbidities, and instrumental support. The strength of these relationships was large ( $r$  values ranged from .53 to .64). Knowledge of treatment options for kidney transplantation was also positively related to knowledge of the medical evaluation process, comorbidities, religious beliefs, and being on dialysis ( $r$  values ranged from .50 to .63). Knowledge of the medical evaluation process was positively associated with health literacy, comorbidities, navigators and having instrumental support ( $r$  values ranged from .52 to .63). Furthermore, health literacy was positively related to medical mistrust, navigators, and having instrumental support ( $r$  values ranged from .53 to .67). The two motivators, having navigators and instrumental support, were also positively related ( $r = .67$ ). Income level and being on dialysis was also positively associated ( $r = .53$ ). The majority of the other associations were

moderately positive ( $r$  values ranged from .30 to .49) and the rest were small ( $r$  values ranged from .28 to .29) (see Table 12).



Table 11

*Pearson's Product Moment Correlations for Perceived Barriers and Motivators for Transplant Professionals*

	1	2	3	4	5	6	7	8	9	10	11	12
1. Insurance status	-	.68**	.06	-.20	.04	.41	.20	.29	.36	-.02	.34	.42*
2. Income	-	-	.41	.16	-.05	.48*	.53**	.30	.44**	.02	.58**	.30
3. Distance to center	-	-	-	.46*	.18	.11	.25	.12	.27	.03	.13	.10
4. Comorbidities	-	-	-	-	.20	.27	.28	-.001	.20	-.04	.19	.32
5. Religious beliefs	-	-	-	-	-	.39	.07	-.01	.24	.46*	.07	-.10
6. Knowledge of treatments	-	-	-	-	-	-	.56**	.15	.47*	.26	.53**	.33
7. Knowledge of evaluation	-	-	-	-	-	-	-	.17	.35	-.07	.29	.24
8. Dialysis	-	-	-	-	-	-	-	-	.50*	.33	.50*	.06
9. Health literacy	-	-	-	-	-	-	-	-	-	.47*	.35	.47*
10. Medical mistrust	-	-	-	-	-	-	-	-	-	-	.23	-.08
11. Navigators	-	-	-	-	-	-	-	-	-	-	-	.21
12. Instrumental support	-	-	-	-	-	-	-	-	-	-	-	-

\*\* $p < .01$ ; \* $p < .05$ .

Table 12

*Pearson's Product Moment Correlations for Perceived Barriers and Motivators for Patients*

	1	2	3	4	5	6	7	8	9	10	11	12
1. Insurance status	-	.45*	.47**	.42*	.16	.34	.29	.26	.21	-.08	.32	.40*
2. Income	-	-	.46**	.42*	.34	.31	.24	.54**	.46*	.23	.13	.42*
3. Distance to center	-	-	-	.55**	.17	.34	.26	.32	.39*	.02	.45*	.47**
4. Comorbidities	-	-	-	-	.28	.43*	.45*	.48**	.36	.12	.35	.34
5. Religious beliefs	-	-	-	-	-	.46*	.37*	.31	.12	.22	.11	.29
6. Knowledge of treatments	-	-	-	-	-	-	.54**	.63**	.11	-.03	.39*	.25
7. Knowledge of evaluation	-	-	-	-	-	-	-	.32	.51**	-.04	.52**	.60**
8. Dialysis	-	-	-	-	-	-	-	-	.19	.19	.25	.21
9. Health literacy	-	-	-	-	-	-	-	-	-	.52**	.65**	.68**
10. Medical mistrust	-	-	-	-	-	-	-	-	-	-	.43*	.32
11. Navigators	-	-	-	-	-	-	-	-	-	-	-	.72**
12. Instrumental support	-	-	-	-	-	-	-	-	-	-	-	-

\*\* $p < .01$ ; \* $p < .05$ .

Table 13

*Pearson's Product Moment Correlations for Perceived Barriers and Motivators for all participants*

	1	2	3	4	5	6	7	8	9	10	11	12
1. Insurance status	-	.46**	.23	.16	.09	.26	.20	.20	.21	-.08	.28*	.30*
2. Income	-	-	.53**	.45**	.29*	.45**	.40**	.53**	.49**	.24	.30*	.47**
3. Distance to center	-	-	-	.64**	.28*	.47**	.42**	.42**	.42**	.23	.45**	.54**
4. Comorbidities	-	-	-	-	.34*	.53**	.53**	.45**	.39**	.12	.38**	.47**
5. Religious beliefs	-	-	-	-	-	.50**	.37**	.28*	.20	.33*	.16	.29*
6. Knowledge of treatments	-	-	-	-	-	-	.63**	.58**	.26	.15	.48**	.42**
7. Knowledge of evaluation	-	-	-	-	-	-	-	.40**	.53**	.07	.52**	.63**
8. Dialysis	-	-	-	-	-	-	-	-	.33*	.31*	.38**	.32*
9. Health literacy	-	-	-	-	-	-	-	-	-	.53**	.62**	.67**
10. Medical mistrust	-	-	-	-	-	-	-	-	-	-	.42**	.33*
11. Navigators	-	-	-	-	-	-	-	-	-	-	-	.67**
12. Instrumental support	-	-	-	-	-	-	-	-	-	-	-	-

\*\* $p < .01$ ; \* $p < .05$ .

## **Test of Between Group Differences**

To help address RQ9, Mann-Whitney  $U$  tests were conducted to examine differences between transplant professionals and patients in perception of barriers to completing the medical evaluation process. Transplant professionals ( $Md = 48, n = 23$ ) reported significantly more perceived barriers than patients ( $Md = 34.5, n = 30$ ),  $U = 133.50, z = -3.78, p = <.001, r = .52$  (a large effect). Two Mann-Whitney  $U$  tests were used to examine participant (i.e. transplant professionals and patients) differences in perceived motivators. Specifically, navigators and instrumental support served as a positive impact on completing the medical evaluation process. There was no significant difference between transplant professionals' ( $Md = 6, n = 23$ ) and patients' ( $Md = 4.50, n = 30$ ),  $U = 281.50, z = -1.16, p = .25$ , perceptions of navigators as a positive impact on completing the medical evaluation process. In contrast, there was a significant difference between providers' and patients' perceptions of instrumental support as a positive impact on completing the medical evaluation process,  $U = 207, z = -2.56, p = .01$ . Specifically, transplant professionals ( $Md = 6, n = 23$ ) reported instrumental support as having a greater positive impact on completing the medical evaluation process than did patients ( $Md = 5, n = 30$ ).

## **Discussion**

Renal patients experience a myriad of barriers throughout the medical evaluation process. The multitude of barriers can overwhelm attempts to finding solutions for overcoming these barriers. Categorizing and prioritizing factors that impact completion of the medical evaluation process is essential to helping African American patients proceed through the evaluation process and be listed for transplantation. The present study sought to determine the most important

factors that facilitate and/or impede progression through the medical evaluation by examining the perceptions of both transplant professionals and patients.

Thematic analyses of both semi-structured interviews with transplant professionals and focus groups with patients revealed that renal patients going through the medical evaluation process are most impacted by barriers at the individual-level. Many of these barriers are socio-economic (e.g., insurance issues, limited income, transportation difficulties and lack of social support). This finding corresponds with past literature which indicates that poor Black patients experience longer commutes to the transplant center, have less access to transportation, and those without good health insurance coverage are more likely to face barriers in attempts to seek kidney transplantation (Axelrod et al., 2010; Clark et al., 2008; Patzer et al., 2012). Concerns about finding a living donor and the costs associated with the evaluation were also reported to impact patients' completion of the medical evaluation process. A recent study by Dageforde and colleagues (2015) reported synonymous findings as patients indicated concerns about their ability to find a living donor, and the costs of medications. Further, patients who reported transportation difficulties were less likely to complete their evaluation. Other types of individual-level factors identified were lack of patient motivation, fears about losing disability benefits after transplantation, fears about the transplant surgery, religious beliefs and medical mistrust. Past research has also suggested that medical mistrust may be a contributing factor to the disparity between African Americans and other racial groups in access to kidney transplantation (Churak, 2005; Moore, 2007).

Transplant professionals and patients differed in the number of informational/educational barriers versus systemic barriers cited as impacting completion of the medical evaluation process. The next category of barriers most reported by transplant professionals were

informational/educational barriers. They identified barriers such as lack of knowledge about kidney transplantation, and more specifically lack of knowledge of the medical evaluation process as well as limited formal education. One explanation for patients' limited knowledge of transplantation is that some patients first hear about transplantation from their doctors and nurses (Weng et al., 2005), particularly during their initial appointment for the pre-transplant workup. Patients' lack of information about transplantation is well documented (Alexander & Sehgal, 1999; Navaneethan & Singh, 2006; Weng et al., 2005), even though dialysis centers are required to educate patients about transplantation annually (CMS, 2008). Gaps in formal education were also found to contribute to barriers in completing the medical evaluation in a study that compared Black and Whites referred for a pre-transplant workup (Patzner et al., 2012).

Patients named systemic barriers as second in the likelihood to impact completion of the medical evaluation process. Specifically, they mentioned poor communication between the patients and transplant staff, scheduling difficulties, having to work with several doctors, long wait times for doctors' appointments and test results, and not having access to the transplant coordinators as well as difficulties navigating the hospital system. Of note, the PI observed a disparity between some patients' report of their activation status on the transplant list and what the transplant center indicated as their activation status – these patients believed they had completed their evaluation even though they had been listed as inactive, lending some support to patients' report of poor communication with the transplant center. While it is possible that the status of some of the patients may have changed between the time in which the PI obtained the list of potential participants and actual participation in the study, other research confirms this finding (Gillespie, Hammer, Lee, Nnewiwe, Gordon & Silva, 2011). Gillespie and colleagues revealed in a survey of hemodialysis patients undergoing the pre-transplant work-up that the

majority of these patients erroneously perceived themselves to be active on the waitlist whereas over half lacked knowledge of their status (Gillespie et al., 2011).

Transplant professionals and patients also differed with regard to the third type of barrier to completing the medical evaluation process. Nephrologists, transplant coordinators, social workers, psychologists and a transplant nurse ranked systemic barriers as third, whereas patients reported health-related barriers as having the third most impact on progress to transplant candidacy. Similar to previous studies, delayed referral processes were cited by transplant professionals as contributing to this barrier (Alexander & Sehgal, 1999; Joshi et al., 2012). Health-related barriers reported by patients included health status (e.g., feeling physically sick or fatigued), not being cleared by psychiatry, and having multiple health conditions that required treatment prior to activation on the transplant waitlist. Comorbidities that increase the number of medical procedures required for clearance have been known to limit renal patients' progression through the medical evaluation (Danovitch et al., 2004; Navaneethn & Singh, 2006).

The fourth type of barrier identified by transplant professionals were health-related barriers. In contrast, patient identified informational/educational barriers. Patients expressed a need for information about the medical evaluation process, especially the number of tests involved and the financial aspects of getting a transplant. Notably, transplant professionals reported more barriers relative to patients. This could be attributed to the fact that transplant professionals have a broader view of some of the problems faced by patients given that they consult with several patients. However, in comparison to the majority of patients who have participated in the medical evaluation, the sample surveyed for the current study may have experienced fewer barriers. For example, the majority of the study participants lived within a twelve-mile radius of the transplant center and had access to transportation.

Motivators were also categorized, with transplant professionals' identifying systemic motivators most frequently, followed by informational/educational motivators and individual-level motivators. Specifically, transplant professionals indicated systemic motivators such as more referrals from local nephrologists, patient navigators, case management, physician rapport, compressed testing and comprehensive insurance. Informational/educational motivators consisted of center-based education, formal education, presenting information in lay terms, and education about transplantation to help improve completion rates. Individual-level motivators included patients' desire to get off dialysis or have a better quality of life, religious beliefs that motivate patients, and knowledge of a successful recipient. Alternatively, patients identified individual-level motivators most frequently followed by systemic and informational/educational motivators. Individual-level motivators consisted of family support, financial support from family members, support from the transplant staff, and religious beliefs. Systemic motivators were good communication with the transplant coordinators, updates on the patient's position on the transplant waitlist, and rehabilitation support for patients without family support. Informational and educational motivators included transplant education, having the transplant information geared to the patient's understanding and knowledge of successful transplant recipients. Many of the motivators reported by patients and transplant professionals aligned with the extant literature. Specifically, social networks (especially instrumental support), previous knowledge of transplantation, information about the benefits of transplantation, comprehensive insurance, support from transplant staff and patient navigators have a positive impact on patients' completion of the medical evaluation process (Clark et al., 2008; Dageforde et al., 2015; Sullivan et al., 2012; Weng et al., 2005). A surprising finding was that for the majority of patients in this



study, religious beliefs actually encouraged completion of the evaluation rather than imposing a barrier.

Given the multitude of factors contributing to completion of the transplant medical evaluation, prioritization is critical to understanding the most important and potentially modifiable factors and identifying solutions for their remediation. Participant rankings of the top five barriers and motivators to completing the medical evaluation served this purpose. Patient and transplant professional similarly ranked insurances issues, low SES/limited income and lack of a personal means of transportation in their top five barriers to completing the medical evaluation process. Transplant professionals also ranked lack of patient motivation and the number of tests or medical procedures required to finish the medical evaluation process in their top five. Patients ranked scheduling difficulties and time constraints in trying to attend their medical appointments, dialysis, and participate in regular activities in their top five. The latter barriers are related to the number of tests required to complete the evaluation process since patients have to undergo several medical procedures to become active on the waitlist. Although, transplant professionals may perceive some patients as lacking in motivation, this could be attributed to a number of factors. For example, patient fears about losing their benefits after transplantation or fear of the transplant operation may lead to reduced motivation. Further, many renal patients are physically ill due to prolonged dialysis therapy or as a result of having several comorbidities. Hence, attending several medical appointments is bound to create additional strain, making patients appear less motivated. Transplant professionals may also fail to acknowledge the informational/educational and systemic barriers patients face which results in the perception of patients as lacking motivation.

Participants' rankings of motivators were also prioritized with both transplant professionals and patients prioritizing social support and informational support. Transplant professionals ranked center-based education, patient's knowledge of the benefits of transplantation over dialysis and patient navigators in their top five. In contrast, patients ranked a desire of get off dialysis, religious beliefs and support from the transplant staff in their top five. Together, improvements in transplant education, and additional services and support from the transplant center facilitate patient's completion of the medical evaluation. Additional solutions to reducing the barriers faced by African American renal patients proposed by transplant professionals and patients include comprehensive insurance, financial assistance, assistance with fundraising, creating programs to motivate and empower patients, and continuous education throughout the medical evaluation process. Also, hearing the success stories of kidney recipients, kidney support groups, patient navigators, case management, good communication between the transplant staff and patients, and liaisons between the transplant center and dialysis center were suggested as solutions.

This current study is the first to demonstrate the value of categorizing and prioritized the multitude of factors that impact completion of the medical evaluation process. The use of a focus group with a NGT to prioritize these factors was both innovative and pertinent to determining what is most beneficial for helping these population complete the pre-transplant work-up. Moreover, categorizing these barriers and motivators has the added value of improving researchers and providers' understanding of their patients' needs and will help target interventions. For example, improving center-based education for patients whose barriers are mostly health-related would likely have minimal benefit for improving their odds of completing the medical evaluation process. The current study indicates that African American patients are

faced with several barriers, many of which are the result of socioeconomic disadvantages. Categorizing barriers and motivators to completing the medical evaluation process is the first step in tackling the disparity in access to transplantation between African Americans and other racial groups. Additional resources such as financial assistance, fundraising, comprehensive insurance plans that include assistance with transportation, encouraging family engagement for instance, would likely enhance African American renal patients' ability to complete the medical evaluation process. This study proposed a structure for categorizing factors that impact completion of the medical evaluation process by dividing barriers and motivators into individual-level, systemic, informational/educational and health-related barriers and motivators. Creating a system that categorizes barriers and motivators to pre-transplant work-up completion better equips transplant centers for honing in on ways to help their African American patients complete their evaluation. The prioritization of the top barriers and motivators is also valuable for prioritizing patient needs.

### **Strengths, Limitations and Future Studies**

There are several strengths to the current study. This study provides a better understanding of the experience of African American renal patients. Although previous literature has identified several barriers and motivators to completing the medical evaluation process, no study to date has employed the nominal group technique to categorize and prioritize these factors. The current study provides a structure to help understand these factors in order to find solutions that will ultimately bring parity in access to kidney transplantation for African American patients. By gathering information from both transplant professionals and patients, this study provides the additional advantage of a broader understanding of the pre-transplant work

up. Furthermore, the use of a mixed methods approach provides a thorough form of analysis which extends the previous literature.

There are a number of limitations to this study. Given that snowballing was used as the main recruitment tool with the transplant professional sample, this may limit findings as those who agreed to participate may be motivated by a desire to know more about this topic. Additionally, with snowballing, information sharing may be restricted to in-group members reducing the diversification of participant responses. Future studies should implement an assortment of recruiting techniques to facilitate the generation of a variety of participant responses. Patients who participated in the study had to come to the study location. This is another limitation to the study given that one of the top five barriers to completing the medical evaluation is access to transportation. Therefore, the study sample may be biased since those who participated may actually have fewer barriers in comparison to the larger population of African American renal patients. Nonetheless, these participants were still able to list a substantial number of barriers, highlighting the magnitude of difficulties faced by all renal patients. Future studies should be conducted with a heterogeneous group of patients. A community-based research study in which the researchers conduct the study at a convenient location for patients would be preferable. For example, at the transplant center during patients' appointment, at a dialysis center or by making house calls. Another limitation is that participants who were more reserved in the focus groups may have felt limited in their ability to voice their opinions during the discussions, possibly limiting the emergence of alternative responses.

Given that this study was able to generate a structure for categorizing patient barriers and motivators, future studies should develop a psychometrically-sound questionnaire that measures these barriers and motivators. Consequently, this could be used for additional exploration of this

phenomenon as well as used in transplant centers to assess possible barriers to completion of the medical evaluation process, and identify services needed to enhance patients' ability to progress through the evaluation process to transplant candidacy. Such a tool would better equip transplant professionals to help patients overcome barriers to completion of the pre-transplant work up.

## **Conclusion**

The findings from the current study are useful for providing vital information to transplant centers nationally as it could help improve centers' ability to meet the needs of all patients seeking transplantation, especially African American patients. In consulting with renal patients, it is recommended that transplant professionals attempt to assess barriers and motivators. For example, one participant indicated that her local nephrologist ordered some of the tests she needed for the medical evaluation prior to her initial appointment. As a result, the patient had completed many of the medical procedures before her appointment, making it easier to complete her evaluation. This is an example of simple process that can become standard procedure for the medical evaluation for kidney transplantation.

These results from the current study could also inform intervention programs targeting African American renal patients' ability to completion of the medical evaluation. For example, an intervention with kidney support groups could be implemented to determine its utility for helping improve completion rates. Given that religious beliefs were revealed as a facilitator of completion of the medical evaluation process, involving churches, faith communities and community organizations has the potential for boosting completion rates.

The results of the current study also suggest that a change in the policy of patients losing their benefits, three years post-transplant is warranted. This policy creates an additional burden for renal patients, many of whom may have been out of the workforce for several years due to

their condition. Although they may be ready to join the workforce three years post-transplant, it may be an unrealistic expectation for all patients as a prolonged departure from the workforce may reduce job prospects and leave patients struggling to find work that pays enough to cover the cost of medications. Comprehensive insurance plans are also critical for renal patients given that some patients may be unable to afford co-pays, especially when they are required to undergo several medical procedures and may have to attend specialist appointments. Out-of-pocket costs associated with transplant such as paying for lodging to attend doctors' appointments and transportation difficulties create an additional burden for patients. Currently, ESRD patients qualify for Medicare part A (Hospital insurance) and can also obtain part B (Medical insurance) which has a monthly premium. Both of these services facilitate a patient's ability to obtain full benefits to cover the cost of certain renal replacement therapies (CMS, 2016). Specific to transportation, these services only cover ambulance services and do not cover doctor's visits or trips to the dialysis center. Patients with a Medicare part C (Medicare Advantage Plan) and those with Medicaid are the only ones eligible for coverage of non-emergency doctors' visits. It may be beneficial to extend transportation services to all ESRD patients to reduce the transportation barriers faced by these patients. Further, patients should be supplied with information about national organizations such as the American Kidney Fund and fundraising tools when they initiate the medical evaluation process to expand their access to resources that can help reduce their financial barriers.

In November 2013, the OPTN policy changed to allow patients with an inactive status to accrue time on the waitlist. It is unknown whether this change in policy will impact African American renal patients' completion of the medical evaluation. Nonetheless, the information gathered from the current study could help inform systemic changes that would in turn narrow

the health disparities in access to kidney transplantation between African Americans and other racial groups.

## List of References

- Alexander, G. C., & Sehgal, A. R. (1998). Barriers to cadaveric renal transplantation among blacks, women, and the poor. *JAMA*, 280(13), 1148–52. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9777814>
- Alexander, G. C., & Sehgal, A. R. (2001). Why hemodialysis patients fail to complete the transplantation process. *American Journal of Kidney Diseases*, 37, 321-328. doi:10.1053/ajkd.2001.21297
- Andrews, A. M., Zhang, N., Magee, J. C., Chapman, R., Langford, A. T., & Resnicow, K. (2012). Increasing donor designation through black churches: results of a randomized trial. *Progress in transplantation*, 22, 161-167. doi:10.7182/pit2012281
- Arriola, K. R. J., Perryman, J. P., & Doldren, M. (2005). Moving beyond attitudinal barriers: Understanding African Americans' support for organ and tissue donation. *Journal of the National Medical Association*, 97(3), 339–50. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2568639&tool=pmcentrez&rendertype=abstract>
- Arriola, K. R. J., Perryman, J. P., Doldren, M. A., Warren, C. M., & Robinson, D. H. Z. (2007). Understanding the role of clergy in African American organ and tissue donation decision-making. *Ethnicity & Health*, 12(5), 465–82. doi:10.1080/13557850701616896
- Ashbury, J. (1995). *Qualitative Health Research*. Thousand Oaks, CA: Sage Publications.
- Axelrod, D. A., Dzebisashvili, N., Schnitzler, M. A., Salvalaggio, P. R., Segev, D. L., Gentry, S. E., ... Lentine, K. L. (2010). The interplay of socioeconomic status, distance to center, and interdonor service area travel on kidney transplant access and outcomes. *Clinical Journal of the American Society of Nephrology*, 5(12), 2276–88. doi:10.2215/CJN.04940610



- Ayanian, J. Z., Cleary, P. D., Keogh, J. H., Noonan, S. J., David-Kasdan, J. A., & Epstein, A. M. (2004). Physicians' beliefs about racial differences in referral for renal transplantation. *American Journal of Kidney Diseases*, 43(2), 350–357. doi:10.1053/j.ajkd.2003.10.022
- Birks, M. & Mills, J. (2011). *Grounded Theory: A practical guide*. London: Sage Publications.
- Boulware, L. E., Troll, M. U., Wang, N. Y., & Powe, N. R. (2006). Public attitudes toward incentives for organ donation: a national study of different racial/ethnic and income groups. *American Journal of Transplantation*, 6(11), 2774–85. doi:10.1111/j.1600-6143.2006.01532.x
- Boulware, L. E., Cooper, L. A., Ratner, L. E., LaVeist, T. A., & Powe, N. R. (2003). Race and trust in the health care system. *Public Health Reports*, 118(4), 358–65. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1497554&tool=pmcentrez&rendertype=abstract>
- Boulware, L. E., Meoni, L. A., Fink, N. E., Parekh, R. S., Kao, W. H. L., Klag, M. J., & Powe, N. R. (2005). Preferences, knowledge, communication and patient-physician discussion of living kidney transplantation in African American families. *American Journal of Transplantation*, 5(6), 1503–12. doi:10.1111/j.1600-6143.2005.00860.x
- Boulware, L. E., Ratner, L. E., Cooper, L. A., Sosa, J. A., LaVeist, T. A., & Powe, N. R. (2002). Understanding disparities in donor behavior: race and gender differences in willingness to donate blood and cadaveric organs. *Medical Care*, 40(2), 85–95. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11802081>
- Cabrer, C., Oppenheimer, F., Manyalich, M., Paredes, D., Navarro, A., Trias, E., ... Gutierrez, R. (2003). The living kidney donation process: the donor perspective. *Transplantation Proceedings*, 35(5), 1631–1632. doi:10.1016/S0041-1345(03)00697-3

Callender, C. O., & Miles, P. V. (2004). Institutionalized racism and end-stage renal disease: Is its impact real or illusionary? *Seminars in dialysis*, 17(3), 177–80. doi:10.1111/j.0894-0959.2004.17300.x

Centers for Disease Control and Prevention (CDC), US Department of Health and Human Services. (2014). *Centers for Disease Control and Prevention National Chronic Kidney Disease Fact Sheet: General Information and National Estimates on Chronic Kidney Disease in the United States*. Retrieved from [https://lintvwivb.files.wordpress.com/2014/04/kidney\\_factsheet.pdf](https://lintvwivb.files.wordpress.com/2014/04/kidney_factsheet.pdf)

Centers for Medicare & Medicaid Services (CMS), U.S Department of Health and Human Services. (2008). *Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities*. Retrieved from <https://www.federalregister.gov/articles/2008/04/15/08-1102/medicare-and-medicaid-programs-conditions-for-coverage-for-end-stage-renal-disease-facilities>[PubMed]

Centers for Medicare & Medicaid Services (CMS), U.S Department of Health and Human Services. (2016). *Medicare Coverage of Kidney Dialysis & Kidney Transplant Services*. Retrieved from <https://www.medicare.gov/Pubs/pdf/10128-Medicare-Coverage-ESRD.pdf>

Chang, A., Anderson, E. E., Turner, H. T., Shoham, D., Hou, S. H., & Grams, M. (2013). Identifying potential kidney donors using social networking websites. *Clinical Transplantation*, 27(3), E320-E326. doi:10.1111/ctr.12122

Christensen, A. J., & Ehlers, S. L. (2002). Psychological factors in end-stage renal disease: An emerging context for behavioral medicine research. *Journal of Consulting and Clinical Psychology*, 70(3), 712–724. doi:10.1037//0022-006X.70.3.712

- Churak, J. M. (2005). Racial and ethnic disparities in renal transplantation, *Journal of National Medicine*, 97(2), 153–160.
- Clark, C. R., Hicks, L. S., Keogh, J. H., Epstein, A. M., & Ayanian, J. Z. (2008). Promoting access to renal transplantation: the role of social support networks in completing pre-transplant evaluations. *Journal of General Internal Medicine*, 23(8), 1187–93.  
doi:10.1007/s11606-008-0628-7
- Cohen, D., & Crabtree, B. (2006). Qualitative Research Guidelines Project. Retrieved from <http://www.qualres.org/HomeSemi-3629.html>
- Coorey, G. M., Paykin, C., Singleton-Driscoll, L. C., & Gaston, R. S. (2009). Barriers to preemptive kidney transplantation. *American Journal of Nursing*, 109(11), 28–37.
- Corbie-Smith, G., Thomas, S., Williams, M., & Moody-Ayers, S. (1997). Attitudes and beliefs of African Americans toward participation in medical research, *Journal of General Internal Medicine*, 14, 537–546.
- Corner, J., Wright, D., Hopkinson, J., Gunaratnam, Y., McDonald, J. W., & Foster, C. (2007). The research priorities of patients attending UK cancer treatment centres: findings from a modified nominal group study. *British Journal of Cancer*, 96(6), 875–81.  
doi:10.1038/sj.bjc.6603662
- Creswell, J. W. (2007). *Qualitative Inquiry And Research Design: Choosing Among Five Approaches*. Upper Saddle River, NJ: Sage Publications, Inc.
- Dageforde, L. A., Box, A., Feurer, I. D., & Cavanaugh, K. L. (2015). Understanding patient barriers to kidney transplant evaluation. *Transplantation*, 99(7), 1463-9. doi: 10.1097/TP.0000000000000543

- Danovitch, G. M., Cohen, B., & Smits, J. M. A. (2002). Waiting time or wasted time? The case for using time on dialysis to determine waiting time in the allocation of cadaveric kidneys. *American Journal of Transplantation*, 2(10), 891–3. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12482138>
- Delp, P., Thesen, A., Motiwalla, J., & Seshadri, N. (1977). *Systems tools for project planning*. Bloomington, IN: International Development Institute.
- Delamere, T. A., Wankel, L. M., & Hinch, T. D. (2001). Development of a scale to measure resident attitudes toward the social impacts of community festivals, part I: Item generation and purification of the measure. *Event Management*, 7(250), 11–24.
- Faul, F., Erdfelder, E., Lang, A.G., & Buchner, A. (2007). G\*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191. doi:10.3758/BF03193146
- Fink, A., Kosecoff, J., Chassin, M., & Brook, R. H. (1984). Consensus methods: characteristics and guidelines for use. *American Journal of Public Health*, 74(9), 979–83. Retrieved from <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1651783&tool=pmcentrez&rendertype=abstract>
- Glasser, B. G., & Strauss, A. L. (2012). *This discovery of Grounded theory: Strategies for qualitative research*. New Brunswick, NJ: Aldine Transaction.
- Gallagher C. (1998). Religious outreach for organ and tissue donation. *Journal of Transplant Coordination*, 8(1), 60–62.
- Garg, P. P., Diener-West, M., & Powe, N. R. (2001). Reducing racial disparities in transplant activation: Whom should we target? *American Journal of Kidney Diseases*, 5(5), 921–931. doi:10.1053/ajkd.2001.23612

- Gaston, R. S., Danovitch, G. M., Adams, P. L., Wynn, J. J., Merion, R. M., Deierhoi, M. H., ... Delmonico, F. L. (2003). The report of a national conference on the wait list for kidney transplantation. *American Journal of Transplantation*, 3(7), 775–85. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12814469>
- Gillespie, A., Hammer, H., Lee, J., Nnewiwe, C., Gordon, J., & Silva, P. (2011). Lack of listing status awareness: Results of a single-center survey of hemodialysis patients. *American Journal of Transplantation*, 11(7), 1522-6. doi: 10.1111/j.1600-6143.2011.03524.x.
- Grubbs, V., Gregorich, S. E., Perez-Stable, E. J., & Hsu, C.-Y. (2009). Health literacy and access to kidney transplantation. *Clinical Journal of the American Society of Nephrology*, 4(1), 195–200. doi:10.2215/CJN.03290708
- Gruessner, R., & Benedetti, E. (Eds.). (2008). *Living donor organ transplantation*. New York, NY: McGraw-Hill.
- Hall, Y. N., Choi, A. I., Xu, P., O'Hare, A. M., & Chertow, G. M. (2011). Racial ethnic differences in rates and determinants of deceased donor kidney transplantation. *Journal of the American Society of Nephrology*, 22(4), 743–51. doi:10.1681/ASN.2010080819
- Harvey, N., & Holmes, C. A. (2012). Nominal group technique: An effective method for obtaining group consensus. *International Journal of Nursing Practice*, 18(2), 188–94. doi:10.1111/j.1440-172X.2012.02017.x
- Heerspink, H. J. L., Ninomiya, T., Zoungas, S., de Zeeuw, D., Grobbee, D. E., Jardine, M. J., Gallagher, M., ...Perkovic, V. (2009). Effect of lowering blood pressure on cardiovascular events and mortality in patients on dialysis: A systematic review and meta-analysis of randomized controlled trials. *Lancet*, 373, 1009-15. doi:10.1016/S0140-6736(09)60212-9

- Held, P. J., Pauly, M. V., Randall, R., Bovbjerg, J. D., Newmann, J., & Salvatierra, O. (1988). Access to kidney transplantation: Has the United States eliminated income and racial differences? *Archives of Internal Medicine*, *148*, 2594 – 2600.
- IBM Corporation. (2015). *IBM SPSS Statistics for Windows, Version 23.0*. Armonk, NY: IBM Corporation.
- Jhamb, M., Weisbord, S. D., Steel, J. L., & Unruh, M. (2008). Fatigue in patients receiving maintenance dialysis: A review of definitions, measures and contributing factors. *American Journal of Kidney Diseases*, *52* (2), 353-365. doi:10.1053/j.ajkd.2008.05.005
- Joshi, S., Gaynor, J. J. & Ciancio, G. (2012). Review of ethnic disparities in access to renal transplantation. *The Journal of Clinical and Translational Research*, *26*(4), E337–E343. doi: 10.1111/j.1399-0012.2012.01679.x
- Kasiske, L. (1998). Race and socioeconomic on the kidney transplant factors influencing list Placement. *Journal of American Society of Nephrology*, *9*, 2142-2147.
- Klag, M. J., Whelton, P. K., Randall, B. L., Neaton, J. D., Brancati, F. L., & Stamler, J. (1997). End-stage renal disease in African American and white men. 16-year MRFIT findings. *JAMA*, *277*(16), 1293-98.
- Klassen. A. C., Hall, A.G., Saksvig, B., Curbow, B., & Klassen, D. K. (2002). Relationship between patient's perceptions of disadvantage and discrimination and listing for kidney transplantation. *American Journal of Public Health*, *92*, 811-817.
- Krefting, L. (1991) Rigor in Qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, *45*, 214-222.

- Ladin, K., Rodrigue, J. R., & Hanto, D. W. (2009). Framing disparities along the continuum of care from chronic kidney disease to transplantation: barriers and interventions. *American Journal of Transplantation*, 9(4), 669–74. doi:10.1111/j.1600-6143.2009.02561.x
- Lebedo, I. (1998). Principles and practice of hemofiltration and hemodiafiltration. *Artificial Organs*, 22 (1), 20-25.
- Lunsford, S. L., Simpson, K. S., Chavin, K. D., Hildebrand, L. G., Miles, L. G., Shilling, L. M., ... Baliga, P. K. (2006). Racial differences in coping with the need for kidney transplantation and willingness to ask for live organ donation. *American Journal of Kidney Diseases*, 47(2), 324–31. doi:10.1053/j.ajkd.2005.10.018
- MacPhee, I., & Fronek, J. (2012). (Eds.). *Handbook of renal and pancreatic transplantation*. Hoboken: Wiley-Blackwell. Retrieved from wiley.com.
- Martins, D., Tareen, N., & Norris, K. C. (2002). The epidemiology of end-stage renal disease among African Americans. *The American Journal of the Medical Sciences*, 323(2), 65–71. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/11863081>
- Maxwell, J.A. (2013). *Qualitative research design: An interactive approach*. (3Ed.). Thousand Oaks, CA: Sage Publications.
- McGrath, M. M., & Rubin, M. F. (2012). Evaluation of renal transplant candidates. In A. Chandraker, M. H. Sayegh, & A. K. Singh (Eds.), *Core concepts in renal transplantation* (pp. 59-80). New York, NY: Springer.
- Moore, W. R. (2007). The Crisis confronting the African American community: Organ and Tissue Donation. *Journal of African American Studies*, 11(1), 42–54. doi:10.1007/s12111-007-9005-6

- Morgan, S. E. (2004). The Power of Talk: African Americans' communication with family members about organ donation and its impact on the willingness to donate organs. *Journal of Social and Personal Relationships*, 21(1), 112–124. doi:10.1177/0265407504039845
- Morton, R. L., Tong, A., Webster, A. C., Snelling, P., & Howard, K. (2011). Characteristics of dialysis important to patients and family caregivers: a mixed methods approach. *Nephrology, Dialysis, Transplantation*, 26(12), 4038–46. doi:10.1093/ndt/gfr177
- Navaneethan, S. D., & Singh, S. (2006). A systematic review of barriers in access to renal transplantation among African Americans in the United States. *Clinical Transplantation*, 20(6), 769–75. doi:10.1111/j.1399-0012.2006.00568.x
- Norris, L., (2014). *Transplant Administration*. Hoboken: Wiley-Blackwell. Retrieved from [www.wiley.com](http://www.wiley.com)
- Ortiz, J. A., Manzarbeitia, C., & Zaki, R. (2002). Pretransplant evaluation: kidney and pancreas. In C. Manzarbeitia (Ed.), *Practical manual of abdominal organ transplantation* (pp. 41). New York: Kluwer Academic/Plenum Publishers.
- Pallant, J. (2010). *SPSS Survival Manual*. Berkshire, England: McGraw Hill.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: Sage.
- Patzer, R. E., Perryman, J. P., Schragar, J. D., Pastan, S., Amaral, S., Gazmararian, J. A., ... McClellan, W. M. (2012). The role of race and poverty on steps to kidney transplantation in the Southeastern United States. *American Journal of Transplantation*, 12(2), 358–68. doi:10.1111/j.1600-6143.2011.03927.x
- Patzer, R. E., Amaral, S., Wasse, H., Volkova, N., Kleinbaum, D., & McClellan, W. M. (2009). Neighborhood poverty and racial disparities in kidney transplant waitlisting. *Journal of American Society of Nephrology*, 20(6), 1333–40. doi:10.1681/ASN.2008030335



- Pham, P. T., Pham, P. T., Pham, S. V., Pham P. T., & Pham, P. C. (2011). New onset diabetes after transplantation (NODAT): An overview. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy, 4*, 175-186. doi: 10.2147/DMSO.S19027
- Pradel, F. G., Mullins, C. D., Bartlett, S. T. (2003). Exploring donor's and recipients' attitudes about living donor kidney transplantation. *Progress in Transplantation, 13*, 203-210.
- O'Hare, A. M., Johansen, K. L., & Rodriguez, R. A. (2006). Dialysis and kidney transplantation among patients living in rural areas of the United States. *Kidney International, 69*(2), 342-9. doi: 10.1038/sj.ki.5000044
- Organ Procurement and Transplantation Network (OPTN). (2016). Retrieved from <http://optn.transplant.hrsa.gov/>.
- Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR), Department of Health and Human Services, Health Resources and Services Administration. (2014) *OPTN/SRTR 2012 Annual Data Report*. Retrieved from [https://srtr.transplant.hrsa.gov/annual\\_reports/2012/pdf/2012\\_SRTR\\_ADR.pdf](https://srtr.transplant.hrsa.gov/annual_reports/2012/pdf/2012_SRTR_ADR.pdf)
- Porter, J. (2013). Be careful how you ask! Using focus groups and nominal group technique to explore the barriers to learning. *International Journal of Research & Method in Education, 36*(1), 33–51. doi:10.1080/1743727X.2012.675554
- Rodrigue, J. R., Cornell, D. L., Kaplan, B., & Howard, R. J. (2008). A randomized trial of a home-based educational approach to increase live donor kidney transplantation: Effects in blacks and whites. *American Journal of Kidney Diseases, 51*(4), 663–70.  
doi:10.1053/j.ajkd.2007.11.027
- Rosenstock, I. M. (1974). The Health Belief Model and preventive health behavior. *Health Education & Behavior, 2*(4), 354-386. doi: <https://doi.org/10.1177/109019817400200405>

- Rovai, A. P., Baker, J.D., & Ponton, M.K. (2013). *Social Science Research Design and Statistics: A Practitioner's Guide to Research Methods and IBM SPSS Analysis* (2<sup>nd</sup> ed.). Virginia Beach, VA: Watertree Press.
- Sanderson, T., Morris, M., Calnan, M., Richards, P., & Hewlett, S. (2010). Patient perspective of measuring treatment efficacy: The rheumatoid arthritis patient priorities for pharmacologic interventions outcomes. *Arthritis Care & Research*, 62(5), 647–56. doi:10.1002/acr.20151
- Serur, D., Saal, S., Wang, J., Sullivan, J., Bologa, R., Hartono, C., ... Cheigh, J. (2011). Deceased-donor kidney transplantation: improvement in long-term survival. *Nephrology*, 26(1), 317–24. doi:10.1093/ndt/gfq415
- Soucie, J. M., Neylan, J. F., & McClellan, W. (1992). Race and sex differences in the identification of candidates for renal transplantation. *American Journal of Kidney Diseases*, 14, 414-19.
- Strauss, A., & Corbin, J. (1998). *Basic qualitative research: Techniques and procedures for developing grounded theory* (2Ed.). Thousand Oaks, CA: Sage Publications.
- Sullivan, C., Leon, J. B., Sayre, S. S., Marbury, M., Ivers, M., Pencak, J. A., ... Sehgal, A. R. (2012). Impact of navigators on completion of steps in the kidney transplant process: A randomized, controlled trial. *Clinical Journal of the American Society of Nephrology*, 7(10), 1639–45. doi:10.2215/CJN.11731111
- Terrell, F., Moseley, K. L., Mosley, K. L., Terrell, A. S., & Nickerson, K. J. (2004). The relationship between motivation to volunteer, gender, cultural mistrust, and willingness to donate organs among Blacks. *Journal of the National Medical Association*, 96(1), 53–60.
- Retrieved from

<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2594755&tool=pmcentrez&rendertype=abstract>

- Terrell, F., & Terrell, S. (1984). Race of counselor, client sex, cultural mistrust level, and premature termination from counseling among Black clients. *Journal of Counseling Psychology, 31*(3), 371–375. doi:10.1037//0022-0167.31.3.371
- Thompson, L. S. (1993). Educating the African-American community on organ donation. *Journal of the National Medical Association, 85*, 17–19.
- Traino, H. M. (2014). Communication self-efficacy, perceived conversational difficulty, and renal patients' discussions about transplantation. *Patient Education and Counseling, 94*, 180-186. Retrieved from <http://dx.doi.org/10.1016/j.pec.2013.10.012>
- Van de Vaen, A. H., & Delbecq, A. L. (1972). The nominal group as a research instrument for exploratory health studies. *American Journal of Public Health, 62*(3), 337-342.
- Waterman, A. D., Rodrigue, J. R., Purnell, T. S., Ladin, K., & Boulware, L. E. (2010). Addressing racial and ethnic disparities in live donor kidney transplantation: Priorities for research and intervention. *Seminars in Nephrology, 30*(1), 90–8. doi:10.1016/j.semnephrol.2009.10.010
- Waterman, A. D., Stanley, S. L., Covelli, T., Hazel, E., Hong, B. A., & Brennan, D. C. (2006). Living donation decision making: Recipients' concerns and educational needs. *Progress in Transplantation, 16*(1), 17-23.
- Weng, F. L., Joffe, M. M., Feldman, H. I., & Mange, K. C. (2005). Rates of completion of the medical evaluation for renal transplantation. *American Journal of Kidney Diseases, 46*(4), 734–45. doi:10.1053/j.ajkd.2005.06.011

Whaley, A. L. (2001). Cultural mistrust and mental health services for African Americans: A review and meta-analysis. *The Counseling Psychologist*, 29(4), 513–531.

doi:10.1177/0011000001294003

United Network for Organ Sharing (UNOS). (2016). Retrieved from <http://www.unos.org/data/>

United States Census Bureau. (2016). Retrieved from

<https://www.census.gov/quickfacts/fact/table/US/RHI225216#viewtop>

United States Renal Data System (USRDS), National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. (1999). *1999 Annual Data Report.*

*Treatment Modalities for ESRD patients.* Retrieved from

<https://www.usrds.org/chapters/ch03.pdf>

United States Renal Data System (USRDS), National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. (2013). *2013 Annual Data Report. Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States.* Retrieved from [https://www.usrds.org/2013/pdf/v1\\_00\\_intro\\_13.pdf](https://www.usrds.org/2013/pdf/v1_00_intro_13.pdf).

United States Renal Data System (USRDS), National Institutes of Health, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. (2015). *2015 Annual Data Report. Epidemiology of Kidney Disease in the United States.* Retrieved from <https://www.usrds.org/2015/view/>

## Appendix A

### Transplant Professionals' Interview Protocol

#### Opening Script:

Thank you for taking the time to speak with me today about your perceptions of the factors impacting the completion of the medical evaluation for renal patients seeking kidney transplantation. My name is Camilla Nonterah and I am a VCU counseling psychology doctoral candidate working on my dissertation research. The purpose of this interview is to gather transplant professionals' perceptions of the factors that facilitate and impede renal patients' completion of the medical evaluation process for kidney transplantation. Please know that your opinions are appreciated and your honesty and experience working with renal patients is valued. The results of the interviews will be incorporated into the second part of my study which will examine the views of patients to have a better understanding of the medical evaluation process for this population. With your permission I would like to record this interview, your identity and what you say will be kept confidential. Your name will not appear in the interview transcript or any summary reports. The interview will last about 45-60 minutes. Do you have any questions before we begin?

#### **Experience:**

1. Please describe your experience working with ESRD patients seeking a transplant? [**Probe:** *How long have you worked with this population? Overall, would you say that your experience with has been generally positive or negative? Why? What challenges have you faced in working with patients seeking kidney transplantation?*]
2. How has your experience differed when working with patients of different sexes (male versus female)? [**Probe:** *That is, in what ways is it easier or more difficult to work with males as compared to females?*]
3. How has your experience differed when working with patients from different racial and/or ethnic backgrounds (for example, African American patients versus Caucasian patients)? [**Probe:** *That is, in what ways is it easier or more difficult to work with African Americans as compared to Whites?*]

#### **Medical Evaluation Process:**

4. Please describe the medical evaluation process at your transplant center? [**Probe:** *What tests and/or medical procedures must patients undergo to be evaluated and listed for transplantation?*]
5. How long does it take the average patient to complete the evaluation process? [**Probe:** *And, how long does it typically take for patients with multiple other health issues, in addition to renal failure, to complete the medical work up?*]
6. At what point in the evaluation are patients most likely to stop completing or drop out of the process?
7. What challenges do patients at your center face in completing the medical evaluation for listing for kidney transplantation? [**Probe:** *For example, perhaps insurance issues, the sheer*

*number of tests, or transportation difficulties interfere with patients' ability to complete the evaluation? Anything else?]*

*As you may already know, ethnic/racial disparities have been found in all aspects of transplantation, including patients' completion of the medical evaluation process and subsequent listing for transplantation. While I'm interested in finding ways to improve the process and reduce barriers to completing the transplant evaluations for all patients, I'm particularly interested in reducing or eliminating these disparities. So, for the following questions, I will ask about potential barriers to completing the process that all patients may face; then, I will ask you to think specifically about barriers for Blacks/African American patients.*

**Barriers:**

8. What individual-level factors impede patients' completion of the evaluation process? [**Probe:** *In your experience, have religious beliefs, medical mistrust, motivation, or some other factors kept patients from completing the process? NB: Write down individual-level factors mentioned by participant*]

9. What health-related factors keep patients from finishing the evaluation process? [**Probe:** *In your experience, have the number or nature of any additional health issues prevented or impeded patients' completion of the medical evaluation? NB: Write down health-related-level factors mentioned by participant*]

10. What system-level factors keep patients from finishing the evaluation process and being listed for transplantation? [**Probe:** *That is, what problems in the healthcare system, such as the evaluation process itself or the lack of patient navigators, affect patients' ability to complete the testing process? NB: Write down system-level factors mentioned by participant*]

11. What information or education-related factors keep patients from finishing the process? [**Probe:** *In your experience, have patients' limited knowledge of transplantation or the medical evaluation process impacted their completion of the evaluation? NB: Write down information or education-related factors mentioned by participant*]

*So, we've now discussed a variety of potential barriers to patients' successful completion of the medical evaluation and subsequent wait listing for kidney transplantation.*

12a. How do you think these barriers differ depending on the patient's gender? [**Probe:** *What factors, if any, are specific to women or specific to men (that is, they do not impede men but do limit women's capacity to compete the evaluation or vice-versa)?]*

12b. How might these factors affect African American and Caucasian patients differently? [**Probe:** *What factors, if any, are specific to African American patients (that is, they do not*

*impede Caucasian patients but do limit African Americans' capacity to compete the evaluation)?*  
**NB: Remind participant of individual, health, systemic, information list above if needed]**

***The following questions focus solely on your experience working with Black/African American patients. Please answer Yes or No to each question.***

13a. In your experience, have Black patients' income level impacted their ability to complete the medical evaluation process? [*Probe for transportation difficulties, ability to pay for food or lodging*]

0  No

1  Yes

2  Depends

**If no skip to next question**

13b. If yes, how?

13c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (income level)?

14a. Do you believe that the distance from the transplant center to a patient's house impacts Black patients' ability to complete the evaluation? [*Probe for difficulties coming to appointments or finding lodging*]

0  No

1  Yes

2  Depends

14b. If yes, in what way or ways?

**If no skip to next question**

14c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (distance from the transplant center to a patient's house)?

15a. Health literacy is defined as the degree to which individuals have the ability to obtain, process and understand basic health information and services in order to make appropriate health decisions. Do you think that health literacy has an impact on African American patients' ability to complete the medical evaluation process?

0  No

1  Yes

2  Depends

**If no skip to next question**

15b. If yes, how?

15c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (health literacy)?

16a. Does knowledge about the different treatment options available impact Black patients' ability to complete the medical evaluation process? [*Probe for lack of knowledge about the benefits of kidney transplantation*]

0  No

1  Yes

2  Depends

**If no skip to next question**

16b. If yes, how?

16c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (knowledge about the different treatment options available)?

17a. Does knowledge about the medical evaluation process, including the time it will take to complete all the necessary tests and the specific tests that will be conducted, impact African American patients' ability to complete the process? [*Probe for a lack of understanding of the process*]

0  No

1  Yes

2  Depends

**If no skip to next question**

17b. If yes, how?

17c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (knowledge about the medical evaluation process)?

18a. Do comorbidities (i.e., other illnesses in addition to ESRD) impact Black patients' ability to complete the evaluation? [*Probe for an increase in the number of tests they need to complete*]

0  No

1  Yes

2  Depends

**If no skip to next question**

18b. If yes, how?

18c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (comorbidities)?

19a. In your experience, have religious beliefs impacted African American patients' ability to complete the medical evaluation process? [*Probe for beliefs regarding personal sacrifice, carrying personal burdens alone, or concerns about desecrating the body through transplantation*]

0  No

1  Yes

2  Depends

**If no skip to next question**

19b. If yes, how?



19c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (religious beliefs)?

20a. *Medical mistrust is defined as concerns about trust and discrimination in populations of patients with chronic illness. Do you believe that medical mistrust impacts Black patients' ability to complete the process? [Probe for discrimination or perceived prejudice by health care providers]*

0  No

1  Yes

2  Depends

**If no skip to next question**

20b. If yes, how?

20c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (medical mistrust)?

21a. *Navigators are individuals who educate patients and help them navigate through the medical system. Does the lack of patient navigators impact African American patients' ability to complete the process?*

0  No

1  Yes

2  Depends

**If no skip to next question**

21b. If yes, how?

21c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (navigators)?

22a. *Instrumental support networks are defined as the number of close friends or family that can help with daily activities at home. This means does the patient have people who help him/her with activities such as cooking, child care, scheduling appointments and transportation?*

Does instrumental support, or the lack thereof, impact African American patients' ability to complete the medical evaluation process?

0  No

1  Yes

2  Depends

**If no skip to next question**

22b. If yes, how?

21c. Are Blacks/African American patients more or less likely than White/Caucasian patients to be affected by this (instrumental support networks)?

**Motivators:**

23. What factors motivate patients to complete the evaluation process? [**Probe:** *What individual, systemic, health or information related factors motivate patients to complete the evaluation process?*]

24. Please complete this statement. In my experience, the typical patient who completes the medical evaluation process is ..... [**Probe:** *Those who complete the medical evaluation are typically of what gender, racial group, age etc?]*

**Potential Solutions:**

25. In your opinion, what might be done to help patients overcome these barriers and complete the medical evaluation process?

26. What would you recommend to help African American patients, specifically, complete the medical evaluation process and reduce disparities in this aspect of transplantation?

Finally, as part of this project, I will compare transplant professionals' rankings of the barriers and motivators to patients' completion of the medical evaluation process to patients' rankings. Please take a moment now to numerically rank the 5 most significant barriers and motivators from the following lists [from the list emailed to you at the start of this interview].

*Closing Script:*

Thank you for your time today. Here is a \$5 Starbuck's gift card as thanks for your time and participation. If you have any additional comments or questions about this research, please contact me, Camilla Nonterah, at nonterahcw@vcu.edu.

Would you like a copy of the results when they are ready?

0  Does not want results

1  Wants results



7. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think an African American patient’s income level impacts their ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

8. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think the distance from the transplant center to the patient’s house impacts an African American patient’s ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

9. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think comorbidities (i.e. a patient having other illness in addition to ESRD) impact an African American patient’s ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

10. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think an African American patient’s religious beliefs impacts their ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

11. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think an African American patient’s knowledge about different treatments impacts their ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

12. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, , how much do you think an African American patient’s knowledge about the medical evaluation process impacts their ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

13. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, , how much does being on dialysis impact an African American patient’s ability to complete the medical evaluation process?



## Appendix C

### **ESRD Patients Nominal Focus group (Status 1 &2) Protocol**

#### **I. Introduction**

Thank you all for coming today/tonight. My name is Camilla Nonterah and I am a counseling psychology doctoral student at VCU. Assisting me today is \_\_\_\_\_. Thank you for agreeing to participate in this study. The information you provide will be very useful in helping us understand the factors which impact the completion of the medical evaluation process for end stage renal disease (ESRD) patients.

#### **II. Description of Focus Group:**

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about 45 minutes to 1 hour. During this time period, I will ask you some questions about your experience as a patient with end stage renal disease (ESRD). While I encourage you to draw on your experience, we do not need to know the details of your medical history or specific visits. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone speaks their mind and participates, particularly if you have a different perspective from others in the group. There are no "right" or "wrong" answers to the questions. We are interested in the full range of perspectives.

My role is to help facilitate the discussion of this topic. I may ask specific individuals about their thoughts or ideas if they have not had a chance to participate very much in the discussion. I also may have to interrupt someone to ask that we get everyone's opinion or to move on to another topic. This is to ensure that we get everyone's views on all the questions in the relatively short time we have together.

Another important ground rule for this meeting is that we will respect the privacy of all group members and keep the content of our discussion confidential. We will call each other only by first names, and your verbal and written comments will be kept strictly confidential. I will be audiotaping the discussion, and you may see me taking notes. These steps are necessary for us to accurately record what is said today/tonight, but we will not include any information that will personally identify you in our notes or recordings. At any point in time, you are free to stop participating in the discussion or even leave. When we analyze our notes from this discussion, we will be most interested in what the group as a whole has to say. After we complete the analysis, we will erase and throw away the tape recording. When we publish the results of our study, no individuals will be identified. Finally, please remember that located on your consent form are the names and numbers of people you can call in future if you have questions about your rights as a research participant.

Does anyone have any questions? [Answer any questions]

### III. Warm up [7 minutes]

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself/herself. Specifically, I would like everyone to tell us their first name (you can also choose a pseudonym) and briefly tell us what their hobbies or interests are.

Let me begin....

[Moderator: Introduces herself/himself and then goes around the table.]

[Moderators Assistant: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to follow more accurately who in the group is speaking when listening to the tapes again as well as confidentially matching forms completed during the focus group with names.]

---

#### TOPIC 1: INTRODUCTION

1. What made you interested in participating in this study? [**Probe:** *Are you interested in the topic? Are you looking for answers? Are you hoping that your participation will help others?*]

#### TOPIC 2: ESRD EXPERIENCE

2. Describe your experience so far as a patient with kidney disease? [**Probe:** *What challenges have you faced as a patient with ESRD?*]

#### TOPIC 3: MEDICAL EVALUATION EXPERIENCE

3. What information have you been given about the medical evaluation process? [**Probe:** *Were you provided with information about the evaluation process itself and the number of tests you would have to take for instance? Were you given with information about the risks and benefits of kidney transplantation? Were you given information about what will happen after transplantation?*]

What information would have been helpful? [**Probe:** *Would you have liked additional information about the evaluation process such as the number of tests you have to take, possible insurance issues, the importance of having others who could support you through the process?*]

4. Where are you in the medical evaluation process? [**Probe:** *Have you completed the process and all necessary requirements?*]
5. What tests did you have to complete? [**Probe:** *That is have you finished the basic blood work and initial testing? What tests are you yet to complete?*]
6. What was it like for you to go through the medical evaluation process? [**Probe:** *Overall, would you say that your experience with has been generally positive or negative? Why? Are there certain things which have been particularly difficult?*]

#### TOPIC 4: MOTIVATORS TO COMPLETING THE MEDICAL EVALUATION

7. What are some things which made it easier to complete the medical evaluation process for kidney transplantation? [**Probe:** *For example, did having the support of your family, the transplant staff or being educated about the evaluation process make it easier to complete the medical evaluation process? Anything else?*]
8. Now I'll like you to list the 5 most important things (on the post it you've been provided) which helped you complete the medical evaluation process. Place rankings beside the motivators you've listed (with 1 being the most significant motivator, followed by 2 and so on) [**Probe:** *group members to list top 5 motivators and build a hierarchy*]

#### TOPIC 5: BARRIERS TO COMPLETING THE MEDICAL EVALUATION

9. What are some things which made it difficult to complete the medical evaluation process? [**Probe:** *For example, perhaps insurance issues, the sheer number of tests, or transportation difficulties, additional health problems, not having close friends or family for support interfered with your ability to complete the evaluation? Anything else?]]*
10. Now I'll like you to list the 5 most important barriers (on the post it you've been provided) which made it difficult to complete the medical evaluation process. Place rankings beside the barriers you've listed (with 1 being the most significant barrier, followed by 2 and so on) [**Probe:** *group members to list top 5 barriers and build a hierarchy*]

#### IV. CLOSING:

Option 1: *Time Still Remaining:* Before we end the session, are there any other comments that you have or topics that we missed in our discussion? Thank you for your time and participation.

Option 2: *Time is Up:* If, after today's session, you think of any other comments or topics that were missed please feel free to contact me (e.g., focus group facilitator) by email. Thank you for your time and participation.



## Appendix D

### ESRD Patients Nominal Focus group (Status 7) Protocol

#### **I. Introduction**

Thank you all for coming today/tonight. My name is Camilla Nonterah and I am a counseling psychology doctoral student at VCU. Assisting me today is \_\_\_\_\_, Thank you for agreeing to participate in this study. The information you provide will be very useful in helping us understand the factors which impact the completion of the medical evaluation process for end stage renal disease (ESRD) patients.

#### **II. Description of Focus Group:**

To begin, I would like to give you an overview of how this focus group will work. As you know, the focus group will last for about 45 minutes to 1 hour. During this time period, I will ask you some questions about your experience as a patient with end stage renal disease (ESRD). While I encourage you to draw on your experience, we do not need to know the details of your medical history or specific visits. The goal is for you to discuss the questions as a group. The most important information will come from the range of everyone's thoughts and ideas. It is very important that everyone speaks their mind and participates, particularly if you have a different perspective from others in the group. There are no "right" or "wrong" answers to the questions. We are interested in the full range of perspectives.

My role is to help facilitate the discussion of this topic. I may ask specific individuals about their thoughts or ideas if they have not had a chance to participate very much in the discussion. I also may have to interrupt someone to ask that we get everyone's opinion or to move on to another topic. This is to ensure that we get everyone's views on all the questions in the relatively short time we have together.

Another important ground rule for this meeting is that we will respect the privacy of all group members and keep the content of our discussion confidential. We will call each other only by first names, and your verbal and written comments will be kept strictly confidential. I will be audiotaping the discussion, and you may see me taking notes. These steps are necessary for us to accurately record what is said today/tonight, but we will not include any information that will personally identify you in our notes or recordings. At any point in time, you are free to stop participating in the discussion or even leave. When we analyze our notes from this discussion, we will be most interested in what the group as a whole has to say. After we complete the analysis, we will erase and throw away the tape recording. When we publish the results of our study, no individuals will be identified. Finally, please remember that located on your consent form are the names and numbers of people you can call in future if you have questions about your rights as a research participant.

Does anyone have any questions? [Answer any questions]

#### **III. Warm up [7 minutes]**

Before moving on to the main topic of our discussion, I would like to take a few moments for everyone to introduce himself/herself. Specifically, I would like everyone to tell us their first

name (you can also choose a pseudonym) and briefly tell us what their hobbies or interests are. Let me begin....

[Moderator: Introduces herself/himself and then goes around the table.]

[Moderators Assistant: Will take notes on where particular people are sitting by creating a diagram similar to the room and focus group layout. Individual first names will then be associated with a numbered position in the diagram. These numbers make it possible to follow more accurately who in the group is speaking when listening to the tapes again as well as confidentially matching forms completed during the focus group with names.]

---

#### TOPIC 1: INTRODUCTION

1. What made you interested in participating in this study? [**Probe:** *Are you interested in the topic? Are you looking for answers? Are you hoping that your participation will help others?*]

#### TOPIC 2: ESRD EXPERIENCE

2. Describe your experience so far as a patient with kidney disease? [**Probe:** *What challenges have you faced as a patient with ESRD?*]

#### TOPIC 3: MEDICAL EVALUATION EXPERIENCE

3. What information have you been given about the medical evaluation process? [**Probe:** *Were you provided with information about the evaluation process itself and the number of tests you would have to take for instance? Were you given with information about the risks and benefits of kidney transplantation? Were you given information about what will happen after transplantation?*]
4. What information would have been helpful? [**Probe:** *Would you have liked additional information about the evaluation process such as the number of tests you have to take, possible insurance issues, the importance of having others who could support you through the process?*]
5. Have you started the medical evaluation process? [**Probe:** *When did you start the process? What do you have left to finish?*]
6. What tests have you done so far and what are you left to complete? [**Probe:** *That is have you finished the basic blood work and initial testing? What tests are you yet to complete?*]
7. What has it been like for you going through the medical evaluation process? [**Probe:** *Overall, would you say that your experience with has been generally positive or negative? Why? Are there certain things which have been particularly difficult?*]

#### TOPIC 4: BARRIERS TO COMPLETING THE MEDICAL EVALUATION

8. What things make it difficult to complete the medical evaluation process? [**Probe:** *For example, perhaps insurance issues, the sheer number of tests, or transportation*]

*difficulties, additional health problems, not having close friends or family for support interfered with your ability to complete the evaluation? Anything else?]]*

9. Now I'll like you to list the 5 most important barriers (on the post it you've been provided) which made/ have made it difficult to complete the medical evaluation process. Place rankings beside the barriers you've listed (with 1 being the most significant barrier, followed by 2 and so on) [**Probe:** *group members to list top 5 barriers and build a hierarchy*]

#### TOPIC 5: MOTIVATORS TO COMPLETING THE MEDICAL EVALUATION

10. What do you think will help you complete the medical evaluation process for kidney transplantation? [**Probe:** *For example, will mobile testing, patient navigators, knowledge about kidney transplantation, more education about the medical evaluation help you complete the evaluation process?*]
11. Let's rank order the most important things which will help you complete the medical evaluation process (with 1 being the most significant, followed by 2 and so on) explain why you chose these rankings [**Probe:** *for group discussion where group members list top 5 barriers, build a hierarchy*]

#### IV. CLOSING:

Option 1: *Time Still Remaining:* Before we end the session, are there any other comments that you have or topics that we missed in our discussion? Thank you for your time and participation.  
Option 2: *Time is Up:* If, after today's session, you think of any other comments or topics that were missed please feel free to contact me (e.g., focus group facilitator) by email. Thank you for your time and participation.

**Appendix E**

**NOMINAL FOCUS GROUP SURVEY**

1. What is your race?

- 1          African American
- 2          Asian/Pacific Islander
- 3          Caucasian
- 4          American Indian/Alaskan
- 5          Mixed race (Specify: \_\_\_\_\_)
- 6          Other (Specify: \_\_\_\_\_)
- 9          NR/NA

2. Respondent's gender:

- 1          Male
- 2          Female

3. What is your age? \_\_\_\_\_(years)

4. What is the highest grade or degree you have completed? \_\_\_\_\_ (Grade/Degree)

- 1          High school or less
- 2          Associate's degree
- 3          Some college, no degree
- 4          More than Associate's degree, but no Bachelor's degree
- 5          Bachelor's degree
- 6          Some graduate school, no degree
- 7          Master's degree
- 8          Uncompleted graduate training beyond a Master's degree
- 9          Doctorate
- 88         NR/NA

5. What is your marital status?

- 1          Single/never married
- 2          Married/cohabit
- 3          Divorced
- 4          Separated
- 5          Widowed
- 8          NR/NA

6. What is your religion?

- 1  Atheist
- 2  Protestant
- 3  Catholic
- 4  Jewish
- 5  Mormon
- 6  Muslim
- 7  Greek/Russian Orthodox
- 8  Other (SPECIFY: \_\_\_\_\_)
- 88  NR/NA

7. What is your annual household income?

- 1  \$0 – 19,999 (<\$20,000)
- 2  \$20,000 – 39,999 (<\$40,000)
- 3  \$40,000 – 59,999 (<\$60,000)
- 4  \$60,000 – 79,999 (<\$80,000)
- 5  \$80,000 – 99,999 (<\$100,000)
- 6  \$100,000 +
- 99  DON'T KNOW
- 88  NR/NA

8. Have you completed the medical evaluation to be waitlisted for a kidney?

- 1  Yes
- 2  No

8a. If yes, how long did it take you to complete the process?

\_\_\_\_\_ (months/years)

8b. If no, how long have you been undergoing the medical evaluation process?

\_\_\_\_\_ (months/years)

9. Do you have health insurance?

- 1  Yes
- 2  No

10. How far are you from the transplant center? \_\_\_\_\_ (Distance in miles)

11. Do you have the appropriate transportation to attend all your doctors' appointments?

- 1  Yes
- 2  No
- 3  Other: Please explain \_\_\_\_\_

*Please tell me how much you think the following impact the medical evaluation process*

12. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think your insurance status impact your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

13. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think your income level (i.e. your annual income) impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

14. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think the distance from the transplant center to the patient’s house impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

15. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think comorbidities (i.e. a patient having other illness in addition to ESRD) impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

16. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think your religious beliefs impact your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

17. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think your knowledge about different treatments impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

18. On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, , how much do you think your knowledge about the medical evaluation process impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

19. *Health literacy is defined as the degree to which individuals have the ability to obtain, process and understand basic health information and services in order to make appropriate health decisions.* On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think health literacy impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

20. *Medical mistrust is defined as concerns about trust and discrimination in populations of patients with chronic illness.* On a scale from 1 to 7, with 1 being “Not at all” and 7 being “Strongly impacts” with 2, 3, 4, 5 and 6 in between, how much do you think medical mistrust impacts your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Strongly impacts

21. *Navigators are individuals who educate patients and help them navigate through the medical system.* On a scale from 1 to 7, with 1 being “No impact” and 7 being “Extremely positive impact” with 2, 3, 4, 5 and 6 in between, how much would navigators impact your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Extremely positive impact

22. *Instrumental support networks are defined as the number of close friends or family that can help with daily activities at home.* On a scale from 1 to 7, with 1 being “No impact” and 7 being “Extremely positive impact” with 2, 3, 4, 5 and 6 in between, how much would instrumental support impact your ability to complete the medical evaluation process?

Not at 1 2 3 4 5 6 7  
all Extremely positive impacts

## **Vita**

Camilla Nonterah was born on July 15, 1981 in Accra, Ghana. She graduated from Achimota Secondary School in Accra Ghana in 1999. She received her Bachelor of Arts in Psychology/Computer Science and a minor in French from Concordia College in Moorhead, Minnesota in 2005. She received a Master of Arts in General Psychology from Central Connecticut State University in New Britain, Connecticut in 2009.