Mitigating Barriers and Inequities to the Pre-kidney Transplant Evaluation

By

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A Dissertation Proposal

Presented to Oregon Health & Science University School of Nursing

in partial fulfillment of the requirements for the degree of Doctor of Philosophy

June 23, 2015

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Dedication

To my mom, your humor, strength, grace, generosity, and courage have inspired me in times when I didn't think I could accomplish this goal. To my dad (and frequent editor), your endless curiosity and passion for living and learning have inspired me to never stop exploring.

To my sister Jennifer (Chris, David and Charlie) and my brother Rob (Joanie, Steven, Sam, and Bob), I thank you for your love and support.

To my west coast family, Sandi, Kirk, Leah and Andy, Trista and Jacob, the Bartletts and the Southern Ueckerts. Your loving support and encouragement (and late night bonfires) made the long days of studying tolerable.

Most importantly, thanks to my soul mates, Tara and Louie. Tara, you have sacrificed a great deal over the last several years to help me realize this dream. You encouraged me when I thought I couldn't succeed, and you did all that you could to create an environment conducive to studying (and that is not easy while living in a condominium in Chicago with an aspiring Jedi, a yappy dog, and an aging cat).

I could not have done this without you.

I love you!

In loving memory of Sid (2001-2013)

Funding Acknowledgement

This work was supported, in part, by internal funds provided by the Department of Medicine at the University of Chicago Medicine, and the International Transplant Nurses Society 2013 research grant award, and the 2013 Sigma Theta Tau Edith Edelman Leadership Award. The content is solely the responsibility of the author and does not necessarily represent the official views of the Department of Medicine at the University of Chicago Medicine, The Honors Society of Nursing: Sigma Theta Tau, or the International Transplant Nurses Society.

Acknowledgements

I would like to acknowledge all of the people throughout my life who have been generous with their time and mentored me, especially my original research mentors, Daniel Brennan, M.D., F.A.C.P. and Denise Canfield, R.N., C.C.R.C. of Washington University in St. Louis.

To my chair and mentor, Christopher Lee, who provided me with the skills to transform my life. To Lissi Hansen and Karen Lyons, who guided me throughout the program and lent an ear when I was in need. I promise I will pay your generosity forward.

To my colleagues at the University of Chicago: Yolanda Becker, Michelle Josephson, W. James Chon, Patrick Cunningham, Claire McGivern, Armando Casas, Marsha Pruitt, and Erin Patrick. I would especially like to acknowledge Milda Saunders for her guidance and mentorship.

To the greatest cohort of colleagues imaginable: Julie Bidwell, Quin Denfeld, Patty Barfield, Basilia Basin, Ellen Tilden, Wafaa Bin Ali, Daniel Mick, Kaori Donohue, and Mary Ann Jesse. Each of you has contributed to my success. I will never forget you, and I look forward to collaborating with you in the future.

Abstract

Background: Achieving the best health for all persons requires valuing everyone equally and avoiding inequities, injustices, and disparities. In the context of organ transplantation, all suitable candidates should have equal access to organs as they become available; however, many marginalized groups, such as African Americans, face numerous barriers to transplantation. Socioeconomic and sociocultural barriers faced by marginalized groups, along with systems that intentionally or otherwise support the status quo of institutionalized racism, place members of these communities at a disadvantage compared with those who are more likely to benefit from the current power structure. Currently, our understanding of barriers as perceived by patients who present for the pre-kidney transplant evaluation is limited.

Purpose: The purpose of this program of clinical research in ESRD was to identify modifiable barriers to pre-kidney transplant evaluation that may contribute to inequities in the process, particularly barriers experienced by African Americans, and propose innovative solutions designed to reduce or eliminate these barriers.

Methods: First, we synthesized current literature related to non-biological barriers to early stages of the pre-kidney transplant process for African Americans in the United States**,** as African Americans face a disproportionate burden related to the incidence of ESRD. Second, we conducted a prospective cohort study of 100 adult patients who presented to the University of Chicago Transplant Center to be evaluated for kidney transplantation in an effort to prospectively quantify self-reported barriers from the patient's perspective and the influence of health related quality of life on evaluation completion. Next, we conducted a cross-sectional survey study to assess the technological capabilities of pre- and post-kidney transplant patients to determine which, if any, information and communication technologies may be used to mitigate long standing barriers and inequities in the transplant process. Finally, we conducted a secondary analysis to identify characteristics of frequent Internet users.

Results: First, we were able to extend the findings of other works on barriers to the early stages of the pre-kidney transplant process for African Americans in the United States, to include additional barriers and interventions, and we proposed a new model that reduces the “silo” perspective when discussing what have been previously described as patient-level and healthcare-level barriers. Second, in our prospective study poor communication between patients and providers and among providers was identified as the most commonly reported barrier to evaluation completion. Third, we identified text messaging as the information and communication platform with the most potential to reduce barriers to evaluation completion. Finally, we determined that those who reported being on dialysis for more than three years were more likely to be frequent Internet users; however, African Americans were less likely report using the Internet more than 5 hours per week when compared to Caucasians. The decline in Internet use began in the 40-54 year old age group, which is younger than what we had anticipated.

Conclusion: Communication barriers between patients and providers and among providers were the most prominent barriers to evaluation completion identified. Strategies to improve communication during the pre-kidney transplant evaluation are desperately needed. The use of trained patient navigators and/or the use of information and communication technologies, specifically the use of text messaging, may be effective in reducing many longstanding barriers and inequities. Further study of the influence of HRQOL on evaluation completion is warranted. Requiring patients to obtain screening testing prior to being seen by the transplant center may have the unintended consequence of worsening existing inequities. Inclusion of mutually agreed upon metrics related to referral and the pre-kidney transplant evaluation should be included in national surveillance databases to enable a better understand of common barriers experienced during the early stages of the transplant process

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Chapter I: Introduction

Background

The pursuit of equity in solid organ transplantation is important from both a moral and ethical viewpoint, particularly when considered in the context of the tremendous organ shortage that exists in the United States (United Network of Organ Sharing [UNOS], 2016). Achieving the best health for all persons requires valuing everyone equally and avoiding inequities, injustices, and disparities (United States Department of Health and Human Services, Office of Minority Health [OMH], 2010). In the context of organ transplantation, all suitable candidates should have equal access to organs as they become available; however, many marginalized groups, such as African Americans, face numerous and perpetual barriers to transplantation. The concept of equitable access to and distribution of organs for transplantation is critical to the philosophies underlying the National Organ Transplant Act (NOTA) and the Organ and Procurement Transplant Network's (OPTN) Final Rule, both of which provide guidance on organ allocation policies in the United States (Organ and Procurement Transplant Network [OPTN], 2016). While neither of these documents is intended to be an ethical guide, both embody the ethical principles which provide the underpinnings of equity: utility, justice and respect for persons (OPTN, 2016). Moreover, these are the same ethical principles that guide the conduct of research involving human subjects as outlined in the Belmont Report (Belmont Report, 1978). Consequently, balancing the principles of utility, justice and respect for persons is essential to ensure the formation of an equitable transplant system.

The quest for equity in access to organ transplantation, particularly for African Americans and other marginalized groups, has shown little progress over the last several decades. Socioeconomic and sociocultural barriers faced by marginalized groups, along with systems that intentionally or otherwise support the status quo of institutionalized racism, place members of these communities at a disadvantage compared with those who are more likely to benefit from the current power structure (Churak, 2005; Hall, Choi, Xu, O'Hare, & Cherlow, 2011; Joshi, et al., 2013; Myakovski, et al., 2012). Thus, identification of modifiable barriers faced by marginalized groups and development of novel strategies to mitigate these barriers may allow for the system to move closer to equity. The complex and multifaceted systems of kidney evaluation and transplantation for the treatment of end-stage renal disease (ESRD) provide a common example wherein these exact issues of equity can be explored.

Epidemiology of kidney disease in The United States

Chronic kidney disease encompasses a spectrum of conditions that are serious, often progressive, and collectively comprise the sixth leading cause of death in the United States (Center for Disease Control ad Prevention [CDC], 2016). Approximately 20 million American adults have some degree of chronic kidney disease (CDC, 2016). End-stage renal disease, also known as kidney failure, is the terminal point of the chronic kidney disease continuum and most commonly occurs in adulthood due to a multitude of conditions related to biological, genetic, and chemical insults to the kidney that have a cumulative effect over the course of a person's life (National Kidney Foundation [NKF], 2016). African Americans are disproportionately affected by kidney disease, and are almost four-times more likely to require renal replacement therapy for ESRD when compared to Caucasians (USRDS, 2016). In addition, African Americans are more likely to carry the APOL1 gene, a gene that in recent years has been linked to kidney disease (Chen et al., 2015; Parsa, et al., 2013).

Uncontrolled diabetes mellitus and hypertension, both conditions being more prevalent in African American communities, are the most common antecedents to ESRD and together make up two-thirds of cases in the United States (Greer & Boulware, 2015; McDonald, Pezzin, Peng, & Feldman, 2009; USRDS, 2016). Glomerulonephritis, a condition that results in damage to the filtering portion of the kidney, is the third leading cause of ESRD. The cause of glomerulonephritis is often idiopathic, but it may be related to genetic inheritance or through immunologic and inflammatory pathways associated with infection (NKF, 2016). Other causes of ESRD include inherited diseases such as polycystic kidney disease, and insults resulting from biological (e.g. kidney stones, cardiovascular shock) or chemical processes (e.g. over the counter pain medications or illegal drugs (NKF, 2016). Despite improvements in understanding of the mechanisms of kidney disease treatment options remain limited.

There are approximately 1.5 million patients who are being treated for ESRD in the United States (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2016). Patients with ESRD would suffer tremendously and die without some form of renal replacement therapy. While renal replacement therapies that require mechanical filtration of toxins such as hemodialysis and peritoneal dialysis are the only option for some, the preferred method of renal replacement therapy is via kidney transplantation. Among hemodialysis patients all-cause mortality is ten times that of an age matched Medicare population without kidney disease (USRDS, 2016). The 1- and 5-

year mortality rates among adults with ESRD who are treated with hemodialysis are 20% and 35%, respectively (USRDS, 2016). This compares to a ten-year mortality rate of 40% for patients who received a kidney from a deceased donor or a kidney from a living donor (Vella, Brennan, & Sheridan, 2016).

Dialysis verses solid organ transplantation

Currently, the only treatment options available to patients with ESRD are renal replacement therapy with dialysis or organ transplantation. Dialysis was first introduced as a viable treatment for ESRD in the 1950's. While significant improvements have occurred since its inception, all forms of dialysis continue to be associated with adverse physical and affective symptoms among recipients (Cukor, Coplan, Brown, Friedman, Cromwell-Smith, Peterson, & Kimmel, 2007; Feroze, Martin, Renia-Patton, Kalantar-Zadeh, & Kopple, 2010). In addition, dialysis requires patients with ESRD to be dependent on mechanical filtration, thereby rendering these patients dependent on a machine. A majority of patients who require dialysis must receive their therapy at a specialized facility with treatments occurring at least three days a week for four hours each session. Patients are often lethargic after the treatment and require several hours to fully recover after each treatment. Thus, this dependence on technology and adverse effects of the treatment often results in a significant disruption in the patients normal daily functioning resulting in lower health related quality of life (HRQOL) (Merkus, et al., 1999; Wyld, Morton, Hayden, Howard, & Webster, 2012).

Over the past 40 years, kidney transplantation has emerged as the gold standard renal replacement therapy for patients suffering with ESRD. Among adults with ESRD, kidney transplantation results in better quality of life, reduced comorbidities and lower mortality compared with remaining on hemodialysis (Tonelli, Klarenbach, Rose, Wiebe, & Gill, 2009; Weng, Joffe, Feldman, & Mange, 2005; Wong et al., 2012). Prolonged delays or failure to complete the required pre-kidney transplant evaluation, however, are common barriers to patients ever being placed on a transplant waitlist (Ayanian et al., 2004; Chandrakantan et al., 2006; Epstein et al., 2000; Hall, Choi, Xu, O'Hare, & Chertow, 2011; Kasiske, London, & Ellison, 1998). Protracted time in the pre-kidney transplant evaluation leads to longer time waiting for a suitable organ. Getting on a kidney transplant list is vitally important because the average wait time to transplantation for patients on the list is extensive (e.g. approximately 5 years at the University of Chicago (UNOS, 2015)), and options such as identifying a potential live donor can only be explored once a patient is placed on the kidney transplant waiting list. Moreover, 5,139 patients died in 2011 while waiting for a kidney transplant in The United States (Scientific Registry of Transplant Recipients [SRTR], 2015). Despite recent changes to the kidney allocation system that places more emphasis on dialysis start time, time on the kidney transplant waitlist is still a key component in determining eligibility for receiving an organ and expeditious completion of the transplant evaluation may result in less time on hemodialysis. Thus, timely completion of the pre-kidney transplant medical evaluation is essential so that access to, and distribution of, available organs can be more equitable by including members of marginalized groups in the process. Moreover, centers can facilitate judicious options, the most important of which is to assist the patient in identifying a living donor.

The kidney transplant process

The kidney transplant process can be described as occurring over a continuum

(Figure 1). Viewing the transplant process in this way allows for tailored interventions depending on where the patient is on the continuum (Ladin, 2009). The kidney transplant process begins with the diagnosis of advanced disease often at the stage of ESRD (Huang & Samaniego, 2011; Rigo, Ziraldo, Monte, Jimenez, Gitto, Guiterrez, Orias, & Novoa, 2011; Yoo, Kwon, & Knag, 2009). Once a patient has expressed interest that he/she would like to pursue a kidney transplant they must be referred to a transplant center and complete a complex medical, financial, and psychosocial evaluation prior to being placed on the kidney transplant waitlist. The pre-kidney transplant evaluation is the focus of this program of research. Once a patient is placed on the pre-kidney transplant waitlist and a suitable organ has been identified that patient receives the transplant and then enters the post-transplant period.

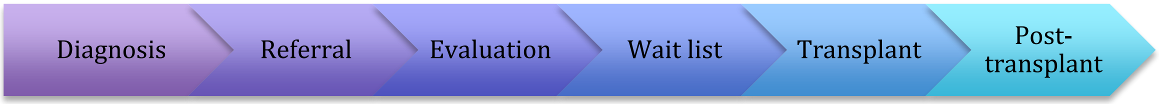

Figure1. Stages of the kidney transplant process. The kidney transplant process begins when a patients is diagnosed with kidney disease. Once a patient reaches advanced stages of kidney disease they can be referred to a transplant center, at which time they are evaluated using eligibility criteria. One the patient is deemed eligible for transplant they are placed on the waitlist. Once a suitable organ is identified the patient receives the transplant and enters the post transplant period.

Kidney transplant: The importance of early access

Patient's prolonging or failing to complete the pre-kidney transplant evaluation is troublesome, particularly in light of the compelling evidence showing the favorable effects of kidney transplantation when compared with remaining on dialysis (Gibney, King, Maluf, Garg, & Parikh, 2007; Gordon, 2001; Lunsford et al., 2006; Roark, 1999). Consequently, drawn out pre-kidney transplant evaluations hinder the possibility for the patient to accumulate points used to calculate position on the transplant list, to receive a perfectly matched kidney from a deceased donor, to address issues that may delay a patient from being an eligible candidate for transplantation, and to benefit from the opportunity of receiving a preemptive transplant via a living donor. Thus, early referral and prompt completion of the pre-kidney transplant medical evaluation is vital to the transplant process.

Successful completion of the pre-kidney transplant evaluation is a critical step in a patient's progression to transplantation. The pre-kidney transplant evaluation involves a through medical evaluation (e.g. assessment of cardiac and renal function, dental health status, infectious disease) and psychosocial evaluation (e.g. assessment of social support, emotional wellbeing, and potential socioeconomic issues) and is essential in determining candidacy, safety and viability of potential kidney transplantation (Dudley & Harden, 2011). There also is substantial variability in transplant centers requirements for the pre-kidney transplant evaluation, with a few large transplant centers having sufficient resources to perform the pre-kidney transplant medical evaluation in one day (Formica, et al, 2012); however, for these one day evaluations to work much of the burden to get testing completed falls on the patient. Moreover, this expectation of patient autonomy, requiring patients to navigate this complex process with little to no assistance, may have the unintended consequence of worsening inequities experienced by those already at risk of not completing the evaluation.

Due to limited resources a majority of transplant centers have to perform the pre-kidney transplant evaluation over the course of several weeks, and in some instances more than 12 months (Weng, 2005). While there are no publically available data about the numbers of people who do not complete the pre-kidney transplant evaluation, anecdotal evidence suggests this is a vexing problem for many transplant centers in the United States. Put simply, the pre-kidney transplant evaluation remains a challenging part of the transplant process for a majority of transplant centers, and importantly, prolonged time in the pre-kidney transplant evaluation causes delay in the receipt of an organ that is desperately needed. Thus, a better understanding of common barriers to pre-kidney transplant evaluation would allow for novel and innovative solutions to mitigate such barriers and foster timely progression to transplantation.

The increasing demand for kidneys in the United States

The sizable gap between the low supply and high demand for organs continues to be a challenge. While the number of patients waiting on the list for a kidney from a cadaveric donor grows the number of organs available for transplantation has remained relatively stable. For example, the number of candidates waiting for a kidney nearly doubled between 2002 and 2013, with nearly 50,000 patients being listed as active on the kidney transplant waitlist in 2002 and nearly 96,000 listed as active in 2013 (Matas, et al, 2015). As of the end of the year 2015 there were over 100,000 people waiting for a kidney, and only 15,068 donors recovered (OPTN, 2016). Consequentially, the national median wait time for a kidney transplant is over 5 years (OPTN, 2016). Despite the substantial gap between supply and demand for organs from deceased donors, equitable access to available organs remains paramount; however, this problem of supply and demand presents a significant challenge for both patients and transplant clinicians.

The option of kidney donation from a live donor

Kidney transplantation via a living donor is one option available to those who have completed the kidney transplant evaluation. Live donation exemplifies a dramatic advancement in the care of ESRD. For instance, patients who identify a live kidney donor can receive their transplant shortly after completing the pre-kidney transplant medical evaluation, bypassing the years for waiting required for an organ from a decreased donor (Gibney et al., 2007). Reducing time from diagnosis of ESRD to transplantation is important, as there is a clear correlation between length of time on dialysis and inferior allograft outcomes (Bratton et al., 2011; Gibney et al., 2007; Gordon, 2001; Robinson et al., 2009;Young & Gaston, 2002). For patients with ESRD, a living kidney donor transplant can result in alleviation from the burden of dialysis and enhanced survival rates; 50% of living kidney donor grafts are still functioning after 20 years versus 10-year mean survival of deceased donor organs (Cetnigok, et al., 2007). Thus, it is evident from the literature that patients who receive an organ from a living donor have superior overall outcomes at reduced costs related to treatment of rejection and other co-morbidities when compared to recipients of deceased donor organs (Davis & Delmonico, 2005; Klop et al., 2013; Sakhuja, et al, 2016). Patients, however, must complete the pre-kidney transplant evaluation to be considered for a living donor transplant.

African Americans are less likely to pursue a transplant from a living donor compared to Caucasians due to a number of factor including cultural and religious beliefs, and lack of knowledge about the transplant process, thereby reinforcing inequities (Bratton et al., 2011; Gordon, 2001; Lunsford et al., 2006). Expeditious completion of the pre-transplant evaluation allows transplant centers the opportunity to educate patients and demystify the transplant process. Equity related issues are important at all stages of the transplant process, however, between-center variability, lack of agreed upon definitions, and absence of publicly reported data make the pre-kidney transplant evaluation a logical focal point to explore potential barriers that result in inequities.

Known barriers to the early stages of the kidney transplant process

Seminal research exploring barriers to transplantation has been largely descriptive and has implicated patient-level factors as influencing delay and/or failure to complete kidney transplant evaluation including demographic, socioeconomic and cultural factors like religiosity and mistrust of medical systems (Alexander & Sehgal, 1998; Ayanian, Cleary, Weissman, & Epstein, 1999; B. L. Kasiske et al., 1998; Kasiske et al., 1991; Weng et al., 2005). In their 2006 review, Navantheen & Singh identified several barriers to the patient’s progression through the pre-kidney transplant evaluation and classified them as patient-specific barriers (i.e. biological, cultural, socioeconomic) and healthcare-specific barriers (i.e. potential racial bias). Many of these patient-level and healthcare-level barriers are more prominent or exclusively found in minority groups. In addition, being an African American male was nearly universally identified as an independent factor associated with failure to successfully progress through the stages of the transplant process (Hall, et al., 2011; Myakovski, et al., 2012; Patzer, et al., 2011). Thus, it seems that many barriers identified, particularly those faced by minorities and specifically those faced by African American males, may be deeply rooted in the system of white privilege that has been the foundation of American culture since its inception.

African Americans face well-documented inequities at all stages of the transplant process (Gibney et al., 2007; Lunsford et al., 2006; Robinson, Borba, Thompson, Perryman, & Arriola, 2009). For example, African Americans are less likely to be referred for transplantation compared to Caucasians (Clark, et al., 2007; Myakovsky et al., 2012). Moreover, African Americans have a disproportionately longer wait for a suitable deceased donor kidney and in general and are less likely to receive either a deceased or live donor kidney when compared with Caucasians (Lunsford et al., 2006; Reese et al., 2009; Roark, 1999; Russell, Robinson, Thompson, Perryman, & Arriola, 2012; Stolzmann et al., 2007; Waterman, Robbins, Paiva, & Hyland, 2010). Many of these inequities faced by African Americans manifest in the early stages of the transplant process and are often related to socioeconomic factors, lack of access to quality healthcare, limited health literacy, and systemic prejudice/racism within the healthcare system (Ayanian, et al., 1998; Myakovski, et al., 2013; Patzer, et al., 2012). Few studies have explored racial differences in completion of the pre-kidney transplant medical evaluation prospectively. Identification of modifiable self-reported barriers is an important step in eliminating longstanding barriers and reducing inequities associated with access to transplantation. Thus, a more rich understanding of barriers to the medical evaluation from the patient's perspective may help reduce inequities and decrease the time patients spend in the evaluation period.

Given that many barriers have changed little over the last several decades, novel approaches to reducing or eliminating these barriers are needed. For instance, little is known about these longstanding barriers from the patient's perspective. Understanding the patient's perspective of barriers that they encounter during the pre-transplant evaluation may provide a more granular view of barriers and lend a critical perspective that is generally lacking, as most studies examining barriers to the pre-kidney transplant evaluation have largely utilized public datasets using retrospective designs (Hall et al, 2011; Johansen et al, 2012; Kucirka et al, 2011, Monson et al, 2015). The data in these public databases are limited. We hypothesize that a by using a prospective design patients will have the opportunity to report barriers that they experience in real time. In addition, by viewing barriers from the perspective of inequitable access to transplantation we hope to empower patients to identify actionable barriers that will be amendable to intervention. Through carefully designed intervention we eventually hope to create a more equitable process. Thus, understanding barriers from the patient's perspective is vital as we move to patient-centered healthcare system models. Moreover, the proposed research builds upon previous findings on biological and clinically oriented barriers, as well as patient-oriented barriers, to the early stages of the pre-kidney transplant process (Navantheen & Singh, 2005). Specifically, the proposed program of research builds upon this prior and seminal work by offering the addition of potentially modifiable barriers that may be amenable to intervention. Finally, the proposed research will enhance our knowledge about long standing barriers to transplantation in a largely African American population, by leveraging previous work and moving the field closer to mitigating barriers to the pre-kidney transplant evaluation.

Is information and communication technology the key to addressing inequities?

Use of information and communication technologies have been described in a number of interventional studies in clinical settings including: diabetes (Harris, Tulfano, & Le, 2010; Patrick, Grisowld, Rash, & Intile, 2008), heart failure (Halafax, Caffazzo, & DPhil, 2007, Chauidry, Mattera, & Curtis, 2010), obesity (Partick, et al., 2008), obstructive sleep apnea (Stepnowski, Palau, Marler, & Gifford, 2007), alcohol and drug addiction (Patrick, et al., 2010), and human immunodeficiency virus (Swedderman & Rotheram-Borus, 2010; Patrick, et al., 2008). There have been a number of proposed uses of ICT including: biometric monitoring (Chauidry, et al., 2010; Harris, et al., 2010; Stepnowski, et al., 2007; Patrick, et al., 2008), medication compliance (Harris, et al., 2010; Patrick, et al., 2008; Miloh, Annunziato, & Aaron, 2009), behavior modification (Swedderman & Rotheram-Borus, 2010; Halafax, et al., 2007), and medical screening (Halafax, et al., 2007; Hardwick, Pulido, & Adelson, 2007). Many intervention studies that utilize information and communication technology platform give an inaccurate picture of overall information and communication technology trends among the chronically ill, as most patients are required to have a relatively high level of sophistication for technology to be eligible to participate in these studies (Lustria, Smith, & Hinnant, 2011). Moreover, descriptions of the use of ICT in transplant populations are rare. Descriptions of transplant related ICT based interventions have been limited to medication adherence (Miloh et al., 2009). Thus, a more in depth understanding of how transplant patients use ICT may inform potential interventions designed to reduce or eliminate many longstanding barriers/inequities to transplantation.

Racial inequities in technology access have been described in the literature; however, little data exists on the influence of race/ethnicity and chronic illness on technology use (Pew Center, 2016). These inequities in technology access and use are often referred to as the digital divide. The digital divide generally refers to the gap between individual households, businesses and geographic areas at different socioeconomic levels with regard to both their opportunities to access information and communication technologies and to their use of the Internet for a wide variety of activities (Rice & Katz, 2003). This gap in access to technologies has the potential to deepen existing inequities and widens the digital gap that currently exists in many parts of the United States and the world. Generally, adoption of technology is more likely if the individual is younger, (Denizard-Thomspon, Feiereisel, Stevens, & Miller, 2011; Miller, & West, 2009), white, (Wang, et al., 2011, Zickuhr, 2013), more highly educated, (Miller & West, 2009; Van Deursen & Van Dijk, 2011), and from a higher socioeconomic group (Fox, & Purcell, 2014; Wang, et al., 2011). Some reports, however, have indicated that African Americans may be more likely to use Smartphones compared with Caucasians (Pew Center, 2016). Thus, it is unclear if information and communication technology (ICT) could provide a much-needed bridge to transplantation for underserved populations.

As we move deeper into the information/electronic age, information and communication technologies could serve as potential solutions to many longstanding barriers and be used to reduce inequities. Understanding how patients with chronic illness use technology is essential as health care systems continue to move from analog to digitized systems. Simply put, our knowledge about how technology may aid in eliminating the barriers to completing the pre-transplant medical evaluation is quite limited among adults with ESRD. This program of research builds upon previous findings related to technology use among patients with chronic illness.

Purpose/Specific Aims

Understanding if there is congruence among patient perceived barriers (subjective barriers) and barriers identified by the transplant center staff (objective barriers) and how these factors influenced successful completion of the pre-kidney transplantation will play a vital role in the development of novel interventions designed to assist patients successfully navigate this challenging process, and create a more equitable system. Capturing barriers from the patient's perspective and the electronic medical record enabled us to identify areas of incongruence in responses. Accordingly, the purpose of this program of clinical research in ESRD was to identify modifiable barriers to pre-kidney transplant evaluation that may contribute to inequities in the process, particularly barriers experienced by African Americans. Because our center has the privilege to serve a large African American community on the South Side of Chicago, we are uniquely positioned to address these issues. Through a combination of a systematic review of barriers to transplantation for African Americans, a prospective clinical trial that assessed barriers to competing the pre-kidney transplant evaluation, and a cross-sectional technology assessment the aims of this program of research were to a) synthesize the literature on barriers to the early stages of the pre-kidney transplant evaluation for African Americans in the United States; b) prospectively quantify subjective and objective barriers to the pre-kidney transplant medical evaluation in an urban population in the United States; c) describe use of information and communication technologies In a largely African American d) describe determinants of internet use among a sample of urban pre-and post-kidney transplant patients in the United States and. The specific aims for this program of research and related chapters can be found in (**Table 1**).

Table 1: Outline of Specific Aims and Papers to Address Each Aim

Specific Aim	***Title of Paper***
Aim #1: Synthesize the literature in the United States on barriers to the early stages of the pre-kidney transplant evaluation. Approach: Systematic review.	(*Chapter II*) Non-biological barriers to referral and the pre-kidney transplant evaluation among African Americans in the United States: A systematic review
Aim #2: Prospectively quantify subjective and objective barriers to the pre-kidney transplant medical evaluation in an urban population in the United States. Approach: Prospective longitudinal clinical study.	(*Chapter III*) Barriers and Inequities Associated with Completion of the Pre-kidney Transplant Medical Evaluation at an Urban Transplant Center from the Patient's Perspective
Aim #3a: Describe use of information and communication technologies among a sample of urban pre-and post-kidney transplant patients in the United States. Approach: Cross sectional clinical study.	(*Chapter VI*) Renal Transplantation and the Digital Divide: Does Information and Communication Technology Represent a Barrier or a Bridge to Transplantation for African Americans?
Aim #3b: Describe determinants of Internet use among a sample of urban pre- and post-kidney transplant patients in the United States. Approach: Cross sectional clinical study.	(*Chapter V*) Determinants of frequent Internet use in an urban kidney transplant population: Characterizing the digital divide.

Theoretical framework

This program of research explored concepts that contributed to our understanding of barriers related to systematic inequities to completing the pre-kidney transplant medical evaluation. But, in order to address the research aims Critical Race Theory (CRT) was selected as a grand theory to guide the program of research.

Critical Race Theory

Critical Race Theory (CRT) was utilized as a grand theory and provided the lens for this program of research. Critical Race Theory emerged from critical legal studies in the 1970s in response to the slow pace of racial reform in the United States (Delgado, 1995). Critical Race Theory examines the role of race and institutionalized racism on social inequities between dominant and marginalized groups (DeCuir & Dixson, 2004; Delgardo, 1995). As indicated in the National Organ Transplant Act of 1984, the pursuit of equity in access to organ transplantation and organ allocation is a vital concept in the transplant process. Despite decades of research showing associations between race/ethnicity and challenges accessing transplantation, little progress has been made for those at greatest risk of being excluded from transplantation. Hence, CRT can play an important role in the quest for equity in transplantation, particularly by promoting equitable access to transplantation by identifying and eliminating modifiable barriers that exist.

There are five tenets that are central to CRT: counter-storytelling; the permanence of racism; Whiteness a property; interest in conversion; and the critique of liberalism (DeCuir & Dixson, 2004). For the purpose of this research program we specifically focused on counter-storytelling and the permanence of racism. Counter-storytelling provides a voice for members of marginalized communities, in this case African Americans with ESRD in Chicago, to be critical of the dominant ideology by providing personal narratives of their experiences (DeCuir & Dixon, 2004). Open-ended questions were included on the Subjective Barriers Questionnaire, an instrument specifically designed for this study to assess patient's perceptions of barriers, in an effort to elicit these narratives in the context of the kidney transplant evaluation.

Permanence of racism in the context of the kidney transplant evaluation suggests that the prevalence of institutionalized racism in society also exists within organizations that regulate organ transplantation the United States (Delgado, 1995). To ignore the presence social barriers that result from institutionalized racism within society and transplant organizations, as experienced by marginalized patients who are seeking transplantation, is to support the status quo. Thus, this study sought to identify modifiable barriers to the kidney transplant evaluation to assist transplant organizations in identifying processes that may better promote equity within existing systems.

Summary

Marginalized populations, such as African Americans, face a number of barriers to the transplant process that result in health inequities in the current system. All suitable candidates for transplantation should have equal access to organs that are available for transplantation. Given the significant difference between the number of organs available for transplantation and the number of patients in need of a transplant, it is imperative that patients complete the pre-transplant evaluation expeditiously so transplant center staff can begin to work with potential transplant recipients to explore timely and appropriate options, such as assisting patients with the identification of a living donor. Few solutions to mitigate existing barriers to the early stages of the pre-kidney transplant have been proposed, and those that exist are often vague and not reproducible. New knowledge on perceived barriers that sustain health inequities and prevent progression through the pre-kidney transplant medical evaluation, viewed through the lens of Critical Race Theory, may allow nurses and other clinicians to develop tailored, culturally specific, clinical and interventional approaches to ameliorate amenable barriers to this early and critical stage of the kidney transplant process.

References for Chapter II (See Cumulative References)

Chapter II

Non-biological barriers to referral and the pre-kidney transplant evaluation among African Americans in the United States: A systematic review

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This manuscript replaces portions of the methods section and results section of the traditional dissertation. Mr. Lockwood was the primary author on this paper, and Dr. Lee a co-author on this paper. Mr. Lockwood completed the analysis and manuscript preparation under the supervision of Dr. Lee. This article was accepted for publication in the Nephrology Nursing Journal on December 31, 2015. This manuscript is in final state.

Citation:
Lockwood, MB, Bidwell, JT, Werner, DA, and Lee, CS. (2015) Non-biological barriers for African Americans associated with referral and the pre-kidney transplant evaluation in the United States: A synthesis of the literature. Accepted for publication in Nephrology *Nursing Journal*, Dec 31, 2015.

Abstract

Purpose: to synthesize current literature related to non-biological barriers to early stages of the pre-kidney transplant continuum for African Americans in the United States**,** as African Americans face a disproportionate burden related to the incidence of ESRD. **Methodology:** In March 2015, a literature search was conducted for research articles published between 2006-2015. Twenty-four articles were included in the final sample. **Results**: Eleven barriers were identified. Barriers were categorized as: socioeconomic-based barriers, culture-based barriers, and knowledge-based barriers. **Conclusion:** Resources to develop educational interventions for both patients and providers may help to reduce existing disparities. Nurses should consider being involved in lobbying efforts to provide immunosuppression coverage for the life of the graft for transplant recipients. Nephrology nurses working in dialysis units are uniquely positioned to assist in reducing these long standing disparities by educating potential transplant candidates about the referral and evaluation process associated with solid organ transplantation.

Goal: to raise awareness about barriers faced by potential African American kidney transplant candidates among dialysis nurses and other healthcare professionals who may be in a position to assist in development of interventions aimed at reducing or eliminating identified barriers.

Learning Objectives:

1.) Discuss how a literature synthesis relates to nursing practice

2.) Identify current barriers to the early stages of the pre-kidney transplant evaluation for African Americans in the United States

3.) Identify current interventions to address existing disparities

Background/Significance

For more than two decades, investigators have conducted research to explain disparities that exist between African Americans and Caucasians in rates of receiving a kidney transplant. Finding solutions to mitigate barriers for African Americans is vitally important because African Americans are four times more likely than Caucasians to develop end-stage renal disease (ESRD) (United States Renal Data System, 2015). Reducing racial disparities associated with access to transplantation, the preferred method of renal replacement therapy for ESRD, is of particular importance because kidney transplantation is associated with better quality of life and better survival at lower costs (Tonelli, Klarenbach, Rose, Wiebe, & Gill, 2009; Weng, Brown, Peipert, Holland, & Waterman, 2013; Yen et al., 2004) compared with remaining on dialysis. Despite progress in elucidating racial barriers, however, there are persistent disparities that influence African Americans' access to transplantation.

The process leading to kidney transplantation is complex and involves several steps that occur on a continuum. The earliest stages of the continuum are patient interest in transplantation, referral of the patient by a physician to a transplant center, and initiation and completion of a pre-kidney transplant medical evaluation (Ladin, Rodrigue, & Hanto, 2009). Once these steps are completed, the patient can be placed on the waitlist for a deceased donor transplant. Critical barriers related to access to, and completion of, the early stages of the kidney transplant evaluation were described in early seminal works (Alexander & Sehgal, 1998; Alexander, Sehgal, & Transplant Task Force of The Renal Network, 2002; Ayanian et al., 2004; Ayanian, Cleary, Weissman, & Epstein, 1999; Epstein et al., 2000; Kasiske, et al., 1998; Kasiske et al., 1991). Findings from these foundational studies included descriptions of patient-level barriers such as race, gender, poverty, education, and insurance (Alexander & Sehgal, 1998; Alexander et al., 2002; Epstein et al., 2000; Kasiske et al., 1998; Weng, Joffe, Feldman, & Mange, 2005; Young & Gaston, 2002). Other studies explored healthcare-level barriers such as potential racial bias and provider's misperception of patients desires regarding transplantation particularly among African American patients (Ayanian et al., 2004; Ayanian et al., 1999; Epstein et al., 2000; Kasiske et al., 1991). While numerous factors were identified as contributors to existing dipartites in these studies, one factor that remained constant was that African Americans were less likely to navigate the early stages of the kidney transplant continuum successfully compared with Caucasians.

While barriers to the early stages of the transplant process may also be found in other racial and ethnic groups African Americans were chosen as the focus of this review due to the higher incidence of ESRD (National Institute of Diabetes and Digestive and Kidney Disease [NIDDK], 2015; USRDS 2016) and well documented disparities in access to the kidney transplant process (Ayanian et al., 2004; Ayanian, Cleary, Weissman, & Epstein, 1999; Chandrakantan et al., 2006; Churak, 2005; Dageforde, Box, Feurer, & Cavanaugh, 2015; Epstein et al., 2000; Kucirka, Grams, Balhara, Jaar, & Segev, 2012).

Therefore, the purpose of this systematic review is to explore the current state of the science related to barriers to successful completion of the early stages of the pre-transplant process, specifically referral for transplantation and completion of pre-kidney transplant evaluation for African Americans in the United States. Methods used to conduct the literature review are described, followed by a description of the sample characteristics. Initially, barriers identified in this review were broadly categorized as being patient-level barriers or healthcare-level barriers, as described in the Navaneethan & Singh review. Upon completion of the literature review, barriers were further divided in to three subcategories: Socioeconomic-based barriers (poverty, education, geography, insurance coverage and financial burden); culture-based barriers (mistrust, perceived discrimination and social support); and knowledge-based barriers (health literacy, transplant knowledge, and patient/provider communication0. Finally, potential interventions designed to address existing disparities are described in addition to potential future directions for research in this area.

Literature Search

In March2015, a literature search was conducted with an experienced reference librarian for research articles published between 2006-2015 using MeSH terms: *kidney transplantation*; *renal transplantation*; AND keywords: *evaluation*; *barrier*; and *African American*. Databases searched included: MEDLINE, CINAHL, and PsycINFO. The review begins with articles dated 2006, as this is the date of the last major review of these barriers (Navaneethan & Singh, 2006). The search was limited to studies that specifically examined non-biological barriers to referral for transplantation and the pre-kidney evaluation, as less is known about this part of the process. This review excluded articles that referred to biological factors, such as barriers related to Human Leucocyte Antigen (HLA) and genetic variability. The search was further limited to adult patients with ESRD, as barriers in pediatric populations likely vary significantly from those experienced by adults, to English language articles, and to research conducted at transplant centers in the United States. The search resulted in a total of 69 returned articles (see Figure 1). Abstracts were reviewed for inclusion and exclusion criteria. A manual search of reference lists of relevant articles was also performed. At the conclusion of the review, 24 articles were included in the final sample. Detailed characteristics of each paper included in this review can be found in Table 1.

Results

Socioeconomic Barriers

Socioeconomic barriers identified in this review include: Living in poverty, insurance status, financial burden of transplantation, education and geographic location.

Poverty

Poverty is of particular concern when discussing racial disparities, as minorities are more likely to live in poverty compared with Caucasians (American Psychological Association, 2014). The impact of poverty on completion of the early stages of the transplant process, specifically referral for transplantation and completing of the medical evaluation, was observed in four studies included in this review (Hall, Choi, Xu, O'Hare, & Chertow, 2011; Joshi et al., 2013; Patzer, et al., 2012b; Schold et al., 2011). In a large study of 503,090 subjects, Hall et al. found poverty and insurance coverage comprised the largest fractions of disparities related to referral and evaluation among African Americans. In a second study, Patzer et al. (2012b) examined the role of poverty in a large cohort in the Southeastern United States and found that African Americans were twice as likely as Caucasians to live in poverty and that poverty was independently associated with completing several steps in the transplant process. African Americans were less likely to start the evaluation (51.5% vs. 60.6% respectively) and took longer from time from start of ESRD diagnosis to referral for transplant compared to Caucasians

(283 days vs. 84 days, respectively). However, no difference was seen between African Americans and Caucasians in rates or time to completion of the medical evaluation. In the third study of 1910 patients at a single transplant center, Joshi et al. found that being African American and living in poverty resulted in significantly longer times to referral and wait listing. Put simply, poverty is a significant barrier to access to the early stages of the pre-kidney transplant process for many African Americans.

Insurance Status

Insurance status is broadly understood to be a barrier to referral and the transplant evaluation, despite Medicare generally being available to patients with ESRD. Barriers to referral for transplantation related to lack of insurance or being underinsured were observed in six studies included in this review (Hall et al., 2011; Johansen, Zhang, Huang, Patzer, & Kutner, 2012; Patzer, et al., 2012a; Schold et al., 2011; Waterman et al., 2013). Specifically, all six studies concluded that racial disparities in referral for transplantation were largely explained by insurance status. For example, Johansen et al. found the lack of private insurance was strongly associated with the odds of not being assessed for transplant, even after adjusting for race and ethnicity. Moreover, this association between the lack of private insurance and not being assessed for transplant was more notable in younger patients. Of the 24 articles included in this review, seven examined the relationship between insurance status and completion of the pre-kidney transplant evaluation. Six of the seven articles described the lack of private insurance as being a major barrier to completion of pre-transplant evaluation (Clark, Hicks, Keogh, Epstein, & . Ayanian, 2008; Hall et al., 2011; Johansen et al., 2012; Joshi et al., 2013; Monson et al., 2015; Patzer, et al., 2012a; Schold et al., 2011). For example, Johansen et al. (2012) observed that African American race and lack of insurance was associated with lower rates of pre-transplant evaluation completion after adjusting for clinical and demographic factors. Similarly, Schold et al. (2011) found that patients with noncommercial insurance were significantly less likely to be evaluated for transplantation compared to those with private insurance regardless of race. Finally, Patzer et al.(2012a) demonstrated African Americans were less likely to have insurance when compared to Caucasians, however they found no difference in completion of the pre-transplant evaluation by race (Patzer et al., 2012a). In summary, insurance status is a frequently cited barrier to the renal transplant evaluation process among African Americans.

Financial Burden of Transplantation

The ability to maintain a kidney transplant financially can be a significant burden, particularly for those living on fixed incomes. For example, immunosuppression coverage under the Medicare entitlement expires 36 months after the transplant, leaving many patients having to cover the costs of these vital medications through alternative sources. Barriers associated with the financial burden of renal transplantation were explored in two studies in this review (Dageforde et al., 2015; Kazley et al., 2014b) In a study of 104 adult patients, Dageforde et al. (2015) found that 67.3% of those in the total cohort expressed concern over their ability to pay for their medication after the survey, though there was no difference by race/ethnicity. Similarly, in a single center study in the Southeastern United States, Kazley, et al. (2014b) observed 14.5% of participants cited concern about the ability to pay for their medications as a reason they did not complete the transplant evaluation. Thus, concern about the ability to pay for medications after renal transplant was a leading reason patients reported for not pursuing transplantation.

Education

Three studies in this review examined the relationship between education and the successful navigation of the pre-kidney transplant process (Axelrod et al. 2014; Goldfarb-Rumyantzev et al., 2006; Patzer, Perryman, Pastan, et al., 2012a). Two of these studies provided evidence that higher levels of education were associated with greater rates of referral for kidney transplantation (Axelrod et al., 2014; Goldfarb-Rumyatzev et al., 2012). All three studies described the significant relationship between higher level of education and completion of pre-transplant evaluation and that African Americans were disproportionately impacted by low education attainment (Axelrod et al., 2014; Goldfarb-Rumyantzev, et al., 2006; Patzer et al., 2012a). Interestingly, having a college education mitigated the negative effect of race on referral and evaluation for transplant (Axelrod et al., 2014; Goldfarb-Rumyantzev, et al., 2006). Overall, education is a crucial independent factor related to the initiation of referral and successful completion of the pre-transplant evaluation for African Americans.

Geography

Barriers to transplantation associated with geographic variability have been garnering the interest of researchers in recent years. Two of the studies in this review explored the relationship between geography and completion of the early stages if the transplant process (Axelrod et al.2014; Saunders et al., 2015). In a study that examined the relationship between racial disparities in access to transplantation within the 11 geographic and administrative organ procurement regions of the United Network of

Organ Sharing (UNOS), Saunders et al. found African Americans were less likely to complete the early stages of the transplant process in 9 of the 11 UNOS regions compared to their Caucasian counterparts (Saunders et al., 2015). In another study, Axelrod et al. (2014) described geographic variation based on 113 distinct Transplant Referral Regions or TRRs based on data obtained from the USRDS and the Organ Procurement and Transplantation Network (OPTN) databases. Detailed descriptions of how these areas were defined be found elsewhere (Axelrod et al., 2014). The authors found being African American was associated with a lesser hazard ratio of completing the early stages of the transplant process (being waitlisted). Thus, geographic location is a barrier to the early stages of the transplant process for many African Americans.

Cultural Barriers

Cultural barriers identified in this review included: Perceived discrimination, mistrust of the medical system, and lack of social support.

Perceived Discrimination

The impact of perceived discrimination completion of the transplant evaluation was described in two of the articles included in this review (Clark, et al., 2007; Myakovsky et al., 2012). Using a modified version of the 7-item perceived discrimination in healthcare measure (Bird & Bogart, 2001; Bird & Bogart 2003), Myakovsky et al. (2012) observed that perceived discrimination, along with less transplant knowledge, more religious objection and lower income explained the racial disparities associated with a longer time to complete the transplant evaluation for African Americans. Similarly, Clark et al. (2007) found that perceived discrimination accounted for a small part of the racial disparity seen in completing the transplant evaluation; however the number of participants reporting previous discrimination was small. It should be noted that a definition of perceived discrimination was not provided in either study. In sum, for African Americans perceived discrimination is a barrier that partially explains racial disparities associated with the early stages the pre-kidney transplant process.

Mistrust of the Medical Profession

Mistrust of the medical profession, particularly among African Americans, has been described in the kidney transplant setting in a variety of contexts (Irving et al., 2012 Ladin et al., 2009; Mauch & Bratton, 2014; Russell, Robinson, Thompson, Perryman, & Arriola, 2012). Two studies included in this review explored medical mistrust as it related to the pre-kidney transplant evaluation (Myakovski et al., 2012; Waterman et al., 2013). Both studies found a strong positive relationship between trust in the medical system and successful completion of the pre-transplant evaluation. Waterman et al. concluded that those who reported trusting the medical system were three times more likely to complete the pre-kidney transplant evaluation than those who reported that they did not trust the medical system (Waterman et al., 2013). In this study, Caucasians were almost twice as likely to complete the pre-kidney transplant evaluation when compared to African Americans. Additionally, in a longitudinal study of 127 African American and Caucasian subjects, Myakovski et al. found that African Americans were more likely to report feelings of mistrust within the context of the healthcare system, and these subjects were less likely to complete the transplant evaluation. Thus, for African Americans distrust in the medical system is a barrier that partially explains racial disparities related to successful navigation of the transplant evaluation.

Social Support

Explorations of psychosocial factors that influence access to transplantation, such as social support, have been gaining interest in the transplant literature. Social support was examined in five of the articles included in this review (Browne, 2011; Clark et al., 2008; Kutner, Zhang, Huang, & Johansen, 2012; Myaskovsky et al., 2012; Sullivan et al., 2012). Social support in terms of support from family and/or friends was the focus of two studies (Clark et al., 2008; Myaskovsky et al., 2012). Myakovsky et al. observed that there were no differences in self-reported social support between African Americans and Caucasians, and therefore no relationship between race, social support, and completion of the transplant evaluation (Myakovsky et al., 2012). In contrast, Clark et al. (2008)) found that high levels of social support, particularly daily support available from friends and family, was associated with higher rates of completed evaluation among African American women, Caucasian women, and Caucasian men, but not African American men. Moreover, in a sample of 228 African American patients on hemodialysis in Chicago, Browne (2011) found that those who reported having people in their social network who were knowledgeable about transplant were more likely to present for transplant than those who did not. In sum, the influence of traditional support networks on completion of the evaluation was inconsistent and varied by gender and race/ethnicity.

While family and friends make up what is considered the traditional social support structure by many people, researchers have also explored the influence of non-traditional social support networks such as dialysis staff (Browne, 2011; Clark et al., 2008), physicians (Kutner et al., 2012), and former transplant patients acting as guides to the pre-kidney transplant process (Sullivan et al., 2012). In a cross-sectional study of 742 patients with ESRD, Clark et al. found patients who reported higher levels of support from dialysis center staff were less likely to complete the evaluation. Of interest, the relationship between higher level of support from dialysis center staff and non-completion of transplant evaluation was seen among African American women, Caucasian women, and African American men, but was absent from the Caucasian men studied (Clark, 2008). In contrast, Browne (2011) only one, other was a duplicate and has been deleted found patients who received informational support about transplantation from dialysis center staff were more likely to be evaluated for transplantation that those who did not. Similarly, Kuntner et al. (2012) found a strong positive relationship between the social support from a nephrologist and the likelihood of a patient being preemptively placed on the kidney transplant wait list though there was no difference seen by race in this relationship (Kutner, 2012). In a study that utilized former patients, Sullivan et al. showed a strongly positive relationship between “patient navigators”-transplant patients who had been trained to help guide newly referred patients through the pre-transplant process-and successful completion of the early stages of the pre-kidney transplant continuum (Sullivan et al, 2012). Thus, from these data it is unclear how race/ethnicity and social support received from non-traditional sources impacts a patient’s likelihood of being evaluated for transplantation.

Knowledge-based Barriers

Knowledge-based barriers identified in this review included: Health related literacy, transplant knowledge, and issues related to patient/provider communication.

Health Related Literacy

Low health literacy has been associated with poor health outcomes in a number of diverse clinical areas (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Morrow et al., 2005). Of the studies included in this review, four examined health literacy as a barrier to the pre-kidney transplant processes (Grubbs, Gregorich, Perez-Stable, & Hsu, 2009; Waterman et al., 2013; Waterman, et al., 2010). Grubbs et al. found a strong relationship between health literacy and referral rates; however, there was not a racial difference seen in health literacy levels (Grubbs et al., 2009). In a study of 293 patients eligible for transplant, Waterman et al. observed that low health literacy was associated with negative opinions related to transplantation and a low likelihood of completing the pre-transplant evaluation; racial differences were not assessed (Waterman et al., 2010). In a study of numerical literacy, Abdel-Kader et al. found that African Americans, along with women and the unemployed, showed lower numeracy literacy (Abdel-Kader et al., 2010). The authors also demonstrated that higher numeracy scores were significantly associated with successful navigation of the early stages of the transplant process (Abdel-Kader et al., 2010). In sum, the relationship between race and health literacy was inconclusive from this review; however, low health literacy was a major barrier to the early stages of the transplant process.

Transplant Knowledge

Sufficient knowledge about transplant outcomes and processes associated with navigation of the early stages of the transplant process are essential for patient's progression to receipt of a kidney transplant. Six of the studies in this review examined the impact of a patient’s transplant knowledge on completion of the early stages of the transplant continuum (Browne, 2011; Kazley, et al., 2014a; Kazley, Johnson, Simpson, Chavin, & Baliga, 2014b; Waterman et al., 2013; Waterman et al., 2010). In a study of 293 patients receiving hemodialysis in the Midwestern United States, Waterman et al. (2010) found that participants, on average, were only able to correctly answer 8.04 transplant related questions out of a total of 18. The authors went on to conclude that transplant knowledge was negatively correlated with identifying the negative aspects of transplantation. No comparison by race was made by race in this study; however the sample was largely comprised of African Americans. In another study examining perceptions of nephrologists and nurses on patient barriers to transplantation, Kazley et al. found clinicians frequently reported that patient’s lack of knowledge about kidney disease and transplantation was a major barriers to kidney transplantation and often resulted in noncompliance with treatment recommendations (Kazley et al., 2014a). In addition, Browne (2010) found that only 36% of a sample of urban African American patients who were on dialysis had correct information about the kidney transplant process. Thus, lack of knowledge about transplantation and kidney disease is a major barrier to successful completion of the early stages of the pre-kidney transplant evaluation.

Patient/Provider Communication

Communication between patients and providers is a critical component of successful navigation of the pre-kidney transplant continuum. Three of the studies included in this review explored racial differences in patient perception of information sharing related by clinicians (Gillespie et al., 2011; Kucirka, Grams, Balhara, Jaar, &

Segev, 2012; Kutner et al., 2012). In a study that utilized data from The Comprehensive Dialysis Study (CDS) conducted by the USRDS, Kutner et al. (2012) observed that African Americans were more likely than Caucasians to be placed on the kidney transplant waitlist preemptively, meaning before initiation of dialysis, if they were presented with transplant information within 12 months of starting dialysis. In another study of the USRDS database, Kucirkia et al. (2012) found that a majority of African American patients surveyed had not been provided information on transplantation as mandated by section 152(b) of the Medicare Improvements for Patients and Providers Act (form 2728). The most reported reason for not providing information was that the patient was not assessed. Patients who reported poor patient-provider communication had a 50% lower rate of access to transplantation compared to those who reported good patient-provider communication (Kucirka et al., 2012). Finally, a study with a majority African American population explored wait listing status awareness of patients who were actively involved the pre-transplant evaluation. Fifty-two percent of those surveyed were unaware of their listing status, and 89% mistakenly thought they were on the waitlist when they were not (Gillespie et al., 2011). Thus, poor patient/provider communication is a major barrier to the pre-kidney transplant process.

Potential Interventions

Educational Interventions

Research on racial disparities and barriers to access to transplantation has evolved to the point where testing interventions to reduce existing disparities is now possible. Of the studies reviewed, two were studies that discussed interventions (Patzer, et al., 2012a; Sullivan et al., 2012). In a retrospective study conducted at a single center designed to assess the effectiveness of an educational program, Patzer et al.(2012a) found that those in the post education program group were 1.7 times more likely to complete the transplant evaluation than those who had not received the intervention (Patzer, et al., 2012a). In fact, the authors found that the educational intervention was most effective for African Americans, even after adjusting for socioeconomic factors such as insurance, poverty, and education (Patzer, et al., 2012a). In the second study, Sullivan et al. recruited former transplant patients to act as “patient navigators”. The patient navigators were trained to educate ESRD patients on how to navigate the pre-kidney transplant continuum (Sullivan et al., 2012). The authors concluded that those who received the intervention (assistance from a navigator) completed twice as many steps of the pre-transplant continuum compare to the control group; however, there was no difference seen by race/ethnicity (Sullivan et al., 2012). Thus, preliminary educational intervention studies, and the use of patient navigators, have shown promise in reducing barriers to the early stages of the transplant process.

Discussion

In summary, this review identified eleven non-medical barriers to the early stages of the pre-kidney transplant process and has provided valuable evidence that may assist in designing interventions that could reduce existing disparities faced by African Americans pursuing a kidney transplant (see Figure 2). In this review, inadequate insurance coverage, lack of education, and issues involving patient/provider communication were the most frequently reported barriers reported, and extends findings from the 2006 review conducted by Navatheenan & Singh.

Figure 3 is a pictorial representation of how these barriers interact on various levels. For instance, because barriers associated with poverty, education and geography are often the result long standing societal policies that may be difficult to change, we have classified these barriers as patient-level barriers, meaning the patient has more influence in creating change at this level than those working in healthcare, even though the alleviation of these barriers may be difficult at the individual level and require larger societal change before equity is achieved. However, our intention is not to say that healthcare providers have no role in working towards changing policies that sustain and reinforce existing social inequities, therefore the domain that includes the socioeconomic-based barriers of poverty, education and geography intersects with the healthcare-level barriers domain. Though not an exhaustive list, potential interventions to address these largely patient-level, socioeconomic-based barriers include public education to raise consciousness and lobbying efforts aimed at creating systematic policy change in order to bring more parity to the evaluation process.

As for financial barriers identified, concern over a patient's ability to pay for their medications after the transplant was identified as a significant barrier for many potential kidney recipients. Medication assistance programs administered by the pharmaceutical industry and related foundations provide a vital link to life saving medications for indigent patients who are either under insured or who lose their insurance once the Medicare entitlement associated with ESRD runs out three years after they receive their transplant. While these programs are generally viewed in a positive light, some have criticized the programs for being overly burdensome on hospital staff charged with registering patients into the programs(Chisholm, Tackett, Kendrick, & DiPiro, 2000;

Pisu, Richman, Allison, Williams, & Kiefe, 2009;Spivey, Chisholm-Burns, Garrett, &Duke, 2014), for their lack of uniformity in administering programs among program providers (Blackstock, Wang, & Fiellin, 2011), and for the motivations of the pharmaceutical industry for administering such programs (Rothman, Ravels, Friedman, & Rothman, 2011). Regardless of these concerns, Medication Assistance Programs provide access to critically important medications for those in need. Because the pharmaceutical industry's administration of these programs is voluntary and could be discontinued at their discretion, however, a more permanent solution to the problem of inadequate insurance coverage continues to be the ultimate goal. Thus, while these economic challenges related to immunosuppression medication coverage are often discussed in the context of the post-transplant setting, it is clear from the results of this review that patient's concerns about the financial burden associated with maintaining the kidney after transplantation is a significant barrier in pre-transplantation setting as well.

Currently, there is a perverse financial incentive for patients with end-stage renal disease to remain on dialysis. All patients who remain on dialysis receive their dialysis treatments for free as part of the Medicare entitlement. However, for those who rely on Medicare alone as their primary source of insurance, medication coverage for vital immunosuppressant medications are covered at 80% for the first three years after the transplant and then abruptly stop for those who are under 65 years of age and/or no longer considered disabled after the transplant (Farney, Doares, Kaczmorski, Rogers, & Stratta, 2010). Insufficient insurance coverage is of particular concern, as the majority of kidney transplant recipients are under 65 years of age. Despite evidence that providing life-long immunosuppression to kidney transplant recipients is both cost effective and extends the life the transplanted organ, legislation to provide these life-saving medications for the life of the transplanted organ have largely been unsuccessful (Axelrod, Millman, & Abecassis, 2010; Gordon, Prohaska, & Sehgal, 2008; Yen et al., 2004).

It is not clear how the Affordable Care Act (ACA) will impact barriers associated with insufficient insurance coverage for transplant patients. It has been suggested that the ACA will exacerbate existing disparities by mandating expensive insurance plans with stripped down coverage (Axelrod, et al., 2010; Rizk & Singh, 2012). In the 2003 Institute of Medicine report entitled Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, the authors acknowledge “defragmentation” of health care financing and delivery as a major barrier contributing to racial disparities, acknowledging a disproportionate number of racial and ethnic minorities are in health plans with fewer benefits (Institute of Medicine [IOM], 2003). Moreover, lifetime coverage of immunosuppressant medications could effectively reduce the financial barriers to the early stages of the kidney transplant process that exists for many, including underserved minority groups and those from a lower socioeconomic status. Given their numbers, and their reputation as one of the most trusted professions (Gallup, 2014), nurses have the potential to be particularly influential when lobbying for policy changes that could reduce existing disparities and extend immunosuppression coverage for transplant recipients for the life of the graft.

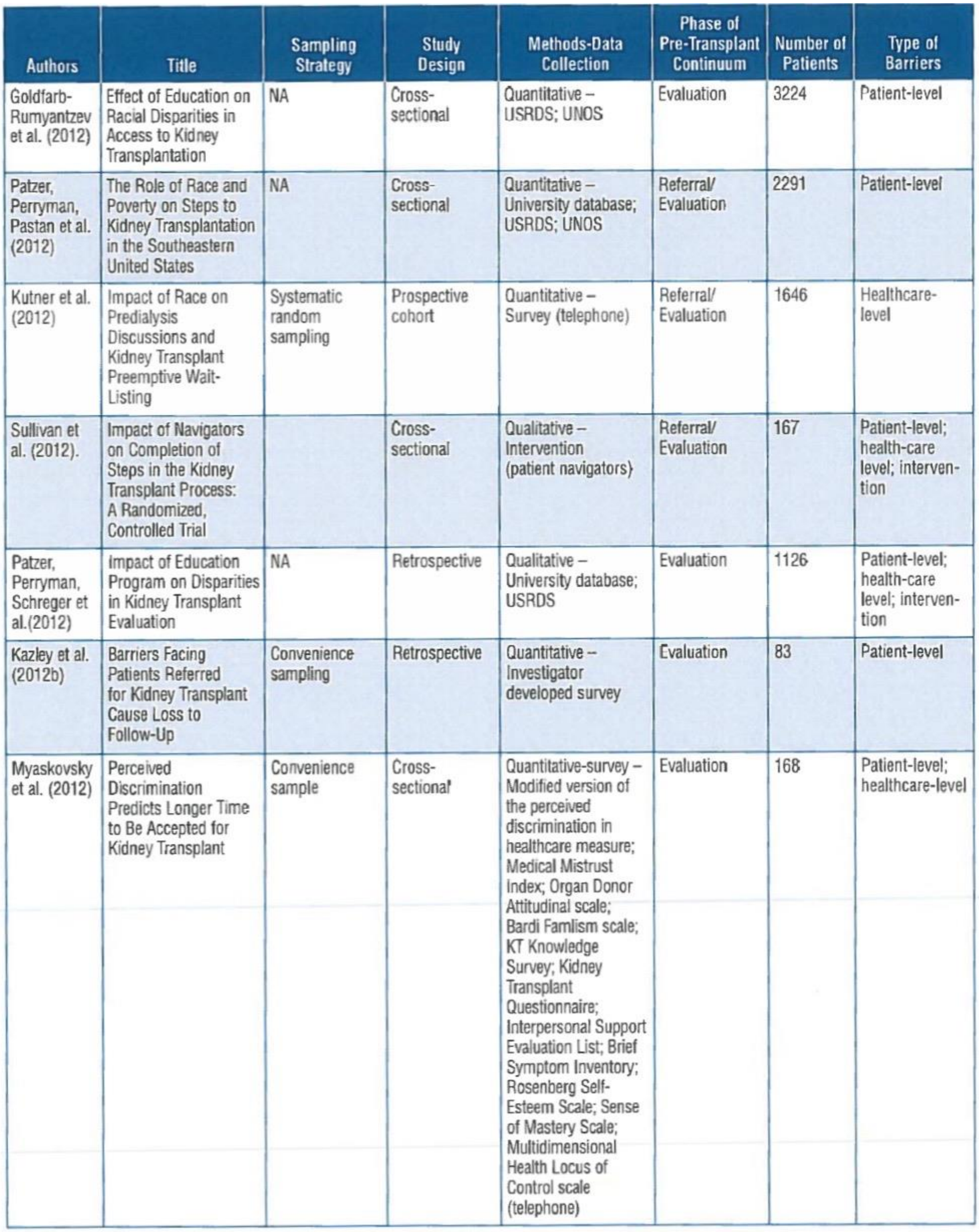
Over the past three decades we have seen an evolution in research exploring barriers to access to kidney transplantation for African Americans. Earlier descriptive studies have informed the current interventions studies. Though few, all of the intervention studies identified in the review centered on novel ways to improve communication and transplant knowledge between health care providers and the patients whom they serve. In their 2012 study on the impact of an education program aimed at reducing existing disparities for African Americans, Patzer et al. (2012a) presented data on the positive impact of a pre-transplant patient education program. Though the study was retrospective, and nature of the program was not fully described, they showed a significant increase in the number of patients who were able to successful overcome barriers to access to transplantation, particularly African Americans. While educational interventions seem to be an obvious solution, these interventions need to be scrutinized and evaluated objectively. In another novel study, Sullivan et al. utilized transplant recipients as patient navigators to assist dialysis patients throughout the pre-kidney transplant process. Not only did this pilot intervention address communication gaps between patients and healthcare providers, it also addressed issues associated with the loss of a social support system after transplant for recipients, and the economic issue associated with the need for employment for patients post-transplant. Further study into the use of patient navigators is warranted, as this approach could be effective in addressing several issues associated with transplantation. Moreover, development of interventions that incorporate educational interventions in concert with patient navigators to improve patient care should be considered.

Interventions that address redundancies and inefficiencies in communication are also warranted. Early studies conducted by Ayanian and Epstein showed clear discrepancies in how patients and providers perceived patient-provider communication (Ayanian et al., 2004; Ayanian et al., 1999; Epstein et al., 2000). For instance, Ayanian et al. surveyed physicians about attitudes held by their African American patients about transplantation. The physicians reported that African Americans were less interested in receiving a transplant compared to Caucasians. However, in another study that surveyed patients about their attitudes about organ donation the authors found there was no difference in self-reported interest in receiving a transplant by race/ethnicity (Ayanian et al., 2004; Ayanian et al., 1999). Many potential solutions to resolve challenges to communication will manifest as we move deeper into the information age. Information in communication technologies (ICT) such as web and mobile based applications that utilize the growing number of devices that are more portable, powerful, and easier to use may aid in the development of more effective communications strategies. However, healthcare providers designing educational interventions using ICT should be diligent in conducting an ICT assessment of the population that they plan to study, as those with chronic illness may not consume ICT in the same way as the general population. Lockwood et al. showed that a two-thirds of an urban transplant population, comprised of mostly African Americans, did not use the Internet more than five hours per week (Lockwood et al., 2013). Thus, understanding the technological capabilities of the desired population is essential so that those who do not utilize technology are not left out. This is of particular importance as these are the people at the greatest risk of not being referred or successfully completing the pre-kidney transplant evaluation. Clinicians must also be aware that not all people learn in the same way, therefore an assessment of the individual’s learning style should be considered and patient preferences honored when choosing the most appropriate patient-specific intervention

Conclusion

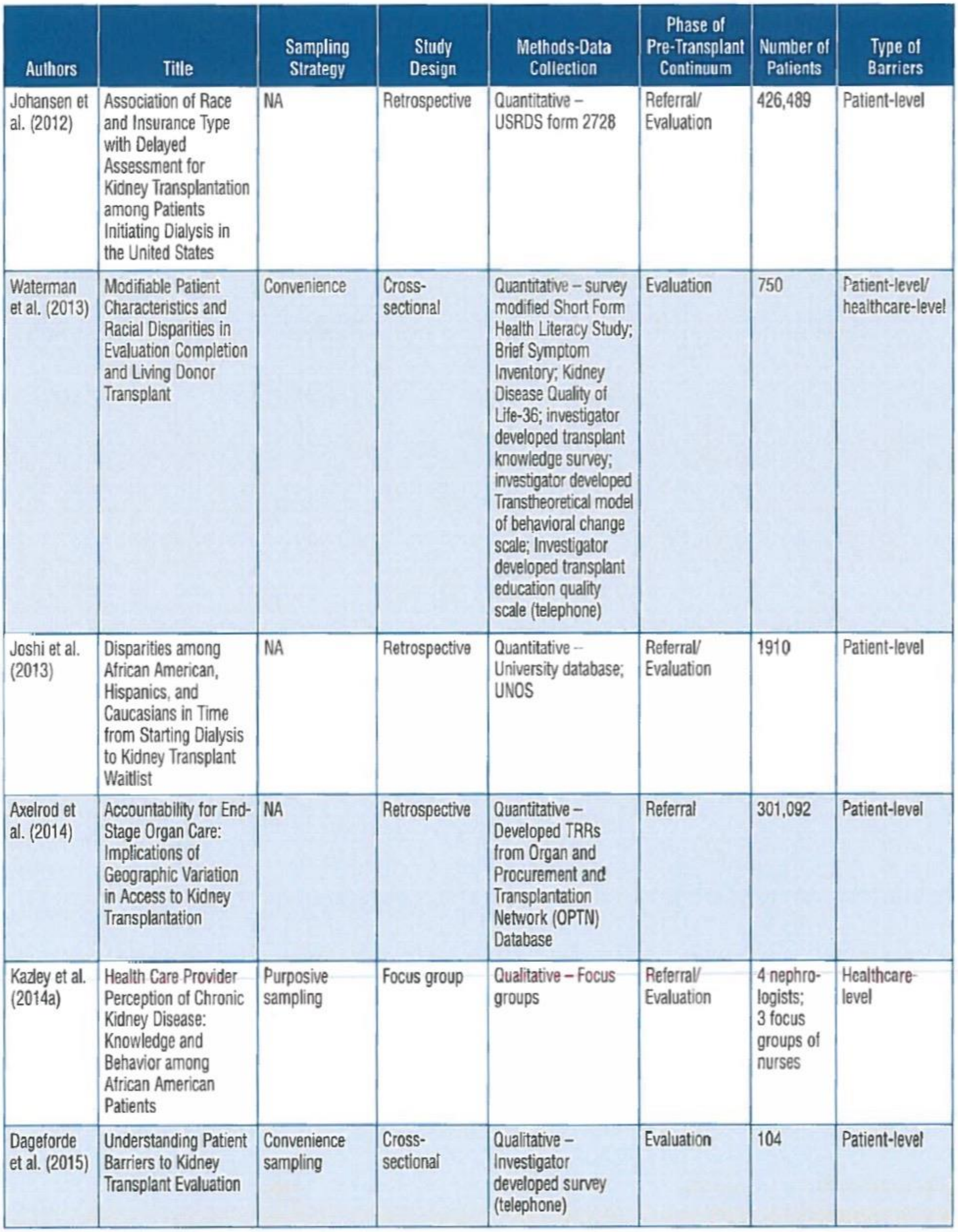
While some of the barriers identified in this review require change at the societal level, others may be more amenable to intervention. Economic barriers, specifically concern about the patient's ability to pay for medications after the transplant due to insufficient insurance coverage, are major barriers to transplantation for many African Americans. Nurses should participate in lobbying efforts to support legislation that would provide immunosuppression coverage to kidney transplant recipients for the life of the graft. Educational interventions designed to enhance patient-provider communication using information and communication technologies and analog technologies should be further explored. Nephrology nurses working in dialysis units are uniquely positioned to assist in reducing these long standing disparities by educating potential transplant candidates about the referral and evaluation processes associated with solid organ transplantation.

Table 2.1 Sample characteristics



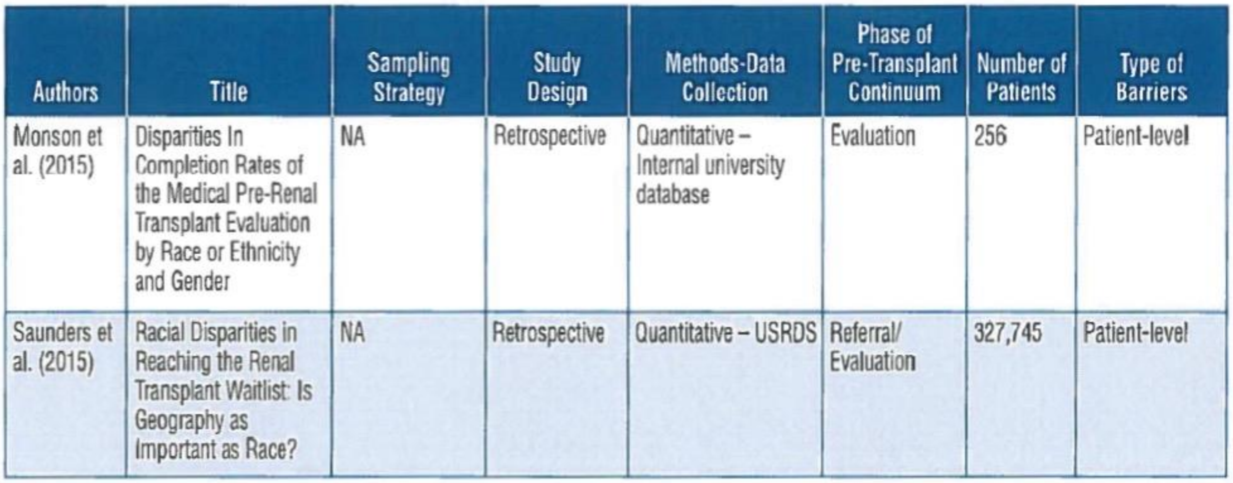
Authors	Title	Sampling Strategy	Study Design	Methods-Data Collection	Phase of Pre-Transplant Continuum	Number of Patients	Type of Barriers
Goldfarb-Rumyantzev et al. (2012)	Effect of Education on Racial Disparities in Access to Kidney Transplantation	NA	Cross-sectional	Quantitative – USRDS; UNOS	Evaluation	3224	Patient-level
Patzer, Perryman, Pastan et al. (2012)	The Role of Race and Poverty on Steps to Kidney Transplantation in the Southeastern United States	NA	Cross-sectional	Quantitative – University database; USRDS; UNOS	Referral/ Evaluation	2291	Patient-level
Kutner et al. (2012)	Impact of Race on Predialysis Discussions and Kidney Transplant Preemptive Wait-Listing	Systematic random sampling	Prospective cohort	Quantitative – Survey (telephone)	Referral/ Evaluation	1646	Healthcare-level
Sullivan et al. (2012).	Impact of Navigators on Completion of Steps in the Kidney Transplant Process: A Randomized, Controlled Trial		Cross-sectional	Qualitative – Intervention (patient navigators)	Referral/ Evaluation	167	Patient-level; health-care level; intervention
Patzer, Perryman, Schreger et al.(2012)	Impact of Education Program on Disparities in Kidney Transplant Evaluation	NA	Retrospective	Qualitative – University database; USRDS	Evaluation	1126	Patient-level; health-care level; intervention
Kazley et al. (2012b)	Barriers Facing Patients Referred for Kidney Transplant Cause Loss to Follow-Up	Convenience sampling	Retrospective	Quantitative – Investigator developed survey	Evaluation	83	Patient-level
Myaskovsky et al. (2012)	Perceived Discrimination Predicts Longer Time to Be Accepted for Kidney Transplant	Convenience sample	Cross-sectional	Quantitative-survey – Modified version of the perceived discrimination in healthcare measure; Medical Mistrust Index; Organ Donor Attitudinal scale; Bardi Famlism scale; KT Knowledge Survey; Kidney Transplant Questionnaire; Interpersonal Support Evaluation List; Brief Symptom Inventory; Rosenberg Self-Esteem Scale; Sense of Mastery Scale; Multidimensional Health Locus of Control scale (telephone)	Evaluation	168	Patient-level; healthcare-level

Table 2.1 (continued) Sample characteristics



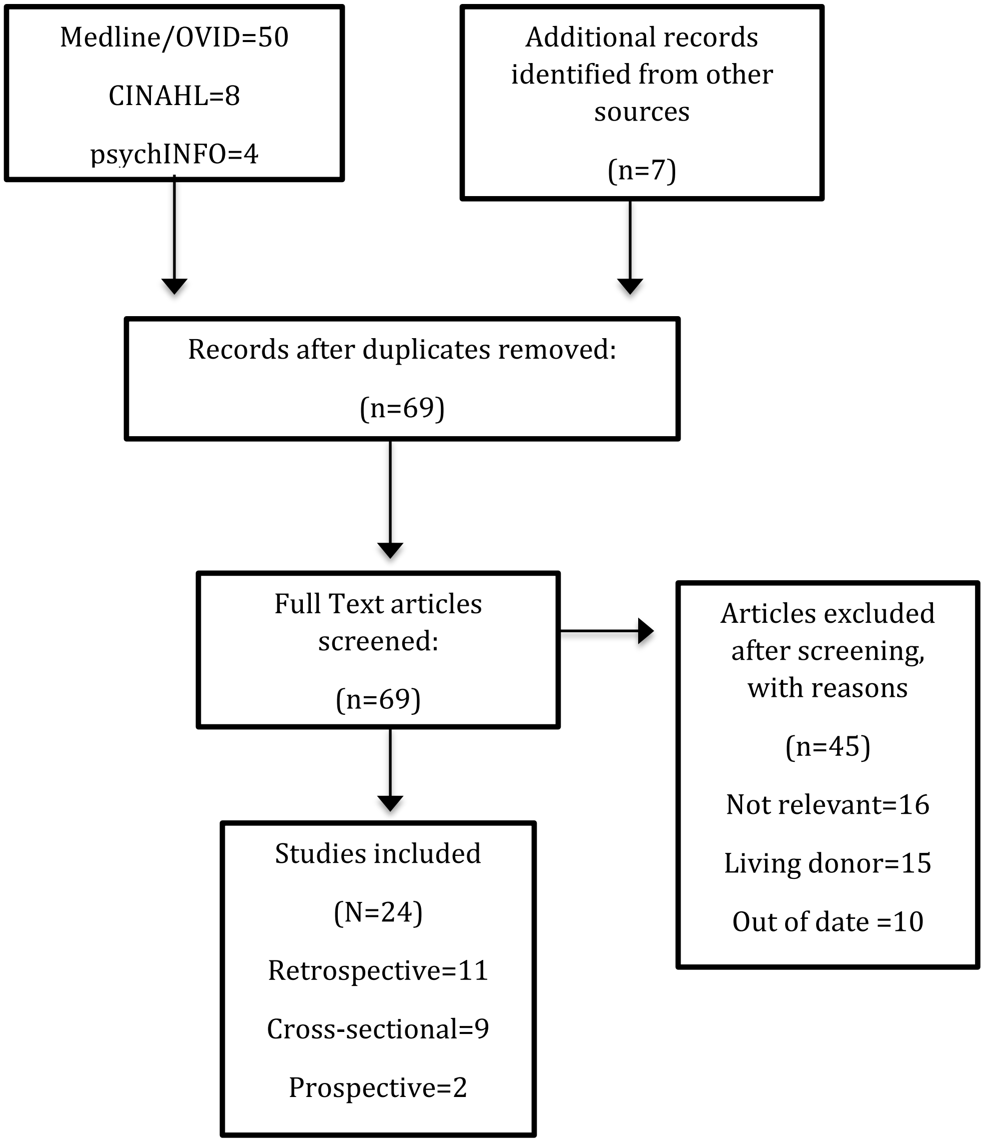
Authors	Title	Sampling Strategy	Study Design	Methods-Data Collection	Phase of Pre-Transplant Continuum	Number of Patients	Type of Barriers
Johansen et al. (2012)	Association of Race and Insurance Type with Delayed Assessment for Kidney Transplantation among Patients Initiating Dialysis in the United States	NA	Retrospective	Quantitative – USRDS form 2728	Referral/ Evaluation	426,489	Patient-level
Waterman et al. (2013)	Modifiable Patient Characteristics and Racial Disparities in Evaluation Completion and Living Donor Transplant	Convenience	Cross-sectional	Quantitative – survey modified Short Form Health Literacy Study; Brief Symptom Inventory; Kidney Disease Quality of Life-36; investigator developed transplant knowledge survey; investigator developed Transtheoretical model of behavioral change scale; Investigator developed transplant education quality scale (telephone)	Evaluation	750	Patient-level/ healthcare-level
Joshi et al. (2013)	Disparities among African American, Hispanics, and Caucasians in Time from Starting Dialysis to Kidney Transplant Waitlist	NA	Retrospective	Quantitative – University database; UNOS	Referral/ Evaluation	1910	Patient-level
Axelrod et al. (2014)	Accountability for End-Stage Organ Care: Implications of Geographic Variation in Access to Kidney Transplantation	NA	Retrospective	Quantitative – Developed TRRs from Organ and Procurement and Transplantation Network (OPTN) Database	Referral	301,092	Patient-level
Kazley et al. (2014a)	Health Care Provider Perception of Chronic Kidney Disease: Knowledge and Behavior among African American Patients	Purposive sampling	Focus group	Qualitative – Focus groups	Referral/ Evaluation	4 nephrologists; 3 focus groups of nurses	Healthcare-level
Dageforde et al. (2015)	Understanding Patient Barriers to Kidney Transplant Evaluation	Convenience sampling	Cross-sectional	Qualitative – Investigator developed survey (telephone)	Evaluation	104	Patient-level

Table 2.1 (continued) Sample characteristics



Authors	Title	Sampling Strategy	Study Design	Methods-Data Collection	Phase of Pre-Transplant Continuum	Number of Patients	Type of Barriers
Monson et al. (2015)	Disparities In Completion Rates of the Medical Pre-Renal Transplant Evaluation by Race or Ethnicity and Gender	NA	Retrospective	Quantitative – Internal university database	Evaluation	256	Patient-level
Saunders et al. (2015)	Racial Disparities in Reaching the Renal Transplant Waitlist: Is Geography as Important as Race?	NA	Retrospective	Quantitative – USRDS	Referral/ Evaluation	327,745	Patient-level

Figure 2.1 Literature search results



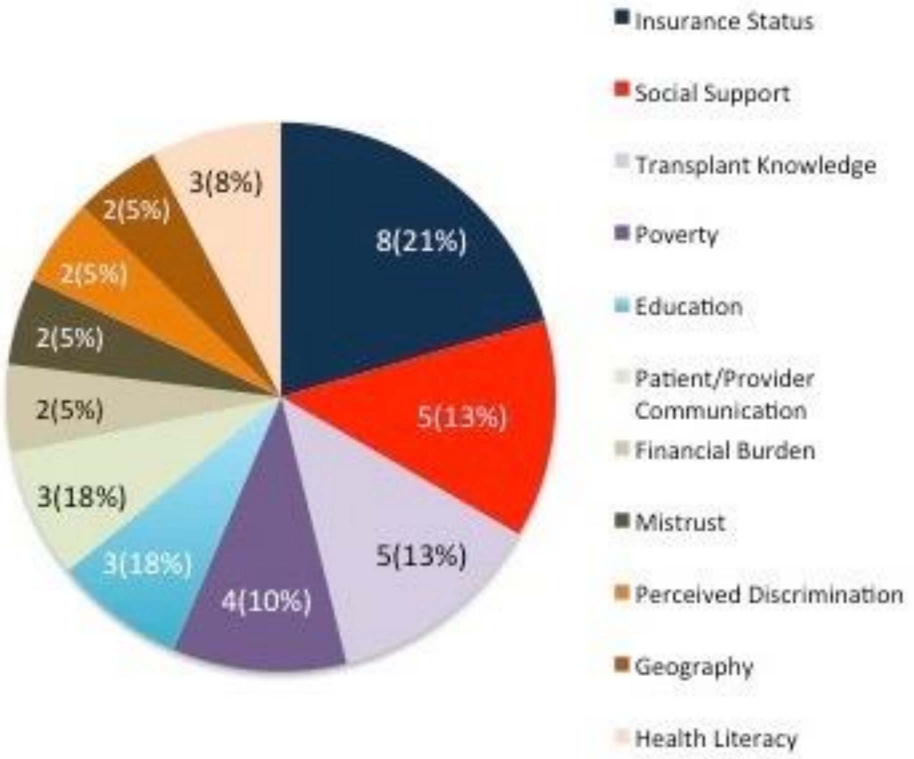


Figure 2.2 Total number of barriers identified in each of the 11 subcategories as a percentage of total number of barriers identified in the review. There were a total of 39 barriers in the 11 subcategories identified in the 24 articles included in this review. Percentages in this chart are based on the number of barriers of each sub category (e.g. insurance status, N=8) as a proportion of the total number of barriers identified (N=39). The total number of barriers identified exceeds the total number of articles. as some articles identified more than one barrier to the early stages of the transplant process.

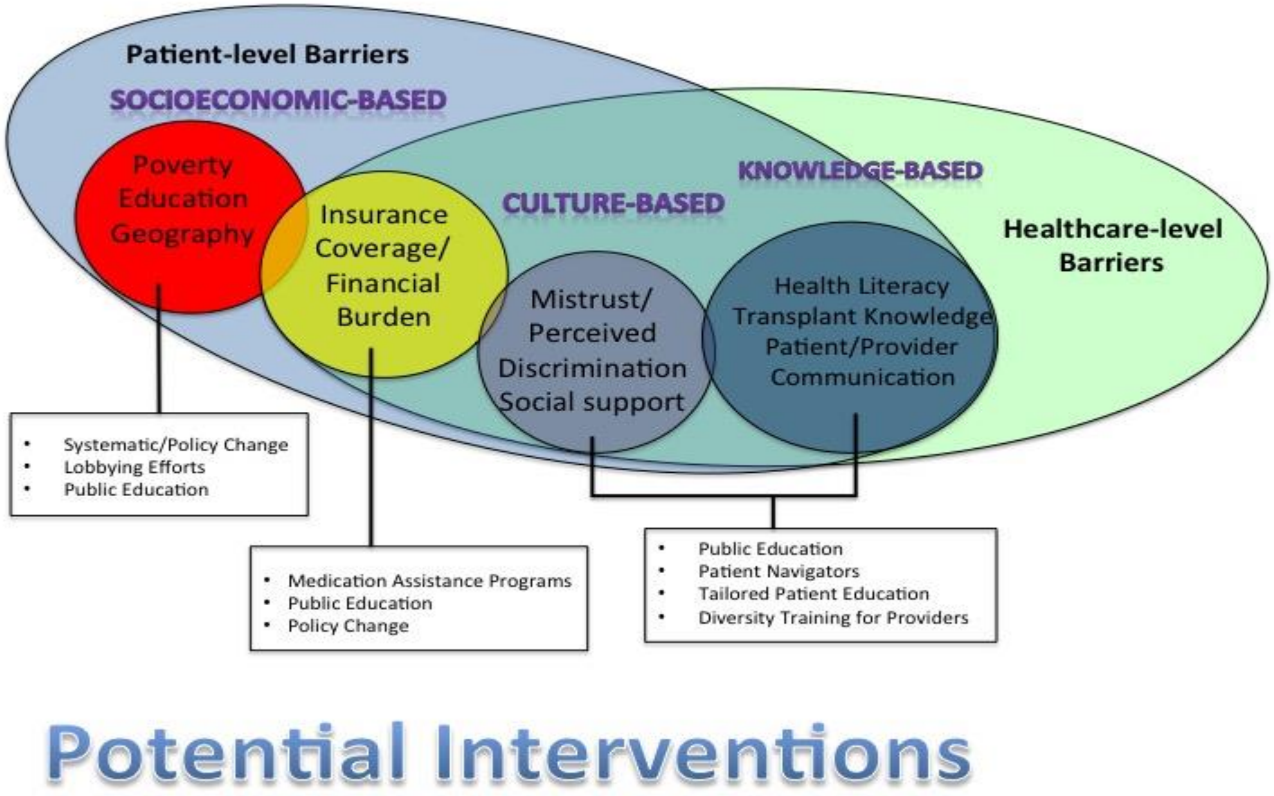


Figure 2.3 is a visual representation of the non-medical barriers African Americans in the United States face during the early stages of the kidney transplant process. The figure depicts the interaction of patient-level and healthcare-level barriers and potential interventions that may be employed to reduce these barriers. Barriers were placed into subcategories, as different barriers will require different levels of interventions in order to address the barrier. (e.g. efforts to change policy vs. efforts to increase awareness among potential recipient

References for Chapter II (See Cumulative References)

Chapter III

Barriers and Inequities Associated with Completion of the Pre-kidney Transplant Medical Evaluation at an Urban Transplant Center from the Patient's Perspective

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This manuscript replaces portions of the methods section and results section of the traditional dissertation. Mr. Lockwood was the primary author on this paper, and Dr. Lee a co-author on this paper. Mr. Lockwood completed the analysis and manuscript preparation under the supervision of Dr. Lee. This article was accepted for publication in the Progress in Transplantation on April 14, 2014. This manuscript is in final state.

Citation: Currently under review

Abstract

Background: Despite our knowledge of barriers to the early stages of the transplant process, we have limited insight into the patient's perspective regarding relevant obstacles to the medical evaluation.

Methods: One-hundred consecutive adults were enrolled at an urban, Midwestern transplant center at the beginning of the transplant evaluation, the first visit with a transplant surgeon/nephrologist. Demographic, clinical and quality of life data were collected prior to subjects' visit. We tracked transplant evaluation completion and subjects completed the Subjective Barrier Questionnaire three-months after the initial medical evaluation appointment, our center goal for transplant work-up completion.

Results: At three months, 40% of participants had not completed the transplant evaluation. In bivariable analysis, African American or "other" (Hispanic, Asian or Pacific Islander) were less likely to complete the pre-kidney transplant medical evaluation compared to Caucasians (OR 0.18 and 0.10, compared to referent, Caucasians); those already on dialysis were less likely to complete (OR 0.27, compared to those on dialysis); those with higher Charlson Co-morbidity index (OR 0.27 compared to CCI<5); etc.), p<0.05. better role-emotional quality of life and greater income were associated with greater odds of completing pre-kidney transplant evaluation., all p<0.05 Poor patient-provider communication, outstanding testing including cancer screening tests, access to periodontal care and issues related to excess weight were major barriers to completion.

Conclusions: Racial and ethnic minorities and those with low income continue to face significant barriers to transplantation. Poor-provider communication and access to cancer screening and dental care are also significant barriers to evaluation completion. The effect of obesity and HRQOL on evaluation completion needs to be better understood. Improving linkages through primary and dental care through patient navigator training for pre-kidney transplant nurse coordinators may be useful in addressing many of these long standing barriers. Development of communication technologies, including patient portals, may also reduce barriers.

Background

Kidney transplantation is the “gold standard” of available renal replacement therapies for the treatment of end-stage kidney disease (ESRD). Despite escalating needs, transplantation rates remain relatively stable with approximately 17,000 kidney transplants performed annually over the last decade (Organ Procurement and Transplant Network [OPTN], 2016). Prolonging or failing to complete the pre-kidney transplant evaluation is troublesome, particularly in light of the compelling evidence showing the favorable effects of kidney transplantation compared with dialysis (Gibney, et al., 2007; Gordon, 2001; Tedla, Brar, Browne, & Brown, 2011). For example, there is an association between length of time on dialysis and inferior allograft outcomes (Bratton, et al., 2011; Robinson, et al., 2009; Young & Gaston, 2000). Moreover, receiving a kidney transplant results in better quality of life, reduced comorbidities and lower mortality compared with remaining on dialysis (Tonelli, et al., 2009; Weng, Joffe, Feldman, & Mange, 2005; Wong et al., 2012). Timely completion of the mandatory pre-kidney transplant medical evaluation is essential so that centers can facilitate timely and appropriate options such as assisting/educating potential recipients on the option of live donation.

Prolonged delays and/or failure to complete the required pre-kidney transplant evaluation, however, are common barriers to patients ever being placed on a transplant wait list (Alexander & Sehgal, 1998; Ayanian et al., 2004; Epstein et al., 2000; Hall, et al., 2011; Kasiske, et al., 1998; Vamos, Novak, & Mucsi, 2009). Socioeconomic factors including living in poverty (Hall et al., 2011; Joshi et al., 2013; Patzer, Perryman, Schrager, et al., 2012; Schold et al., 2011), lack of access to quality education (Axelrod et al., 2010; Goldfarb-Rumyantzev et al., 2006; Patzer, Perryman, Schrager, et al., 2012) geographic location (Axelrod et al., 2010; Saunders et al., 2015), inadequate insurance (Clark,et al., 2008; Hall et al., 2011; Johansen, et al., 2012; Joshi et al., 2013; Monson et al., 2015; Patzer, et al., 2012; Schold et al., 2011; Waterman et al., 2013), and the financial burden associated with receiving a transplant (Dageforde, et al., are known to influence delay and/or failure to complete the evaluation. Cultural factors including mistrust of the medical system (Irving et al., 2012; Ladin, et al., 2009; Mauch & Bratton, 2014; Russell, et al., 2012), perceived discrimination (Clark et al., 2008; Myaskovsky et al., 2012), lack of social support (Browne, 2011; Clark et al., 2008; Myaskovsky et al., 2012; Sullivan et al., 2012), and religious objection to transplantation (Myaskovsky et al., 2012) have also been implicated as barriers to the early stages of the kidney transplant process, particularly for minority groups. Healthcare-level barriers to kidney transplant evaluation have been identified including poor patient-provider communication and potential bias by providers when referring patients for evaluation (Ayanian et al., 2004; Ayanian, Cleary, Weissman, & Epstein, 1999; Sullivan et al., 2012). Finally, health-related quality of life (HRQOL) that is associated with mortality and rehospitalization in ESRD may also play a role in identifying patients who are more or less likely to complete pre-kidney transplant evaluation (Lopes et al., 2007). A new, in-depth and patient-oriented understanding of existing barriers would allow transplant centers to create patient-centered interventions to improve completion rates, reduce workflow redundancies related to intensive follow up and optimize patient outcomes.

Accordingly, the purpose of this study was to prospectively identify: 1) subjective barriers (i.e. those identified by patients with ESRD) to completing pre-kidney transplant medical evaluation and compare with barriers identified in the patient’s electronic medical record, and 3) identify the elements of HRQOL that are influential to completing pre-kidney transplant medical evaluation.

Materials and Methods

The results reported in this paper involved the primary aims of a prospective cohort study of pre-kidney transplant patients that was conducted at a single urban Midwestern transplant center. All English-speaking patients 18 years of age or older who presented to the transplant center for kidney transplant evaluation between November 2013 and June 2014 were offered the opportunity to participate in the survey. All aspects of the study were reviewed and approved by the Institutional Review Board at the University of Chicago prior to implementation of the study.

In an effort to expedite patient progression through the pre-kidney transplant medical evaluation, our center implemented a strategy that mandated patients presenting to the transplant center for evaluation complete all required testing related to the medical evaluation within 90 days. If patient was not actively pursuing testing or had not been in contact with the transplant center after 90 days the patient’s file was closed and a letter send to the patient, the patient’s nephrologist, and the dialysis center if the patient is on dialysis notifying them of their status. However, those patients who were actively pursuing testing were allowed to continue in the evaluation despite reaching or passing the 90-evaluation endpoint. Thus, the goal of this strategy was to improve efficiency by reducing the number of patient who may linger in the pre-kidney transplant period.

Demographic, clinical and HRQOL data were collected on all subjects who agreed to participate and provided written informed consent prior to their first visit with the transplant surgeon /nephrologist. In an effort to reduce the potential of social desirability bias, participants were encouraged to complete the surveys unassisted; although trained study personnel were available to participants who requested assistance. Participants were also informed that the person conducting the interview was not a member of the transplant team responsible for their medical care, and would not share their results with the transplant team. Three months after the initial appointment, subjects were contacted via telephone to complete the Subjective Barrier Questionnaire. A study flow diagram is presented in **Figure 1**. Participants were offered a $25 gift card to compensate them for their time completing the survey. Evaluation outcomes for participants were categorized as: 1) completed the transplant evaluation (i.e. those who had successfully completed the evaluation and those who were deemed ineligible for transplantation within 3 months) or 2) did not complete the kidney transplant evaluation (i.e. those whose files were closed due to inactivity and those still actively pursuing transplantation but who were delayed beyond 3 months).

Measurement

Demographic data included self-reported age, gender, race/ethnicity, education and income. Disease specific data collected included previous transplants, years of kidney disease, current dialysis status and type and comorbid illness burden using the Charlson Comorbidity Indices (CCI). The CCI is a prognostic index that takes into account the numbers and severity of comorbid disease (Charlson, Pompei, Ales, & MacKenzie, 1987; Hemmelgarn, Manns, Quan, & Ghali, 2003). The CCI has been validated in ESRD populations for the assessment of comorbidities (Hemmelgarn et al., 2003).

Kidney Disease Quality of Life Short Form (KDQOL-SF ™)

Health-related quality of life was measured using the disease specific KDQOL SF™ version 1.2. The core of the KDQOL SF™ includes the generic SF-36 health survey used in the Medical Outcomes Study (Tarlov et al., 1989). The SF 36 is a psychometrically based generic HRQOL instrument consisting of eight subscales (Physical Functioning, Role-Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional, and Mental Health). The eight subscales result in two distinct composite scores: the Physical Composite Score (PCS) and the Mental Composite Score (MCS) (Butt, Yount, Caicedo, Abecassis, & Cella, 2008). In addition to the core measures, the KDQOL-SF™ includes 43 kidney-disease specific items divided into domains including: symptoms/problems, effects of kidney disease, burden of kidney disease, work status, cognitive function, quality of social interaction, sexual function, sleep, social support, staff encouragement, and patient satisfaction (Butt et al., 2008; Hays, 1997). Higher scores indicate a higher level of HRQOL. In previous studies, internal consistency reliability estimates were greater than 0.80 for kidney disease items (except for cognitive function=0.68 and quality of social interaction=0.61), and between 0.78 and 0.92 for the items of the 36 item core (Barotfi et al., 2006). Scores are standardized to range from 0-100 with 0 indicating worst possible HRQOL score and 100 indicating best HRQOL.

Subjective Barriers Questionnaire

Patient perceived barriers were measured using an investigator-developed Subjective Barriers Questionnaire that was designed by the study team specifically for this study. A multidisciplinary team, including input from pre- and post-kidney transplant patients, was vital in establishing content validity of the instrument. The instrument was modified based on feedback from experts and patients. The first domain explored barriers to keeping appointments and included the question: “Was there anything that prevented you from keeping your scheduled appointments?”. The question included ten dichotomous response variables (yes/no) that were based on previous reports in the literature and the experiences of the pre-transplant kidney coordinators and the call center staff. An open-ended question, “Were there any other barriers to you keeping your appointment?” was included to capture responses not elicited by provided responses. The second domain explored barriers to completing the pre-kidney transplant evaluation, and included the questions “Was there anything that prevented or delayed you from completing the pre-kidney transplant evaluation?”. The question included fourteen dichotomous response variables (yes/no). An open-ended question, “Were there any other barriers to you keeping your appointments?” was included to capture any responses not elicited by the provided responses. The Flesh-Kincaid reading level of the questionnaire was grade level 5. The internal consistency for the Subjective Barriers Questionnaire was acceptable (Cronbach’s α =0.71).

Analysis

The primary outcome was completion status. Barriers identified in the patient’s EMR were confirmed by the pre-kidney transplant nurse coordinator familiar with the case in question and categorized and described using descriptive statistics of frequency. Subjective barriers that were captured on the Subjective Barriers Questionnaire also were categorized and described using descriptive statistics of frequency. One hundred participants completed the surveys at time point #1. Those who were deemed ineligible for transplant after their initial medical evaluation appointment (n=14) did not complete the surveys at time point #2, therefore 86 participants completed the Subjective Barriers Survey at time point #2. Patient flow though the study can be found in **Figure 3.1**.

Demographic variables included in univariate models were: age, race/ethnicity, education, self-reported income, and gender. Disease specific variables included in univariate models were: number of previous transplants, years of kidney disease, dialysis status, type of dialysis and the CCI. All composite scores and subscales scores for the KDQOL SF were split into below and above the sample mean to facilitate entry into logistic regression modeling. Candidate predictor variables were identified by using chi-square, Students *t* or Fischer's exact tests where appropriate and included in multivariate logistic regression models if the p-value in univariate models was less than or equal to 0.1. A final multivariate logistic regression model was used to identify predictors of successful completion of the pre-kidney transplant medical evaluation. All statistical analyses were conducted using Stata 11.0 (Stata Corporation, College Station, TX). All p-values <0.05 were deemed significant except where noted.

Results

A majority of the 100 participants were male, identified as African American, and were between the ages of 40-65 (**Table 3.1**). Education was evenly divided between high school or less and some college and college and beyond. A majority of participants made less than $40,000 per year. Most participants had kidney disease for more than five years, were on hemodialysis, and had never had a transplant before. Of the 100 participants 60 had completed the pre-kidney transplant evaluation within three months (46 waitlisted, 14 deemed ineligible), and forty of the participants did not (**Figure 3.2**).

Of the latter, ten had their files closed due to inactivity and thirty had incomplete evaluations but were still actively pursuing transplantation.

Racial/ethnic barriers to completing the pre-kidney transplant medical evaluation

Those participants who identified their race/ethnicity as African American or “other“ (Hispanic, Asian or Pacific Islander) were less likely to complete the pre-kidney transplant medical evaluation when compared to Caucasians (55%, 40% and 87% respectively). The difference in proportion was significant, χ^2 (2, n=100)=10.15, p= 0.006. In addition, those who reported their race/ethnicity as African American or “other” were more likely to report an annual household income of less than $40 ,000 per year when compared to Caucasians (81%, 53%, and 39% respectively). The difference in proportion was significant, χ^2 (2, n=100)=14.57, p= 0.001. Participant who identified as African American were more likely to be on dialysis compared to those who identified as “other” race/ethnicity and those who reported white as their race/ethnicity (84%, 60%, and 57% respectively). The difference in proportion was significant, χ^2 (2, n=100)=8.31, p= 0.016. No difference in proportion by self-identified race/ethnicity was noted in education, comorbid burden, number of previous transplants, or frequency of reporting barriers to the pre-kidney transplant medical evaluation (*data not shown*).

Barriers to keeping evaluation appointments

Self-reported barriers to keeping pre-kidney transplant medical evaluation appointments are presented in **Table 3.2**. Of the 86 eligible participants, all completed the Subjective Barriers survey at time point 2. Thirty-three self-reported barriers were identified. The most frequently reported barrier to keeping appointments associated with the pre-kidney transplant medical evaluation was participants indicating that they were “too sick” (n=10). All ten self-reported barriers were confirmed in the electronic medical record: three participants required cardiac rehabilitation, three patients had seizures, two patients were hospitalized for unknown reasons, and two patients were hospitalized for nausea/vomiting. Additional self-reported barriers included: unspecified financial difficulty (n=5), a personal issue came up (n=5), forgetting about appointments (n=4), transplantation issues (n=4), patients reported that the appointment did not fit their schedule (n=4), and because the patient reported they were feeling better (n=2).

Barriers causing incomplete or delayed evaluations

Self-reported barriers to that resulted in incomplete or delayed evaluations are presented in **Table 3.3.** Fifty self-reported barriers that resulted in incomplete or delayed evaluations were identified. Of those, barriers related to poor patient-provider communication were the most frequently reported (n=15). Communication barriers consisted of responses: I thought I had done everything I was supposed to do (n=5); No one from the transplant center called me back (n=4), and I didn’t know I was supposed to call the transplant center (n=6). In ability to lose weight was the second most frequently reported barriers (n=9). Additional Barriers included: Patients not able to get their test results from their doctor (n=8); did not have or did not want to see the dentist (n=6), problems scheduling appointment (n=3), lack of childcare as barriers (n=3), unspecified insurance related issues (n=2), not ready for the transplant at the time (n=2), afraid to learn bad news from the testing (n=1), and did not have a primary care physician (n=1).

Health Related Quality of Life

There were no significant differences seen between those who completed and those who did not on the PCS or MCS scales of the KDQOL-SF™. Several of KDQOL-

SF™ subscales met the criteria for inclusion in the final logistic regression model based on univariate analysis of mean score comparisons of non-completers vs. those who completed the evaluation: role-physical (42.5 vs. 59.5, p=0.0602), physical functioning (57.4 vs. 66.2, p=0.1346) and role emotional (63.3 vs.77.19, p=0.088). Only role-emotional was included in the final logistic regression model due to multicollinearity and model goodness of fit (*data not shown*).

Multivariate Modeling of Evaluation Completion

Determinants of pre-transplant evaluation completion are presented in **Table 3.2**. In an unadjusted model, those who identified the race/ethnicity as African American or "other" were significantly less likely to complete the pre-kidney transplant medical evaluation when compared to those who identified as white. However, identifying as African American was no longer statistically significant after adjusting for covariates. Better role-emotional quality of life and greater income were associated with completing pre-kidney transplant evaluation. Being on dialysis, having comorbid burden and reporting an household income less than $40 ,000 per year were also associated with incomplete evaluation pre-kidney transplant evaluation.

Discussion

To our knowledge this is the first study to prospectively quantify the patient's perception of barriers to completing the pre-kidney transplant medical evaluation. This perspective is critical as systems move toward patient-centered care models.

Patient Reported Outcomes

Several self-reported barriers were identified in this prospective study including: 1) incomplete cancer screening tests, 2) lack of access/desire to access dental care, 3) inability to lose weight, 4) health related quality of life, and 5) communication-based barriers. In addition we offer suggestions on potential solutions to these issues.

Incomplete Cancer Screening

Age appropriate cancer screening is a critical part of the pre- transplant evaluation. . Because the chronic immunosuppression necessary to ensure graft survival has been linked to a number of cancers, it is vitally important that a thorough cancer screening be performed prior to the initiation of immunosuppression therapy (Butt et al., 2008; Collins et al., 2012; Gautam et al., 2014; Stojanova, Caillard, Rousseau, & Marquet, 2011; Therrien, Giard, Hebert, & Bouin, 2014). We found there was a discrepancy between the number of outstanding cancer screening reported by patients and the number of outstanding cancer screening identified in the patient's electronic medical record, indicating that some patients did not report that they had outstanding cancer screening tests. This discrepancy between patient self-report and what was recorded in EMR could be the result of lack of awareness on the part of the patient about the status of cancer screening. This discrepancy could be improved by addressing the significant barriers related to poor patient-provider communication that were identified. Thus, patients should be educated on the importance of age-appropriate cancer screening early in the evaluation process, and novel strategies should be developed to combat gaps in communication between patients and their care providers.

Lack of Access/Desire to Obtain Dental Care

Barriers related to dental screening were identified in both objective and subjective analyses. Literature related to dental screening is sparse, however lack of dental insurance has been implicated as a barrier to access to dental care (Guay, 2004;

Wilczynska-Borawska, Baginska, & Malyszko, 2010). While our study did not explicitly examine the issue of dental insurance, nineteen percent of the subjective barriers that cause delayed or incomplete medical evaluations were related to patient's not having or not wanting to go to a dentist.   Patient navigators may be useful by providing encouragement and helping patients identify affordable dental care. Future studies examining dental care in this context are warranted as those who suffer from ESRD are at higher risk of dental complications related to poor dental hygiene (Wilczynska-Borawska et al., 2010).

Obesity/Weight Loss

Nine of the forty patients who did not complete the pre-kidney transplant medical evaluation remained in the evaluation due to their inability to meet the transplant center's body mass index requirement (BMI<40). Obesity has been associated with an increased incidence of would dehiscence and wound infections postoperatively (Chung et al., 2015; Gill, Hendren, Dong, Johnston, & Gill, 2014). However, evidence has emerged that patient BMI has little impact on long term graft outcomes (Pieloch, Dombrovskiy, Osband, Lebowitz, & Laskow, 2014). The heterogeneity of acceptable pre-transplant BMI criteria by transplant center complicates evaluation of the influence of obesity/weight loss on progression through the stages of the transplant process (Lu, Kalantar-Zadeh, Ma, Quarles, & Kovesdy, 2014). Exercise interventions in obese dialysis patients have shown beneficial effects including increased muscle mass (Sawant, House, & Overend, 2014), reduction in antihypertensive medications (Miller, Cress, Johnson, Nichols, & Schnitzler, 2002), and increased quality of life (Takhreem, 2008), however there are few studies correlating pre-transplant weight loss with successful completion of the medical evaluation or with improved post-transplant graft and patient survival. Thus, future research should explore and assess the relationship of weight and progression through the stages of the transplant process.

Health Related Quality of life

The KDQOL-SF™ has emerged as one of the most frequently used HRQOL assessment tools in chronic kidney disease and transplantation due to its well-established psychometric profile and its ability to predict morbidity and mortality (Butt et al., 2008; Gillespie et al., 2011; Glover, Banks, Carson, Martin, & Duffy, 2011; Kimmel & Patel, 2006; Kucirka, Grams, Balhara, Jaar, & Segev, 2012; Kutner, Zhang, Huang, & Johansen, 2012). Our prospective study found that while the physical and mental composite scores of the KDQOL-SF™ showed no statistically significant difference between those who completed and those who did not, differences were seen on the role emotional subscale. Lower scores the role-emotional subscales, taken in conjunction with data on objective and subjective barriers, indicate that mental barriers may play a significant role in successful completion of the medical evaluation. Thus, further exploration of the role of mental functioning and its relationship to HRQOL and successful navigation through the early stages of the kidney transplant process is warranted.

Communication-based Barriers

Despite several decades of research describing barriers related to poor patient-provider communication during the early stages of the transplant process, our data showed that there has been little progress made in this area. Barriers related to miscommunication between patients and providers were identified as the most frequently self-reported barrier on the Subjective Barriers Questionnaire. Miscommunication between patients and providers, as well as miscommunication among providers, has been identified elsewhere as significant barriers to the early stages of the pre-kidney transplant process (Ayanian et al., 2004; Ayanian et al., 1999; Epstein et al., 2000; Gillespie et al., 2011; Kucirka et al., 2012; Kutner et al., 2012). These communication issues must be addressed more aggressively. We suggest two potential solutions: 1) training pre-kidney transplant nurses a patient navigators, and 2) development strategies utilizing information and communication technology (ICT), specifically patient portals that link patients and providers via the EMR.

Potential Interventions

The level of communication between patients and providers required for successful completion of the pre-kidney transplant medical evaluation is complex. Moreover, it is not unusual for centers to view a patient’s ability to navigate these complex processes independently as a proxy for patient compliance and/or level of desire to receive a transplant. This view of patient autonomy is incomplete, and may place an unfair burden on some patients, particular those from marginalized communities. Shifting the responsibility to complete evaluation requirements to patients without offering adequate support is particularly concerning given the decades of research demonstrating the high prevalence of deficits in general health literacy, lack of transplant knowledge, and lack of resources, all of which have been demonstrated to be significant barriers to transplantation, in populations at highest risk of developing ERSD.

Pre-transplant Nurses as Patient Navigators

Many of the barriers identified in this study could potentially be resolved, or at the very least minimized, through the use of trained patient navigators. Since its inception, patient navigator programs have been developed in several areas of oncology and successes have been reported (Enard et al., 2015; Freeman, 2015; Ohlstein et al., 2015; Rodday et al., 2015). Patient navigation has been so effective at improving outcomes in oncology that patient navigation services are now a requirement for accreditation by the American College of Surgeons Commission on Cancer (Jolly et al., 2015). Though literature on the use of patient navigators in transplantation is limited, successful use of patient navigators has been reported (Sullivan et al., 2012). In their single center study, Sullivan et al described the use of former kidney transplant patients as navigators, resulting in a reduction in the time it took for potential transplant patients to advance through the various stages of the kidney transplant process. However, transplant centers may not have the resources to hire and train former patients as patient navigators. In essence, pre-kidney transplant nurses already function as “navigators” of sorts. However, it is rare that these care clinicians ever receive formalized training on how to most effectively and efficiently assist a patient through the early stages of the transplant process. Therefore, pre-transplant nurse coordinators may benefit from formalized patient navigator training/certification. There are several patient navigator training programs available in the United States that offer patient navigator certificates. Thus, randomized trials designed to expedite patient progression through the early stages of the transplant process are needed to establish the effectiveness of pre-kidney transplant nurses certified as patient navigators in the transplant setting. It may be that the large volume of patients pre-nurse coordinators are assigned to follow, and the level of assistance required by the patient, may be a limiting factor in the success of such an endeavor.

Information and Communication Technologies/Patient Portal Systems

Patient portal systems, systems which allow patients to access their EMR via the Internet, have gained in popularity in recent years as a result of incentives provided under The Center for Medicare and Medicaid Services (CMS) meaningful use (MU) provision (Center for Medicare and Medicaid Services, 2016). The goal of these systems is to engage patients in preventative and chronic illness management. Among early adopters, features such as appointment scheduling, and access to lab results have generally been well received by both patients and providers (Neuner, Fedders, Caravella, Bradford, & Schapira, 2015; Taha, Sharit, & Czaja, 2014). However, overall adoption of these systems has been slow (Black et al., 2015; Dhanireddy et al., 2014; Neuner et al., 2015), and systems vary widely in their functionality from center to center (Kruse, Bolton, & Freriks, 2015). Concerns have also been raised about potential disparities related to race/ethnicity (Axelrod et al., 2010; Kruse, Argueta, Lopez, & Nair, 2015; Kruse, Bolton, et al., 2015; Lockwood et al., 2013; Neuner et al., 2015; Sarkar et al., 2011; Taha et al., 2014), age (Kruse, Argueta, et al., 2015; Neuner et al., 2015; Sarkar et al., 2011; Taha et al., 2014), and health literacy (Sarkar et al., 2011; Taha et al., 2014). Despite these potential pitfalls, consideration should be given to the development of protocols that utilize patient portal systems to help reduce missed appointments, improve patient/provider communication, reduce disparities related to low health literacy by providing multimedia educational resources, and assist self-care strategies that may aid patients with symptoms management.

Limitations

While the study was successful in identifying novel barriers to completing the transplant evaluation in an urban transplant population it has limitations. The kidney transplant medical evaluation period varies widely for center to center; therefore, clear definitions of when the evaluation begins and ends can be debated. Subjective barriers were recorded using an instrument developed by the study team based on prior information though content validity and reliability were established. HRQOL results can be difficult to interpret. In this study, a signal was seen in relation to evaluation completion and several subscales of the KDQOL-SF in univariate analyses, but was no longer seen after adjusting for covariates in regression models. Further research is needed to link symptomology and biomarkers with HRQOL scores to aid in interpretation of these results. Finally, transplant centers that serve other communities such as suburban or rural populations may find barriers that we did not, and some barriers that we identified may not exist in these populations.

Conclusion

Self-identified race/ethnicity continues to be a significant barrier to transplantation, as is poor patient-provider communication. Outstanding testing was also a significant barrier to evaluation completion. The effect of obesity and HRQOL on evaluation completion needs to be better understood. Offering patient navigator training/certification to pre-kidney transplant nurse coordinators may be useful in addressing many of these long standing barriers. Development of communication technologies, including patient portals, may also reduce barriers.

Table 3.1 Sample Characteristics

	Completed (n=60)	Not completed (n=40)	P value
Gender			
Male (n(%))	38(60)	25(40)	0.933
Female (n(%))	22(59)	15(41)	
Race/ethnicity			
White (n(%))	20(87)	3(13)	0.006*
African American (n(%))	34(55)	28(45)	
Hispanic/Asian/PI (n(%))	6(40)	9(60)	
Education#			
High school or less (n(%))	16(52)	15(48)	0.339
Some College (n(%))	22(60)	15 (40)	
College and beyond (n(%))	21(70)	9(30)	
Age			
18-39 (n%))	11(73)	4(27)	0.626
40-54 (n(%))	24(57)	18(43)	
55-64 (n(%))	15(46)	18(54)	
>65 (n(%))	3(33)	6(67)	
Income%			
< $40,000/ year (n(%))	34(51)	33(49)	0.007*
$40,000/year or < (n(%))	26(79)	7(21)	
Charlson Comorbidity index			
less than 5 (n(%))	45(68)	21(32)	0.020*
5 or < (n(%))	15(44)	19(56)	
Years of kidney disease			
Less than 5 years (n(%))	33(62)	20(38)	0.624
5 years or < (n(%))	27(57)	20(43)	
Dialysis status			
Yes (n(%))	29(39)	45(61)	0.003*
No (n(%))	19(73)	7(27)	
Dialysis type			
Not Yet on dialysis (n(%))	19(73)	7(27)	0.012*
Hemodialysis (n(%))	25(38)	41(62)	
Peritoneal dialysis (n(%))	4(40)	4(50)	
Previous transplant			
Yes (N(%))	14(78)	4(22)	0.089
No (N(%))	46(56)	36(44)	

*Statistically significant difference

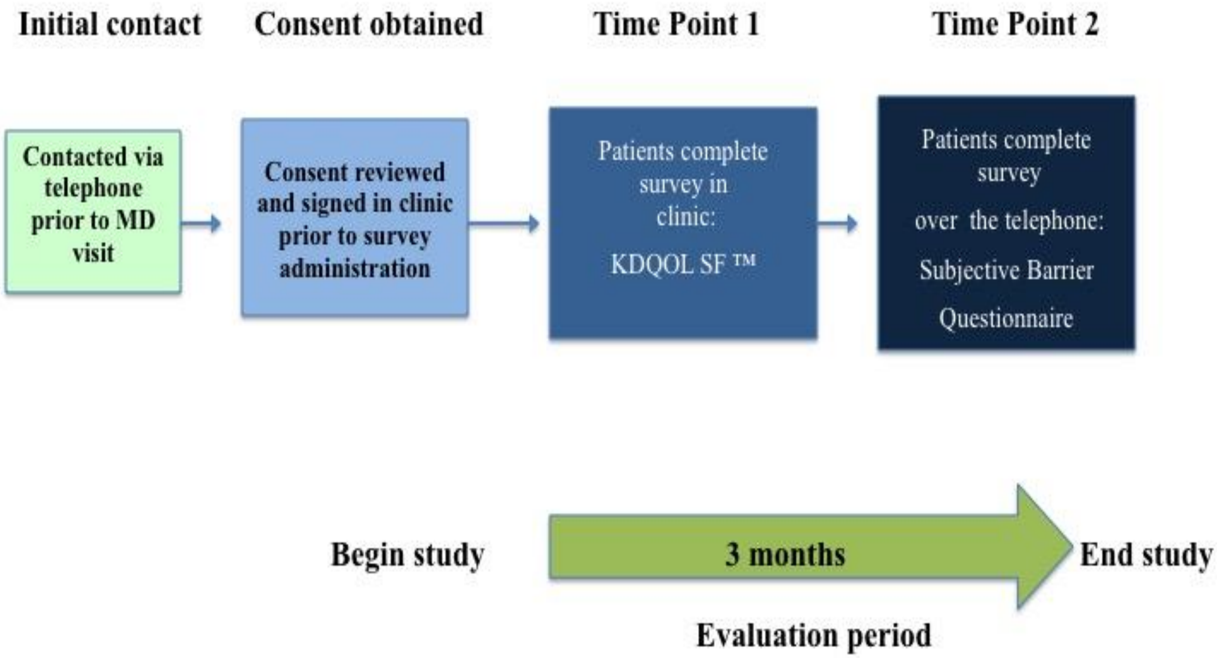

Figure 3.1. Study flow diagram depicting patient flow through the study. Patients were initially contacted by telephone prior to the initial pre-kidney transplant medical evaluation appointment with the transplant nephrologist/surgeon. The study coordinator consented the patient on the day of the medical evaluation appointment prior to the patient seeing the transplant surgeon/nephrologist and prior to completing the KDQOL SF™. Once the KDQOL SF™ was completed, visit one is complete. Next, patients 90 days after the initial pre-kidney transplant medical evaluation the study coordinator called the patient to complete the Subjective Barriers Questionnaire. Once completed, the patient was discharged from the study.

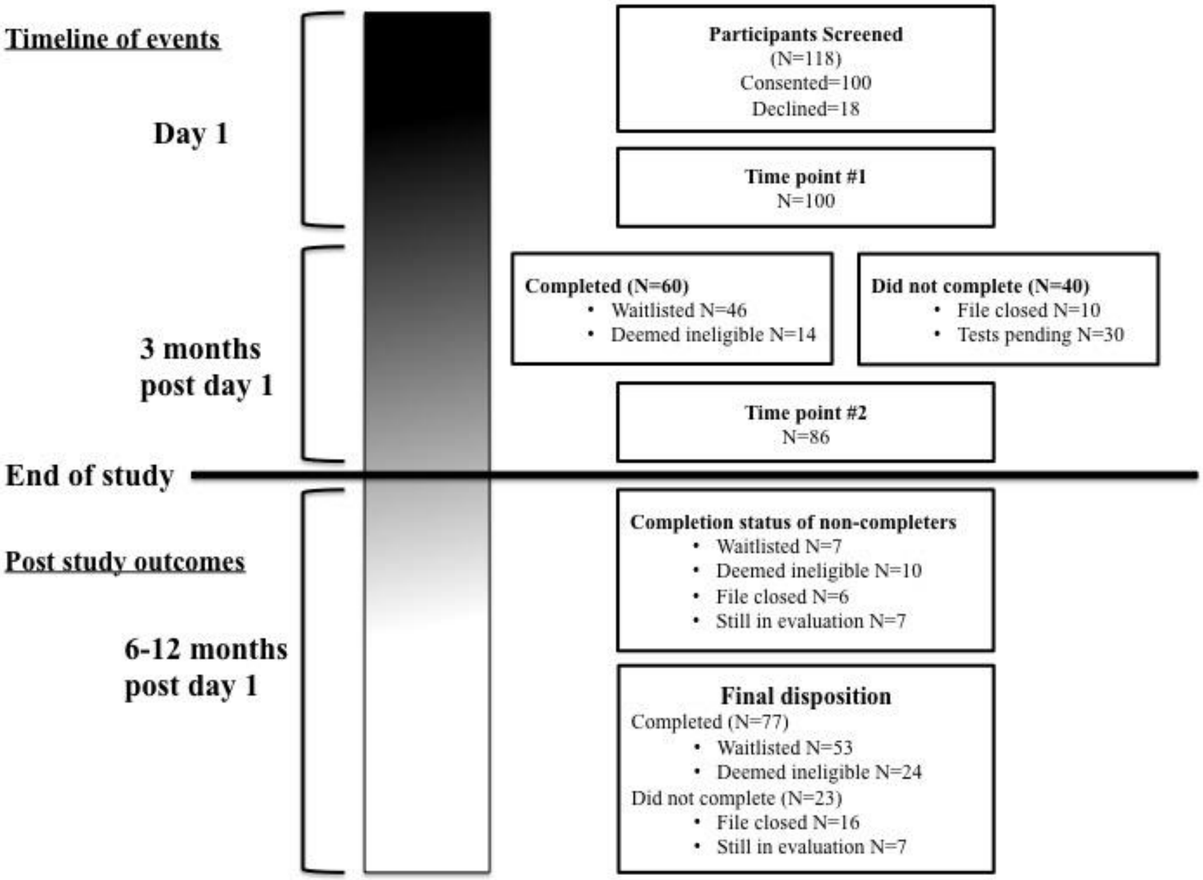

Figure 3.2 Flow of patients through the various stages of the study. All patients were followed through the completion of the evaluation after the study had ended.

Table 3.2 Self-reported barriers to keeping evaluation appointment compared to barriers identified in the patient Electronic Medical Record (N=86)*

Barrier	Self-reported N=33	Electronic Medical Record N=22
I was too sick N(%)	10(30)	10(46)
Financial difficulty (unspecified) N(%)	5(15)	NA
A personal issue came up N(%)	5(15)	2(9)#
Forgot appointment N(%)	4(12)	4(18)
Transportation issues N(%)	4(12)	NA
Appointment did not fit schedule N(%)	4(12)	4(18)
I was feeling better N(%)	2(6)	2(9)

*Self-reported barriers to keeping pre-kidney transplant medical evaluation appointments were assessed in 86 patients who had either completed the medical evaluation, had their file closed due to inactivity, or were still in the evaluation 90 days after the initial visit with the transplant surgeon or nephrologist. Of those patients, nineteen reported barriers to keeping evaluation appointment. Several patients reported more than one barrier to keeping medical evaluation appointments. Self-reported barriers where then compared to barriers identified in the patients electronic medical record. The pre-kidney transplant coordinator assigned to the case confirmed barriers identified in the EMR.

# Indicates discrepancy between self-reported barriers and those identified in the patient's electronic medical record

Table 3.3 Self-reported barriers to evaluation completion compared to barriers identified in the Electronic Medical Record (N=86) ¥

	Self-reported N=50	Electronic Medical Record N=41
Barriers		
Communication issues* N(%)	15(30)	NA#
Need to lose weight	9(18)	9(22)
Was not able to get test results from my doctor N(%)	8(16)	21(51)€#
Did not have/Did not want to see a dentist N(%)	6(12)	5(12) €#
Problems scheduling appointments N(%)	3(6)	3(7)
Did not have childcare N(%)	3(6)	NA#
Insurance related issues N(%)	2(4)	2(5)
Was not ready for a transplant at the time N(%)	2(4)	NA#
Was afraid to get bad news from the tests N(%)	1(2)	NA#
Did not have a primary care physician N(%)	1(2)	1(2)

¥ Self-reported barriers to completing the pre-kidney transplant medical evaluation were assessed in 86 patients who had either completed the medical evaluation, had their file closed due to inactivity, or were still in the evaluation 90 days after the initial visit with the transplant surgeon or nephrologist. Of those patients, twenty-nine reported barriers to keeping evaluation appointment. Several patients reported more than one barrier to keeping medical evaluation appointments. Self-reported barriers where then compared to barriers identified in the patients electronic medical record. The pre-kidney transplant coordinator assigned to the case confirmed barriers identified in the EMR.

* Communication issues is comprised of three answers from the Subjective Barriers Questionnaire: I thought I had done everything I was supposed to do (N=5); No one from the transplant center called me back (N=4), and I did not know I was supposed to call the transplant center (N=6).

# Indicates discrepancy between self-reported barriers and those identified in the patient's electronic medical record

€ Outstanding testing identified in the patient's electronic medical record included: Cancer screenings tests (N=11), cardiac testing (N=5), hepatology testing (N=2), psychological testing (N=1), neurology testing (N=1), and radiologic testing (N=1)

Table 3.4 Determinants of completion of the pre-kidney transplant evaluation

	Unadjusted OR(95%CI),p-value	Adjusted OR(95%CI),p-value
Race/ethnicity (relative to white, non-Hispanic)		
Black, non-Hispanic	0.18(0.05-0.68), 0.011	0.27(0.59-1.26),0.096
Other (Hispanic, Asian, Pacific Islander)	0.1(0.02-0.49), 0.005	0.07(0.01-0.43),0.004
Previous transplant (relative to no previous transplant)	2.74(0.83-9.0),0.098	1.4(0.31-6.23),0.659
Dialysis status (relative to not yet on dialysis)	0.27(0.09-0.78), 0.016	0.20(0.04-0.90),0.036
Charlson Comorbidity Index (relative less than 5)		
5 or greater	0.37(0.16-0.86), 0.022	0.30(0.11-0.85),0.024
Self-reported income (relative to <$40,000)		
$40,000 or greater	3.78(1.36-10.50), 0.011	3.95(1.19-13.14),0.025
HRQOL Role-emotional (relative to less than the mean)		
Greater than the mean	1.95(0.86-4.50), 0.112	3.09(1.06-8.98),0.038

Post hoc test of sensitivity, specificity, and rate of correct classification were 83.33%, 62.50%, and 75.00% respectively. LR chi^2= 33.02. McFadden's R^2=0.2453, ROC area under the curve=0.8046.

References for Chapter III (See Cumulative References)

Chapter IV

Renal Transplantation and the Digital Divide: Does Information and Communication Technology Represent a Barrier or a Bridge to Transplantation for African Americans?

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This manuscript replaces portions of the methods section and results section of the traditional dissertation. Mr. Lockwood was the primary author on this paper, and Dr. Lee a co-author on this paper. Mr. Lockwood completed the analysis and manuscript preparation under the supervision of Dr. Lee. This article was accepted for publication in the Progress in Transplantation on April 14, 2014. Progress in Transplantation is a quarterly journal, the official journal of NATCO, and provides peer-reviewed original research, case studies, international papers, review articles and policy papers. The journal offers a multi-disciplinary team approach to organ and tissue donation and transplantation (Progress in Transplantation, 2016). PIT has an impact factor of 0.835. This manuscript is in final state.

Funding Acknowledgment

This work was supported, in part, by internal funding from the Department of Medicine at the University of Chicago Medicine. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Department of Medicine at the University of Chicago Medicine.

Declaration of Conflicting Interests

None Declared

Key Words: Digital divide, kidney transplantation, Information and communication technology

Citation:

Lockwood, M. B., Saunders, M. R., Lee, C. S., Becker, Y. T., Josephson, M. A., & Chon, W. J. (2013). Kidney transplant and the digital divide: is information and communication technology a barrier or a bridge to transplant for African Americans? *Progress in Transplantation*, *23*(4), 302-309.

Abstract

Context: Barriers to renal transplantation for African Americans (AAs) are well documented in the literature. There is little published data describing information and communication technology (ICT) ownership and use in transplant populations.

Objective: The purpose of this study was to characterize racial differences related to ICT ownership and usage in renal transplant patients. **Design**: A single center, cross-sectional survey study **Setting:** An urban Midwestern transplant center **Participants:** 78 pre- and 177 post-transplant patients **Main outcomes measures:** The survey consisted of six demographic questions, three disease-related questions, and nine technology related questions. Dichotomous (yes/no) and Likert-scale items were the basis for the survey.

Results: Cellular phone usage was high and comparable between groups (94% AAs vs. 90% White, p=0.22). A vast majority (75% of AAs and 74% of Caucasians) reported being “comfortable” sending and receiving text messages. Computer ownership (94.3% vs. 79.3%) and Internet access (97.7% vs. 80.7%) were greater among Caucasians than AAs (both p<0.01). Fewer AAs were frequent users of the Internet (27.1% vs. 56.3%) and email (61.6% vs. 79.3%) compared with Caucasians (both p<0.01). More AAs than Caucasians preferred education in a classroom setting (77% vs. 60%) (p<0.01) and educational DVDs (66% vs. 46%) (both p<0.01). **Conclusion:** The use of cellular phone technology and text messaging was ubiquitous and comparable between groups, but, computer and Internet access and frequency of use were not. Reaching out to the AA community may best be accomplished by using cellular/text messaging as opposed to Internet-based platforms.

Introduction

As information and communication technologies (ICT) continue to advance, reports describing interventions using ICT have become more prevalent in the literature. The aim of this manuscript is to describe Phase I of a tri-phasic assessment of ICT use in pre and post renal transplant patients. More specifically, we will describe ICT ownership, comfort of use, and frequency of use trends in the context of race/ethnicity. The overarching goal of Phase I of this study is to identify any disparities/barriers or potential opportunities that the use of ICT may present.

African Americans (AAs) face significant disparities at each step of the transplant process. AAs are at significantly greater risk of developing end-stage renal disease (ESRD) than Caucasians, and AAs constituted almost one third of those with ESRD (Young & Gaston, 2002). Further, AAs comprise 34% of the kidney transplant waiting list but only 13.8% of deceased donors (Bratton, et al., 2011). AAs have a disproportionately longer wait for a suitable deceased donor kidney and in general are less likely to receive either a deceased or live donor kidney compared with Caucasians (Reeves-Daniel, et al, 2009).

Several barriers to renal transplantation among AAs have been described in the literature: religious/cultural beliefs (Bratton, et al, 2011; Cort & Cort, 2008; Morgan, 2006), mistrust of the medical community, unwillingness to donate (Lundsford, et al, 2006), lack of knowledge related to transplantation (Bratton, et al, 2011; Cort& Cort, 2008; Edwards, Essman, & Thornton, 2007), refusal to ask someone to donate (Edwards, et al, 2007: Roark, 1999; Gibney, King, Maluf, Garg, & Parikh, 2007; Robinson, Borba, Thompson, Perryman, & Arriola, 2009; Reese, Shea, & Bloom, 2009), economic factors

(Young & Gaston, 2002; Morgan, 2006), and co-morbidities (Young & Gaston, 2002; Bratton, et al, 2011; Lundsford, et al, 2006). AA transplant candidates are also less likely to be referred for transplantation than Caucasians (Young & Gaston, 2002). While not all of the barriers are modifiable, we hypothesize that using ICT could be effective in eliminating some barriers to transplantation in the AA community.

The purpose of this study is to characterize racial differences related to ICT ownership and usage in renal transplant patients in an effort to identify potential barriers and opportunities that will support future development of interventions using ICT.

Background/Significance

Information Communication Technology (ICT), such as cellular phones, Smartphones, text messaging, the Internet and email have increasingly become ubiquitous features of modern life in many cultures (California Health Foundation, 2011; International Telecommunications Union [ITU], 2012; Pew Center, 2011; Plaza, Martin, Martin, & Medrano, 2011). Mobile cellular is the most rapidly adopted technology in history and the most widespread technology on the planet with an estimated 4.6 billion subscriptions globally (ITU, 2012). As of 2009, more than a quarter of the world's population was using the Internet (ITU, 2012). Some 39% of Americans have positive and improving attitudes about their mobile communication devices, which in turn draws them further into engagement with digital resources – on both wireless and local area network (LAN) line platforms (Pew Center, 2011). While increased Internet adoption and the rise of mobile connectivity have reduced many gaps in access to technology over the past decade, digital disparities still remain significant barriers for implementation of ICT with some patient populations (ITU, 2012).

ICT interventions used in the clinical setting have been described in connection with a variety of chronic medical conditions including diabetes (Harris, Tulfano, & Le, 2010; Patrick, Griswold, Rash, & Intile, 2008), heart failure (Chauidry, Matera, & Curtis, 2010; Halafax, Caffazzo, & DPhil, 2007), obesity (Patrick et al, 2008), obstructive sleep apnea (Stepnowski, Palau, Marler, & Gifford, 2007), alcohol and drug addiction (Patrick, et al, 2008), and human immunodeficiency virus (18,26). Uses of ICT include: biometric monitoring (Canady, 2008; Rice, et al,, 2003; Swendeman, et al., 2010; US Department of commerce, National Telecommunications and Information Administration, 1995), medication compliance (Canady, 2003; Harris, et al., 2010), behavior modification (Canady, 2008; Rice, et al,, 2003; Swendeman, et al., 2010; US Department of commerce, National Telecommunications and Information Administration, 1995), and medical screening (Harris, et al, 2010; Patrick, et al., 2008; Swendeman, et al., 2010).

Fox and Purcell, in their 2010 report for the Pew Research Center: Internet and the American Life Project titled *Chronic Disease and the Internet*, found that adults living with chronic disease were significantly less likely than healthy adults to access the Internet: 81% of healthy adults go online vs. 52% of those with two or more chronic diseases. They went on to conclude that when all demographic factors associated with chronic illness were controlled, living with chronic disease in and of itself had an independent, negative effect on someone’s likelihood to have Internet access (Pew Center, 2011).

To the best of our knowledge there are no data in the literature that describe racial differences in the use of information and communication technology in renal transplant recipients. The University of Chicago Medical Center, because of its enriched population of AAs, is a suitable center to conduct this survey characterizing racial differences in technology ownership and usage trends in pre and post renal transplant patients. Based on the Organ Procurement and Transplantation Network (OPTN) center specific and national data reports retrieved on August 1, 2012, AAs comprised 53% of renal transplant recipients at the University of Chicago Transplant Center from 2005 to 2011 (OPTN, 2011a) compared to 25% of persons that received a transplanted kidney nationally during the same time period (OPTN, 2011b). AAs comprised 55.3 % of the survey population sample from this study. In comparison, the 2010 census report shows that AAs make up 33% of the population of the city of Chicago (Bureau of the Census, 2012).

The literature describing access to and use of ICT in transplant populations is sparse. Transplant related ICT based interventions described in the literature are limited to medication adherence (Miloh, Annuziato, & Aaron, 2009). Miloh et al. (2009) saw a significant improvement in medication adherence and a reduction in rejection after implementation of a text message reminder system in pediatric liver transplant patients.

Methods

We completed a cross-sectional survey study of pre- and post-renal transplant patients. Data were collected during scheduled transplant education sessions and during post-transplant follow-up appointments at a single urban renal transplant center from January 15, 2012 to June 1, 2012. The study was approved by the University of Chicago Institutional Review Board prior to the administration of the study survey. All participants provided informed consent prior to participation in the study.

All English speaking patients 18 years of age and older that presented either for a pre-renal transplant education session or a post-renal transplant clinic visit during the study period were invited to participate in the survey. Of the 270 surveys that were distributed, 255 surveys from this sample of convenience were returned, for a response rate of 94%. Those that self-identified as “Hispanic/Latino” or “other” were excluded from the analysis due to small and under-representative sample sizes (Hispanic /Latino n=21, “other” n=6). Median income data was derived from 2010 Census data based on self-reported zip code.

The survey was developed after extensive literature review and focus group testing. The focus group included a transplant nephrologist, a living donor advocate physician, a PhD prepared nurse, a pre transplant nurse coordinator, a post-transplant nurse coordinator, a transplant nurse educator, a transplant clinical research nurse, and five post renal transplant patients (both genders, and a variety of age, race, and economic/educational background). The focus group then rated the extent to which the survey items represented the dimensions being measured, such as technology ownership, and determined if any content was ambiguous or missing from the survey. After a thorough review, the survey questions were modified for clarity and simplicity.

The final survey consisted of six demographic questions, three disease specific questions and nine technology related questions. Yes/no and 5-point Likert scale questions were used in the survey. A test of the readability of the survey was conducted using the Flesch Kincaid readability test. The Flesch Reading ease score was 67.8 indicating that the survey would be easily understandable by 13-15 year old students and written at a seventh grade level. Subjects seen in person were given the option to complete the survey with the Investigator present or complete the survey in private. Technologies included in the survey were briefly described to participants prior to the administration of the survey to ensure clarity of technological devices, and subjects were given an opportunity to have questions about the survey answered prior to and after administration of the survey.

Statistical Method/Data Analysis

Categorical variables describing comfort of use and frequency of use of various ICTs were collapsed into “comfortable” (very and somewhat comfortable) or “uncomfortable” (somewhat or very uncomfortable, and do not use). Categorical variables describing frequency of email use were collapsed into “frequently” (every day and once a week), or “infrequently” (once a month and never use). Categorical variables for frequency of Internet use were collapsed into “frequent” (6-10 hours and >10 hours per week), or “infrequent” (1-5 hours and less than 1 hour per week) (**Table 4.1**). Unadjusted differences in categorical data by self-identified race were quantified using chi-square analyses. Multivariate logistic and linear regression modeling were used to quantify the independent effect of self-identified race on ICT use controlling for the confounders of age, gender, income, and education level. All statistical analyses were conducted using Stata 11.0 (College Station, TX).

Results

A majority of the patients surveyed reported having kidney disease for 5 years or more and were post-transplant (**Table 4.2**). More AAs reported being on dialysis compared to Caucasians. More of the AA respondents were female compared with white respondents. Education level was equally distributed between groups, but, median zip code income was significantly lower among AA than white participants.

Cellular and Smart Phone Trends

Cellular and smart phone ownership was comparable between Caucasians and African Americans (**Figure 4.1**). There were no differences in the proportions of AAs and Caucasians who reported being comfortable using their cell phones, sending and receiving text messages, and using smart phones (**Figure 4.2**). It should be noted that participants who reported owning a cellular phone did not make a distinction between the smart phone and a cellular phone and answered yes to both Smart phone and cellular phone ownership.

Computer, Internet, and Email Trends

Fewer AAs than Caucasians reported owning a computer and having Internet access, though ownership was high in both groups (**Figure 4.1**). Controlling for age, gender, education, and income, Caucasians were more likely to have a computer (OR 3.2, 95% CI (1.11-9.4), $p=0.03$); Caucasians also were more likely to have the Internet compared to AAs (OR 8.5, 95% CI (1.8-40.0), $p<0.01$) adjusting for these same factors. There were no differences in the proportions of AAs and Caucasians who reported being comfortable using computers and the Internet; more Caucasians than AAs reported being comfortable using email (**Figure 4.2**). More Caucasians than AAs were frequent users of the Internet and email (**Figure 4.3**). Adjusting for age, gender, education and income, Caucasians were more likely to be frequent users of the Internet compared with AA participants (OR 3.75, 95% CI (1.85-7.6), $p<0.01$). Caucasians were numerically, but not significantly, more likely to be frequent users of email compared with AA participants (OR 2.1, 95% CI (1.00-4.6), $p= 0.05$).

Educational Preferences

AAs and Caucasians had similar preferences for a transplant specific educational website and written instructions. More AAs than Caucasians preferred education in a classroom setting (77% vs. 60% respectively) ($p<0.01$) and educational DVDs (66% vs. 46% respectively) ($p<0.01$). White and AA participants had comparable interest in using a transplant based education website; 90% of AAs and 92% of Caucasians indicated interest in web-based education ($p=0.52$).

Discussion

To our knowledge this is the first survey to assess racial differences related to ICT ownership and usage in a transplant population. Cellular phone ownership trends were similar between groups. Cellular phone ownership trends exceeded those reported in the Pew Research Center's: The Internet and the American Life Project (Pew Center, 2011). Both groups reported being "comfortable" using cellular phones and text messaging. Further study is needed to better characterize how patients use their cellular phones. The fact that cellular phone ownership is ubiquitous in both the AA and White populations surveyed presents a novel opportunity to harness ICT as a tool to improve care in the pre- and post-renal transplant populations. We are currently working on Phase II of this technology assessment designed to assess the use of ICT, specifically text-messaging, in an effort to improve patient care at an urban transplant center. The goal of Phase II is to evaluate factors/barriers that would the most effectively be addressed with the use of an ICT based intervention. We also plan to expand on our characterization of how patients use their phones.

While statistically significant differences were noted in relation to computer ownership and access to the Internet between AA and White pre- and post-renal transplant patients, the sheer number of patients that reported owning computers and the Internet, as reported in our survey, may negate any potential negative effects that may result from this difference. Despite this slight incongruity in computer and Internet ownership, both AAs and Caucasians reported being “comfortable” using computers and the Internet.

What is not clear from the data is what potential impact these technological differences between AAs and Caucasians may have on interventions utilizing these communications technologies. As previously stated, Fox and Purcell described Internet use among those with chronic illness compared to those with no history of illness and showed that adults living with chronic disease were significantly less likely than healthy adults to access the Internet: 81% of adults reporting no chronic illness go online vs. 52% of those with two or more chronic diseases. The authors of the Pew study concluded that when all demographic factors associated with chronic illness were controlled, living with chronic disease in and of itself had an independent, negative effect on someone’s likelihood to have Internet access (Pew Center, 2011). Our survey found that 97.7% of Caucasians and 80.7% of AAs surveyed, transplant patients with multiple chronic illnesses, had access to the Internet (**Table 3**). This is of interest because the authors of the Pew study went on to conclude that once someone was online, living with chronic disease was also associated with a greater likelihood to access user-generated health content such as blog posts, hospital reviews, doctor reviews, and podcasts (Pew Center, 2011). It is not clear if the difference we saw between our data and the Pew

Research Center's data was related to the temporal difference between the two surveys or was a representation of the difference in the populations that were surveyed. Further characterization of this trend would be helpful in informing future Internet-based ICT interventions. A larger multi-center study is needed to better characterize these differences in computer and Internet usage and elucidate if these potential barriers are similar to the larger renal transplant population. A larger study should include a wider demographic to better understand these technological trends in Hispanics/Latinos, Asians, and other racial/ethnic groups.

Finally, AAs showed a strong preference for more traditional educational strategies. AAs were significantly more likely to prefer education in a classroom setting. AAs were also significantly more likely to prefer an educational DVD than their White counterparts. This preference for more traditional forms of education should help inform the development of culturally specific education plans.

Cellular phone technology, particularly text messaging, represents a potential opportunity to connect with AA patients and help reduce barriers and disparities that currently exist. ICT could play an important role in designing outreach programs that dispel myths and reduce barriers that prevent AAs from completing the transplant evaluation, registering as organ donors, or presenting as a live donor for a friend or family member. ICT-based interventions coupled with traditional educational strategies such as existing classroom education and educational DVD's could act to increase knowledge about the transplantation process, and allay existing myths about transplantation in the AA community.

Limitations

We used a sample of convenience for this study and result are likely not generalizable to the broader renal transplant population. The sample was drawn from an urban population and results may vary in rural areas. Hispanics/Latinos and other ethnic groups were not represented in this sample. A larger multi-center study that includes a wider demographic would be useful in understanding general ICT trends. We did not explore how people use their cellular phones and smart phones in Phase I of this technology assessment but plan to include this in Phase II. The incongruity between the ICT ownership data, comfort of use data, and frequency of use data, particularly as it pertains to Internet and email use, may be an indication that transplant patients surveyed were not clear about some of the terminology associated with ICT. For example, more participants reported using email than the Internet. Participants may not consider accessing their email on their phone as accessing the Internet. Finally, we did not assess the stability of cell phone use. There is anecdotal evidence that patient’s cell phone numbers change frequently. We will explore this issue in Phase II of this ICT assessment.

Conclusion

The necessity to understand disparities and barriers to transplantation for underserved populations is essential to finding solutions to reduce the gap that currently exists. This urgency to abate existing barriers is driven by the positive impact that kidney transplantation has on survival and quality of life of recipients. Simply understanding the barriers means little without a plan to address these longstanding disparities. Increasing the number of AAs that register as organ donors or present as living donors, for example, is essential to make up for the disproportionate demand for organs in AAs. While differences in some forms of ICT were seen others, such a text messaging, could represent a much-needed bridge to transplantation in the twenty-first century.

Table 4.1. Description of variables

Do you have the following?	**Potential answers**	**Variable type**
A Computer	Yes/No	Binary
A cell phone	Yes/No	Binary
A Smart phone (iPhone of Android)	Yes /No	Binary
DVD Player	Yes/No	Binary
How comfortable are you using the following?		
Using your cell phone	Comfortable/uncomfortable	Continuous collapsed*
Sending and receiving text messages	Comfortable/uncomfortable	Continuous collapsed*
Using your Smart phone	Comfortable/uncomfortable	Continuous collapsed*
Using your computer	Comfortable/uncomfortable	Continuous collapsed*
Using the Internet	Comfortable/uncomfortable	Continuous collapsed*
Using email	Comfortable/uncomfortable	Continuous collapsed*
Frequency of use		
How many hours per week do you use the Internet?	Frequently/infrequently	Continuous collapsed**
How often do you use email?	Frequently/infrequently	Continuous collapsed**
If there were a website to teach you about your transplant would you use it?	Yes/No	Continuous collapsed***
I learn best by:		
Someone teaching me in class	Yes/No	Binary
Using the Internet/Health websites	Yes/No	Binary
Reading instructions in writing	Yes/No	Binary
DVD or video I can watch at home	Yes/No	Binary

Note: Quantification codes were assigned to each survey answer, (1)-yes and (2)-no to assist in quantitative analysis. The 5-point Likert scale questions were coded as follows: Survey question 3: How comfortable are you using the following?*: (1) very comfortable, (2) somewhat comfortable, (3) somewhat uncomfortable, (4) very uncomfortable, (5) I don't know how to use; Survey question 5: How many hours per week do you use the Internet?** : (1)-less than an hour, (2)- 1-5 hours, (3)- 6-10 hours, (4) more than 10 hours, (5)- I never use the Internet; Survey question 6: How often do you use email?** : (1)- Every day, (2)- once a week, (3)- once a month, (4)- I never use email, Survey question 7: If there were a website to teach you about your transplant would you use it?*** : (1)- definitely, (2)- probably, (3)- maybe, (4)- probably not, (5)- no, I would not

Table 4.2. Sample Characteristics (n=228)

Variables	African American	White	P-value
Kidney Transplant			
Pre (n(%))	45(31.9)	27(31.0)	P =0.89
Post (n(%))	96(68.1)	60(69.0)	
Years of Kidney Disease			
Less than 1 year (n(%))	17(12.1)	9(10.3)	P =0.395
2-3 years (n(%))	29(20.6)	12(13.8)	
4-5 years (n(%))	20(14.2)	10(11.5)	
More than 5 years (n(%))	75(53.2)	56(64.4)	
Dialysis			
Yes (n(%))	115(81.6)	53(61.0)	P < 0.01*
No (n(%))	26(18.4)	34(39.1)	
Type of dialysis			
Hemodialysis (n(%))	89(74.2)	31.0 (58.49)	P=0.03*
Peritoneal (n(%))	13(11.30)	14 (26.42)	
Both (n(%))	13 (11.30)	8 (15.1)	
Age (Median (Range))	50.2	49.6	P =0.4
Gender			
Male (n(%))	70(49.7)	58(66.7)	P < 0.01*
Female (n(%))	71(50.4)	29(33.3)	
Race/ethnicity	141(55.3)	87(34.1)	
Education			
High School or less (n(%))	48(34.0)	27(31.0)	P = 0.11
Some college (n(%))	53(38.0)	24(28.0)	
College and beyond (n(%))	40(28.4)	36(41.4)	
Median Household Income (Mean (Range)	39511.6	56482.73	P < 0.01 *

* Statistically significant unadjusted differences

Table 4.3 Pew Research: Internet and the American life (Chronic Illness and the Internet) vs. University of Chicago pre and post-renal transplant patients ICT use

% that use:	**African American (U of C)***	**White (U of C)***	**Mean (U of C) ***	**Pew Study****
Cell phone (%)	94.3	95.4	94.9	70
Text messaging (%)	75.7	72.4	74.1	23
Email (%)	72.9	85.1	79	91
Internet (%)	72.1	86.2	79.2	52

* Data collected January 15 to June 1, 2012

** Data collected summer/fall 2009

Figure 4.1. ICT Ownership by Self-Identified Race

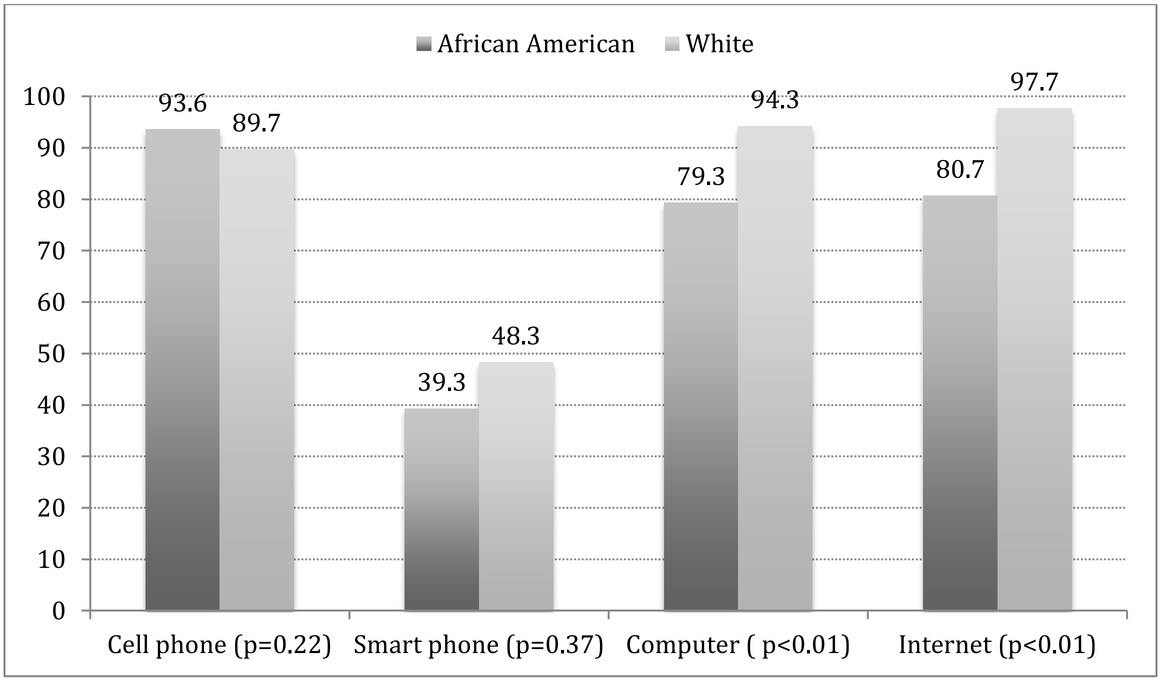


Figure 4.2. Proportions of Respondents who were Comfortable with ICT by Self-Identified Race

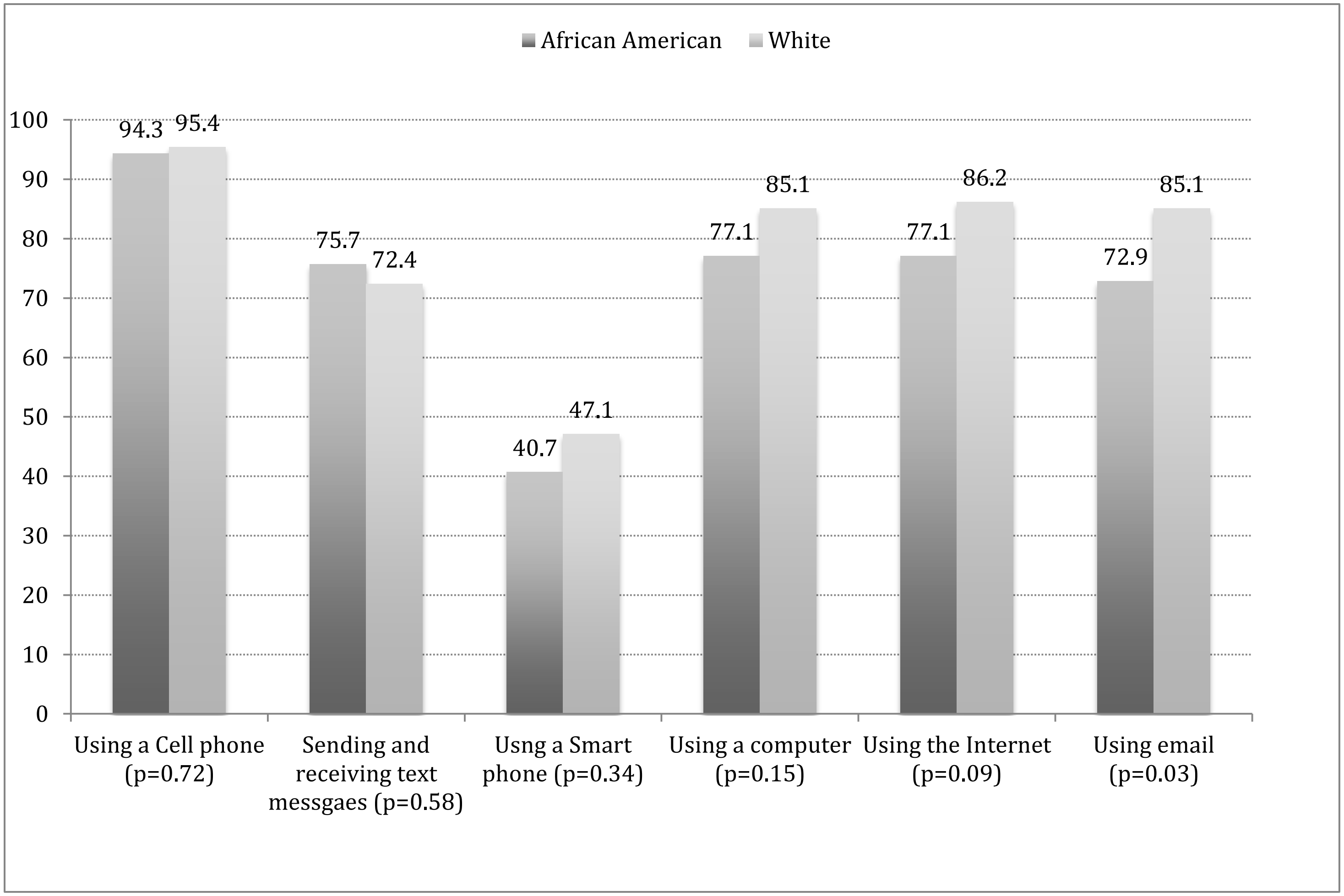
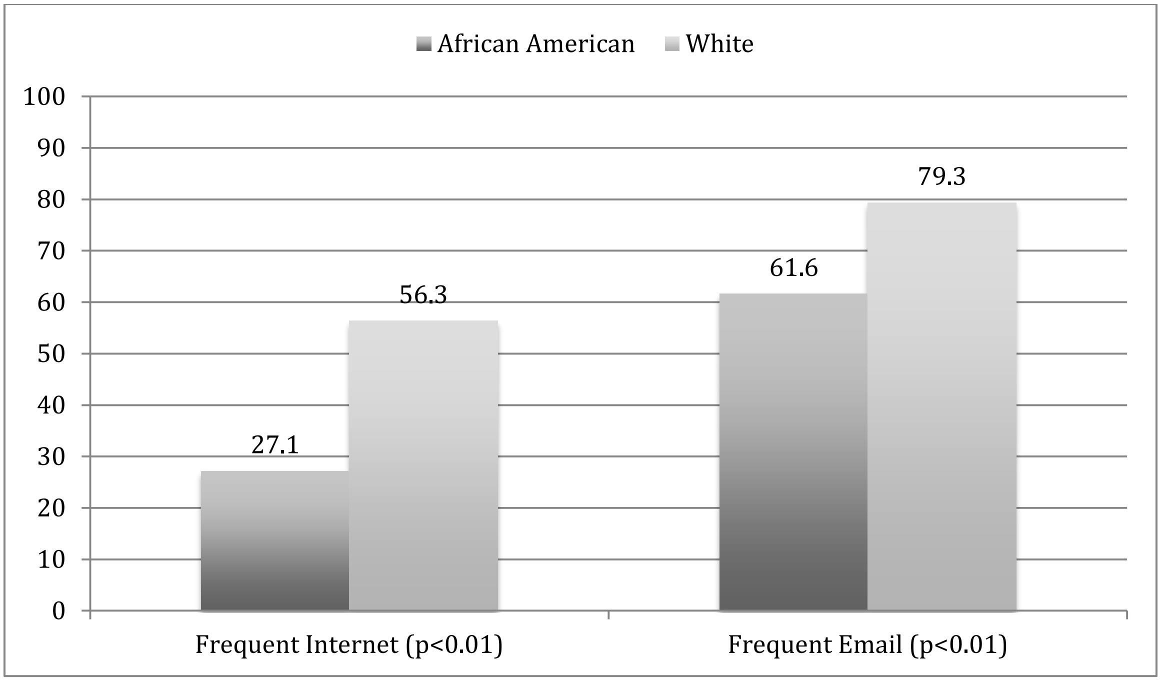


Figure 4.3. Frequent Users of the Internet and Email by Self-Identified Race



References for Chapter IV (See Cumulative References)

Chapter V

Determinants of frequent Internet use in an urban kidney transplant population: Characterizing the digital divide.

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This manuscript replaces portions of the methods section and results section of the traditional dissertation. Mr. Lockwood was the primary author on this paper, and Dr. Lee a co-author on this paper. Mr. Lockwood completed the analysis and manuscript preparation under the supervision of Dr. Lee. This article was accepted for publication in the Progress in Transplantation on April 14, 2014. Progress in Transplantation is a quarterly journal, the official journal of NATCO, and provides peer-reviewed original research, case studies, international papers, review articles and policy papers. The journal offers a multi-disciplinary team approach to organ and tissue donation and transplantation (Progress in Transplantation, 2016). PIT has an impact factor of 0.835. This manuscript is in final state.

Funding Acknowledgment

This work was supported, in part, by internal funding from the Department of Medicine at the University of Chicago Medicine. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Department of Medicine at the University of Chicago Medicine.

Declaration of Conflicting Interests

None Declared

Key Words: Digital divide, kidney transplantation, Information and communication technology

Citation:

Lockwood, M., Saunders, M., Josephson, M. A., Becker, Y. T., & Lee, C. (2015). Determinants of frequent Internet use in an urban kidney transplant population in the United States: characterizing the digital divide. *Prog Transplant, 25*(1), 9-17. doi: 10.7182/pit2015957

Abstract

Context: The Internet is a staple of electronic communication and is essential to the emerging telemonitoring and health information technology interventions for adults with chronic diseases. **Objective:** The purpose of this study is to identify determinants of frequent Internet use in an urban kidney transplant population in the United States. **Design**: A single center, cross-sectional survey study . **Setting:** An urban Midwestern transplant center. **Participants:** 78 pre- and 177 post-transplant patients. **Main outcomes measures:** The main outcome of this study was frequent Internet use, defined as using the Internet more than five hours per week. **Results:** Thirty-eight percent of participants reported being frequent Internet users. Non-Hispanic blacks were 74% less likely than Caucasians to report being frequent Internet users. Those who report their race/ethnicity as "other" were 94% less likely to report frequent Internet use compared to Caucasians. Women were 59% less likely to be frequent users of the Internet compared to men. Those who reported having kidney disease for more than 3 years were more likely to report being frequent Internet users. As education increased, Internet use increased. As age increased, Internet use decreased. **Conclusion:** Only 38% of participants reported being frequent Internet users. For kidney patients, younger, male, educated, white patients, and those who have had kidney disease more than three years are the most frequent users of the Internet. Alternatives to electronic information sources and/or additional resources should be considered for those who may fall in the so-called digital divide.

Introduction

Most research related to information and communication technology (ICT) use comes from regions outside the United States (US) including Europe, Asia, Australia and the Nordic regions, all of which rank higher in Internet accessibility when compared to the United States. According to the International Telecommunication Union (ITU) the world's top broadband economies are from Europe, Asia, and the Pacific (International Telecommunications Union, 2013). Additionally, the United States ranks sixteenth in broadband Internet connections, seventeenth in fixed broadband Internet subscriptions, and thirty-fifth in Internet bandwidth out of 148 nations worldwide. The United States ranks 50th out of 90 nations in cost of broadband Internet access. Because of these technological differences, not to mention cultural and political differences, it is difficult to generalize studies on ICT or Internet trends from outside the US and apply them to populations within the US.

Since the introduction of the Internet 25 years ago, many in the health care arena have suggested that this technology would have the potential to revolutionize health care as we know it. And while many advances in technology have occurred over that period of time, a health care revolution with the Internet at its core has been slow to materialize. It has been suggested in the literature that the Internet could be utilized in the discipline of solid organ transplantation for a number of uses including patient education, (Hanif, Read, & Clancy, 2012; Neyhart, 2008; Possemato, & Gellar, 2007; Slakey & Nowfar, 2003) to promote integration of care (Trisolini, et al, 2004), and to aid in the process of selection of potential donors and recipients (Bramsted & Young, 2006; Moore, et al, 2013). However, there are conflicting reports in the literature on the quality of transplant websites and their potential benefit, (Bramstedt, & Dave, 2013; Dew, et al, 2004; Hanif, et al, 2007; Possemato & Geller, 2007). Interest in harnessing the potential of the Internet has grown as technology has improved, as evidenced by the $38 billion investment in health information technology authorized under the American Recovery and Reinvestment Act of 2009 (Lustria, Smith, & Hinnant, 2006). But while the promise of the Internet is a reality for some, the benefits have not been extended to all.

As we move deeper into the digital age the ostensible ubiquity of digital technology has led to an explosion of health related electronic data sources including electronic medical records and patient portal systems, web-based health education materials and digitized remote biometric monitoring. There are thousands of health related websites available for health consumers to access. Internet-based technologies such as personal health records and patient portals are increasingly viewed as essential components of patient-centered care (Kruse, et al., 2012). According to the American Hospitals Association, health care expenditures on health information technology grew from $19 to $31 billion between 2000 and 2006 (Miller & West, 2009). While the general perception is that access to these digital technologies is abundant, there is a growing body of literature expressing concern about the growing gap between those who have access to these technologies and those who do not (Cresci, Yardandi, & Morrell, 2010; Dew, et al, 2004; Mayberry, Kripalani, Rothman, & Osborn, 2011; Neter, & Brainin, 2012; Sun, 2012; Wang, Bennet, & Probst, 2011; Zach, Dalrymple, Rogers, & Williver-Farr, 2011). This disparity in access to digital technologies is often referred to as the digital divide.

Background

According to the Pew Center's Internet and American Life study 15 million, or 1 in 7, Americans do not use the Internet (Zickuhr, 2013). In another report from the Pew Center's Internet Project, titled *Chronic Disease and the Internet*, Fox and Purcell (2010) described Internet use among those with chronic illness compared to those with no history of illness. The study found that 81% of adults reporting no chronic illness go online vs. 62% with one chronic illness, and 52% of those with two or more chronic diseases. Fox and Purcell concluded that when all demographic factors associated with chronic illness were controlled, living with chronic disease in and of itself had an independent, negative effect on someone's likelihood to have Internet access. These findings suggest that those with chronic illness consume technology differently than those in the general population.

The digital divide generally refers to the gap between individual households, businesses and geographic areas at different socioeconomic levels with regard to both their opportunities to access information and communication technologies and to their use of the Internet for a wide variety of activities (The Organization of Economic Cooperation and Development [OECD], 2014). This gap in access to technology is particularly concerning as we shift from an analog society to a digital society. There is a growing body of literature to suggest that adoption of technology is more likely if the individual is younger, (Denizard-Thompson, Feiereisel, Stevens, Miller, & Wofford, 2011; Kruse, et al, 2012; Miller & West, 2009; Netter & Brainin, 2012; Wang, et al, 2011; Van Deursen & Van Dijk, 2011), white, (Wang, et al, 2011, Fox & Purcell, 2014), more highly educated (Koivusilta, Lintonen, &Rimpela, 2007; Kruse, et al, 2012; Miller

& West, 2009; Netter & Brainin, 2012; Wang, et al, 2011; Van Deursen & Van Dijk, 2011) and from a higher socioeconomic group (Koivusilta, et al, 2007Miller & West, 2009; Wang, et al, 2011; Zickuhr, 2014). The link between the digital divide and low socioeconomic status was illustrated in a 2009 national survey on Internet use and self-rated health among older adults conducted by Garcia and Hero. The authors suggest that addressing the digital divide cannot be considered without addressing the current socioeconomic divide that exists. The authors concluded that the digital divide is an expression of social inequalities. The authors go on to say that efforts to reduce the digital divide without addressing existing social inequalities "may contribute to existing socioeconomic inequalities and may benefit those already advantaged" (Garcia & Herero, 2009).

The purpose of the current study is to characterize the determinants of frequent Internet use in pre- and post-kidney transplant patients at an urban United States transplant center to broaden our understanding of how patients with chronic illness, specifically pre- and post-kidney transplant patients, utilize the Internet.

Methods

This is a secondary analysis of data collected during a cross-sectional study of health information technology among pre- and post-renal transplant patients (Lockwood, et al., 2013). In brief, data were collected during scheduled transplant education sessions and during routine post-transplant follow-up visits at a single urban renal transplant center at the University of Chicago Medicine from January 15, 2012 to June 1, 2012. The study was approved by the University of Chicago Institutional Review Board prior to the administration of the study. Full results of this assessment and description of the methods can be found elsewhere (Lockwood et al., 2013).

Statistical Method/Data Analysis

Categorical variables were initially compared by self-reported race, level of education, gender, age, dialysis status years of kidney disease and median income using descriptive statistics and chi-square test of independence and Fisher's exact tests (**Tables 5.1 & 5.2**). Covariance was assessed using the covariance matrix of coefficients of regression models and the variance inflation factor (VIF). Categorical variables were then re-coded into binary variables for use in regression models. Years of kidney disease variable included: less than 1 year, 2-3 years, 4-5 years, and greater than 5 years. All variables that resulted in a p value of less than 0.2 were retained for logistic regression analysis with the exception of "type of dialysis" which was excluded due to collinearity with dialysis status (r=0.72, p<0.001). The correlation matrix of coefficients for regression model had a mean VIF of 1.42.

Multiple logistic regression model regressed frequency of Internet use on gender, race/ethnicity, education, age, years of kidney disease, dialysis status, and median income. For race/ethnicity, Caucasians (0) represented the reference group, while non-Hispanic blacks (1), Latino/Hispanics (2), and other (3) were the comparison group. The "other" subgroup consisted of four self-identified Asians and two self-identified Native Hawaiians or Pacific Islanders. For gender, males (0) represented the reference group, while females (1) were the comparison group. For dialysis, "yes, currently on dialysis" (0) represented the reference group, while "not yet on dialysis" (NYOD) represented the comparison group. For years of kidney disease, less than 1 year (0) represented the reference group, while 1-3 years (1), 4-5 years (2), and greater than 5 years (3) represented the comparison group. For education, less than high school (0) represented the reference group, while some college (1) and college and beyond (2) represented the comparison groups. For age, 18-39 year olds represented the reference group (0), while those 40-54 years old (1), 55-64 years old (2) and >65 years old (3) made up the comparison groups. Median income was derived from Census data based on self-reported zip code. Median income was stratified into five categories: 0-$24,999 (0), $25,000-%39,999 (1), $40,000-$74,999 (2), $75,000-$99,999 (3), and $100,000 and over (4). Post hoc tests were used to assess model fit. All statistical analyses were conducted using Stata 11.0 (Stata Corporation, College Station, TX). A p-value of <0.05 was deemed statistically significant.

Results

We distributed 270 surveys, 254 surveys from this sample of convenience were returned for a 94% response rate. A majority of participants surveyed were status post kidney transplant (see **Table 5.1**). Fifty-five percent of the sample self-identified as non-Hispanic black. Most participants reported having had kidney disease for over five years, and were on hemodialysis as renal replacement therapy. A majority of patients were in the 40-54 year old age category. Most subjects' median income was between $25,000-$75,000 per year. Participants were evenly distributed by self-reported education. A majority of patients reported using the Internet less than five hours per week.

Frequency of Internet use

Thirty-eight percent of participants (n=96) reported being frequent Internet users (**Table 5.3**). There were unadjusted differences in frequency of Internet use by pre-vs.

post-transplant (χ^2 =0.096, P=0.756), (race/ethnicity (χ^2 =19.69, P=<0.001), gender (χ^2 =4.89, P=0.027), level of education (χ^2 =35.80, P=<0.001), years of kidney disease (χ^2 11.66, P=0.009), dialysis status (χ^2=5.65, P=<0.017), type of dialysis (χ^2 =7.19, P=0.066), age (χ^2 =16.17, P=0.001, and median income (χ^2 =8.84, P=<0.065).

The multivariate regression model predicting frequent Internet use is presented in **Table 5.4**. All variables except dialysis status were statistically significant in a multivariate regression model that controlled for race, gender, age, education, years of kidney disease, dialysis status, and median income. Non-Hispanic blacks were 72% less likely than Caucasians to report being frequent Internet users. Those who report their race/ethnicity as "other" were 94% less likely to report frequent Internet use compared to Caucasians. There was not a significant difference in reported Internet use between those who reported their race/ethnicity as Latino/Hispanic when compared to Caucasians. Women were 59% less likely to be frequent users of the Internet compared to men. Those who reported having kidney disease for more than 3 years were more likely to report being frequent Internet users. Those with a college education were more than seven times more likely to be frequent users of the Internet when compared to those with high school education or less. As age increased Internet use decreased. Those who were in the 40 to 54 years of age group were 73% less likely to be frequent users of the Internet compared to those in the 18-39 years of age groups. Those 55-64 years of age were 89% less likely to use the Internet compared to those 18-39 year of age. Those 65 years of age and older were 92% less likely to be frequent users of the Internet than those 18-39 years of age. Median income and dialysis status were not determinants of Internet use.

Discussion

To our knowledge, this is the first study to characterize the frequency of Internet use in a pre- and post-kidney transplant population in the United States. We found that race/ethnicity, gender, age, level of education, and years of kidney disease were predictors of frequent Internet use. These findings have serious implications as we move further into the electronic age. Our findings indicate that barriers to Internet use do not occur at the level of device ownership, but rather at the level of Internet use. This is further compounded by findings indicating that 80% of patients surveyed reported being comfortable using these devices, and 90% expressed interest in using a transplant specific educational website (Lockwood, et al., 2013). Understanding that the consumption of ICT by those with chronic illness is more nuanced than that of the general United States population, particularly in urban areas, is critical for future research design, technological development and for designing comprehensive communication/education platforms that will benefit all patients. Our findings that pre-and post-kidney transplant patients are less likely to utilize the Internet are consistent with results of other studies looking at chronically ill populations (Fox & Purcell, 2014; Zach, et al. 2011). Zach, et al. (2011) studied Internet use in a medically underserved population and found that 74% of participants reported having access to the Internet, but only 21% of those participants reported using the Internet to look for health information.

Interestingly, while we saw an underutilization of the Internet in this population, we found that those who had reported having kidney disease for three years or more were significantly more likely to report being a frequent Internet user. This finding contradicts other studies that have shown people with chronic illness are less likely to use the

Internet than the general population (Fox & Purcell, 2014; Zach, et al. 2011; Zickuhr, 2014). It is likely that those who have had more time to deal with their kidney disease are more desperate for knowledge on potential alternatives to dialysis, including transplantation. This increase in Internet use associated with prolonged disease may represent an opportunity to educate patients with advanced kidney disease about transplantation. A larger national study is needed to better characterize this trend.

Technological disparities related to race/ethnicity have been described in the ICT literature (Fox & Purcell, 2014; Smith, 2014; Zach, et al. 2011) but little has been reported related to kidney transplantation. In our study, non-Hispanic blacks were the least likely to report being frequent Internet users compared to all other racial/ethnic groups studied. The digital divide between Caucasians and blacks in America was confirmed in a recent Pew Center study that focused on non-Hispanic blacks use of technology. Smith (2014) reported that non-Hispanic blacks trailed Caucasians by seven percentage points when it came to overall Internet use (87% or Caucasians and 80% of non-Hispanic blacks); however, how frequently the participants accessed the Internet was not reported. Some of this gap in Internet use may be explained by socioeconomic factors, as the study goes on to say that this gap between Caucasians and non-Hispanic blacks disappears for younger, college-educated, and higher income non-Hispanic blacks. More research is needed to characterize these socioeconomic differences in ICT use in US transplant populations.

There was not a significant difference in frequent Internet use between people who identified as Latino/Hispanic and white, though the frequency of Internet use in the Latino/Hispanic group studied was substantially lower than what is reported in the Pew

Center Internet study on Internet use by Hispanics (Lopez, Gonzalez-Barrera, & Patten, 2013). There were, however, significant differences between those who self-identified as “other”, this included four self-reported Asians and two Native Hawaiian/Pacific Islanders, when compared to Caucasians. This is a demographic that is often underrepresented, but is one of the fastest growing segments of the US population. However, the numbers in both the Latino/Hispanic and the Asian/Native Hawaiian/Pacific Islander group were small, therefore a study with a larger sample of Latino/Hispanics, Asians, and Native Hawaiian/Pacific Islanders is needed to confirm these findings.

While it is not surprising that technology use declines as age increases, it is notable that the decline in technology use in our study begins much earlier than we had anticipated. Advanced age is often associated with non-use of the Internet (Denizard-Thompson, et al, 2011; Fox & Purcell, 2014; Kruse, et al, 2012; Miller & West, 2009; Neter & Brainin, 2012; Wang, et al., 2011; Van Deursen & Van Dijk, 2011). In this study the decline in Internet use began in the 40-54 year old age group. This group is part of Generation X, roughly defined as those born between 1961 and 1981, making up approximately 84 million people in the United States. Most members of Generation X learned about technology on computers that would be considered crude by today’s standards. As such, technology may not be as central to the lives of many Generation Xers when compared to subsequent generations. Members of Generation X tend to use technology for its conveniences, but do not necessarily view ICT as a vital social or communication platform in the way members of the millennial generation do. Therefore, it is not surprising that members of Generation X would represent a significant portion of the population that may not use the Internet to its full capacity. Further research is needed to characterize Internet trends in those with chronic illness who are under the age of 65.

There is growing interest in harnessing interventions that utilize the Internet in healthcare settings. Technological interventions have been used for telemonitoring (Castren, Huttunen, & Kunttu, 2008; Kitsiou & Janna, 2013; Sanders, et al, 2012; Wooten, 2012), medication adherence (Miloh, Annunziato, & Aaron, 2009; Rice & Latz, 2003), biometric monitoring (Cady, Finklestein, & Lindgren, 2009; Canady, 2008; Chaudry, Mattera, & Cutris, 2010; Halafax,et al, 2007), health literacy (Egbert & Nana, 2009; U.S. Department of Health and Human Services, 2014), and patient empowerment (Kuijpers, Groen, Aaronson, & Van Harten, 2013; Minatodani, Chao, & Berman, 2013). After decades of research on the efficacy of ICT interventions there continues to be conflicting data on the efficacy of such interventions (Kitsiou & Jaana, 2013). This lack of consensus on the efficacy of ICT interventions is further complicated by vague definitions about what constitutes an ICT intervention. Concepts and terminology related to the area of health technology need to be further clarified and standardized as much as possible to ensure that concepts are measured consistently across the spectrum of health. Further, accepting the assumption that technology is ubiquitous has led to dearth of adequately designed studies. Kitsiou & Laana, in their 2013 systematic review and meta-analysis of home telemontioring interventions, suggest that efforts should be made to improve ICT/telemontioring research by improving study design, conduct, reporting, and publication of systematic reviews and meta-analysis in this area.

One of the strengths of our study is that it was designed to include participants who were not technologically savvy. By including a paper-based survey we insured that patients at all levels of technological sophistication were included in the sample. Caution should be exercised when examining ICT studies that either erringly bolster the premise that ICT interventions are successful by excluding those who do not have adequate access, or that erroneously condemn ICT as a failure by including those in ICT designs who do not have adequate technological proficiency to successfully utilize the technological intervention to their benefit. In a critical review of 141 ICT based randomized controlled trials (RCTs), 22 of which were systematic reviews, Wootton (2011) found almost all of these studies reported positive results, suggesting a publication bias. An accurate characterization of ICT trends in populations with chronic illness has yet to immerge from the literature.

Even though a majority of our patients had access to the Internet and Internet enabled devices, a majority did not use these devices on a frequent basis. It is likely that those who underutilize technology need to receive encouragement and gain confidence when approaching these technologies. Mayberry et al, (2011) suggest the use of family delegates. These delegates are often younger members of the family who can act as a delegate or mentor of sorts to the patient. The delegate can help the patient navigate web pages and effectively utilize electronic health information. Aside from the obvious benefit of increasing patient knowledge and autonomy, this approach has the added benefit of encouraging the family to participate in the patient’s care and become knowledgeable about the family member’s health condition, thereby increasing the family’s health literacy. More research is needed to better understand the relationship between health literacy, social support, and Internet use.

When designing electronic information for patients, one should consider potential deficits in technological skill of patients. Efforts designed to make information available via the Internet or via mobile applications should be informed by the knowledge that many of the patients may not possess the technological skill to access the content. Web or application based content should be constructed in a way that is friendly to the entry-level consumer. The authors of web and application-based content should include basic instructions on how to use health websites or health mobile applications. Electronic information should be simple to use and content on each page should be limited to avoid overwhelming the patient. This effort to create user-friendly electronic information is supported by other studies that have shown that once people with chronic illness adopt technology they become regular users of health information (Fox & Purcell, 2014; Minatodani, et al, 2013). Patients should be active partners in the development and design of health related ICTs.

Descriptive studies on Internet use for seeking health information in transplantation dates back nearly a decade. In 2001, Slakey and Nowfar conducted a survey of Internet use in patients attending a multidisciplinary liver transplant clinic. They found that 41% of non-Hispanic blacks and 69% of Caucasians had access to the Internet. They also found that 28% of non-Hispanic blacks and 64% of Caucasians surveyed reported using the Internet to seek out medical information. Ten years after Slakey & Nowfar reported these findings in their study of patients at a multidisciplinary liver clinic we found that while access to the Internet and Internet enabled devices increased dramatically, particularly in minority groups, the percent of self-reported Internet use in our transplant population remained largely unchanged from reports a decade ago. In a 2003 JAMA article, Baker, et al, warned that discussions of the role of the Internet in health care and the development of policies that might influence this role should not assume that use of the Internet for health information is universal or that the Internet strongly influences health care utilization. Unfortunately, ten years after this report was published, it seems that their words of caution still ring true today.

In their 2012 study of out of Australia, Baum, Newman, and Bierdrzycki identified what they refer to as the "digital vicious cycle". The authors describe the nature of this cycle, implicating factors that influence social determinants of health. They conclude that some people are being caught in a vicious cycle whereby lack of digital access or the inability to make beneficial use reinforces and amplifies existing disadvantages including low levels of writing and literacy (Baum, Neuman, & Biedrzycki, 2012). This is of particular concern in transplant populations since low health literacy has been linked to poor medication compliance (Gordon & Wolf, 2009). While median income was not a determinant of Internet use in our sample, the underutilization of the Internet that was observed in our urban transplant population could be the result of other social processes that are currently not recognized. Further research into the potential link between Internet use and social determinates of health is warranted. A larger sample is needed to determine if the trends seen in our study reflect a regional trend or if these results may be a harbinger of a wider trend toward Internet underutilization in transplant populations.

While many descriptive studies on Internet use have been conducted over the last 20 years, we have yet to find a modern assessment of Internet use in either the general population or populations experiencing chronic illness that show such a dramatic underutilization of the Internet. The trend toward underutilization of the Internet seen in our study is even more concerning, as it occurred in the presence of the Internet, among people who reported feeling comfortable using the Internet, and among people who expressed interest in using a transplant educational webpage. These findings have serious implications on the way we design educational materials, promote organ donation, and communicate with our patients.

While this technological gap may have been described in other populations, most studies having occurred outside the United States, it is important that these findings be interpreted in the context of the population under study-a marginalized, minority, urban renal transplant population. This group has attracted a lot of attention regarding strategies to improve health, technology being on the short list for widespread adoption. Simply put, technology-based interventions are likely to fail in this population unless the gap is rectified.

Limitations

This study is not without limitations. We found that median income was not a determinant of frequent Internet use. This contradicts other reports in the literature (ITU, 2014; Hanif, et al, 2007; Lustria, et al, 2011; Miller & West, 2009; Slakey & Nowfar, 2003). Because the median income was based on Census data linked to self-reported zip code, so it is possible that our estimates of median income understate the influence of income on Internet use. The number of subjects who identified as Hispanics and “other” was small. Future research with a larger, more representative sample for these groups should be designed to assess Internet use in these populations. Because the survey was anonymous, we were not able to follow up with participants to extend our inquiry into reasons why they do not use technology despite having technologies at their disposal. Access to broadband technology is limited in many communities around the medical center. This lack of access to a high speed Internet connection could be a potential explanation for lower use. Future research should focus on non-users of technology to elucidate why they do not use the Internet.

Conclusion

A majority of our study participants reported having access to computers and the Internet, reported being comfortable using computers and the Internet, and reported interest in an educational website. Only 38% of these study participants reported being frequent Internet users. Pre- and post-kidney transplant patients who were younger, male, educated, white, who have been on dialysis longer than three years, were the most frequent users of the Internet. Alternatives to electronic information sources and/or additional resources should be considered for those who may fall in the so-called digital divide.

Table 5.1 Description of Variables

Variables	Variable type	Description
Internet ownership	Binary (Yes/No)	Do you own the following?: 1) a computer, 2) a cellphone, 3) a Smartphone (ex. iPhone or android. 4) access to the Internet
Internet frequency	Categorical (collapsed into binary)	How many hours per week do you use the Internet? 1) I never use the Internet, 2) less than 1 hour, 2) 1-5 hours, 3) 6-10 hours, 4) more than 10 hours
Internet comfort	Likert-type (collapsed into binary)	How comfortable are you using the following (ICT as described in ownership variable): 1) I don't know how to use, 2)Very uncomfortable, 3) Somewhat uncomfortable, 4) Somewhat comfortable, 5) Very comfortable.
Interest in Transplant educational website	Categorical (collapsed in binary)	If there were a website to teach you about your transplant would you use it? 1) No, I would not, 2) Probably not, 3) Maybe, 4) Probably, 5) Definitely.

Table 5.2. Sample characteristics (N=254)	
Transplant Status	
Pre N(%)	77 (30)
Post N(%)	177(70)
Gender	
Male N(%)	147(58)
Female N(%)	107(42)
Race/ethnicity	
White N(%)	87(34)
Black N(%)	140(55)
Latino/Hispanic N(%)	21(8)
Other N(%)	6(2)
Years of Kidney Disease	
< 1 year N(%)	30(12)
1-3 years N(%)	47(19)
4-5 years N(%)	34(13)
more than 5 years N(%)	143(56)
Dialysis	
Yes N(%)	188(74)
No N(%)	66(26)
Type of Dialysis	
NYOD N(%)	66(26)
Hemodialysis N(%)	137(53)
Peritoneal N(%)	31(19)
Both N(%)	21(15)
Age	
18-39 N(%)	63(25)
40-54 N(%)	93(37)
55-65 N(%)	62(24)
>65 N(%)	35(14)

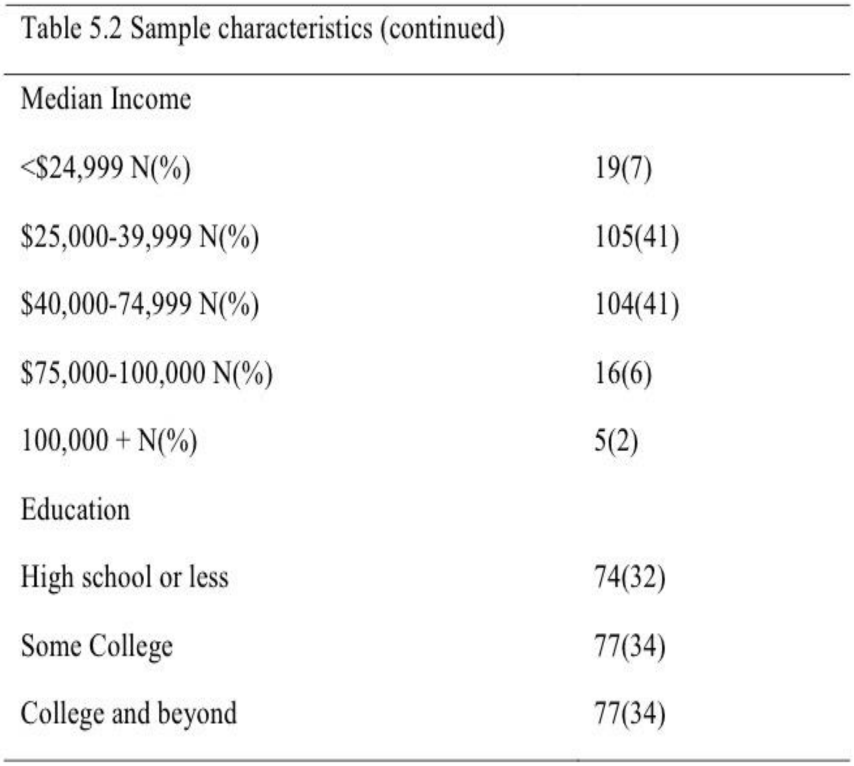


Table 5.2 Sample characteristics (continued)

Median Income	
<$24,999 N(%)	19(7)
$25,000-39,999 N(%)	105(41)
$40,000-74,999 N(%)	104(41)
$75,000-100,000 N(%)	16(6)
100,000 + N(%)	5(2)
Education	
High school or less	74(32)
Some College	77(34)
College and beyond	77(34)

Column percentages are based on N from frequent vs. infrequent Internet use categories (to the reviewers: this comment is related to Table 3).

Table 5.3 Unadjusted analysis of frequent Internet use (N=254)

	Frequent Internet use N=96(39)	**Infrequent Internet use N-158(61)**	**P Value**
Transplant Status			
Pre N(%)	28(29)	49(31)	0.756
Post N(%)	68(71)	109(69)	
Gender			
Male N(%)	64(67)	83(53)	0.027*
Female N(%)	32(33)	75(47)	
Race/ethnicity			
White N(%)	49(51)	38(24)	<0.001*
Black N(%)	38(40)	102(65)	
Latino/Hispanic N(%)	7(7)	14(9)	
Other N(%)	2(2)	4(3)	
year of Kidney Disease			
< 1 year N(%)	5(5)	25(16)	0.006*
1-3 years N(%)	14(15)	33(21)	
4-5 years N(%)	11(11)	23(15)	
more than 5 years N(%)	66(69)	77(49)	
Dialysis			
Yes N(%)	63(66)	125(79)	0.019*
No N(%)	33(34)	33(21)	
Type of Dialysis			
NYOD N(%)	33(34)	33(21)	0.066
Hemodialysis N(%)	42(44)	94(59)	
Peritoneal N(%)	12(13)	19(12)	
Both N(%)	9(9)	12(8)	

Table 5.3 Unadjusted analysis of frequent Internet use (continued) (N=254)

	Frequent Internet use N=96(39)	Infrequent Internet use N-158(61)	P Value
Age			
18-39 N(%)	36(38)	27(17)	0.001*
40-54 N(%)	35(37)	58(37)	
55-65 N(%)	17(18)	45(28)	
>65 N(%)	8(8)	27(17)	
Median Income			
<$24,999 N(%)	4(4)	15(9)	0.068
$25,000-39,999 N(%)	36(38)	69(44)	
$40,000-74,999 N(%)	45(47)	59(37)	
$75,000-100,000 N(%)	10(10)	6(4)	
100,000 + N(%)	1(1)	4(3)	
Education			
High school or less	20(21)	55(10)	<0.001*
Some College	19(20)	58(37)	
College and beyond	50(52)	27(17)	

Column percentages are based on N from frequent vs. infrequent Internet use categories

Table 5.4 Determinants of frequent Internet use

	Adjusted OR(95%CI),p-value
Race/ethnicity (relative to white, non-Hispanic)	
Black, non-Hispanic	0.26(0.120-0.583), 0.001*
Latino/Hispanic	0.51(0.145-1.810), 0.298
Other	0.06(0.007-0.552), 0.012*
Gender (relative to male)	0.41(0.202-0.842), 0.015*
Years of kidney disease (related to less than one year)	
1-3 years	4.70(1.105-20.010) 0.036*
4-5 years	5.26(1.120-23.152), 0.028*
Greater than 5 years	7.152(1.978-25.861),0.003*
Dialysis status (relative to being on dialysis)	0.58(0.271-1.23), 0.154
Education (relative to high school of less)	
Some college	1.30(0.564-3.009), 0.535
College and beyond	9.37(3.88-22.600), <0.001*
Age(relative to 18-39years old)	
40-54 years old	0.27(0.114-0.640),0.003*
55-64 years old	0.11((0.039-0.287),<0.001*
65 and over	0.08(0.023-0.288),<0.001*
Median income (relative to <$24,999)	
$25,000-$39,000	1.77(0.401-7.758), 0.451
$40,000-$74,000	1.49(0.337-6.563), 0.601
$75,000-$99,999	3.01(0.458-19.735), 0.251
$1000,000 and over	0.17(0.008-3.870), 0.273

Post hoc test of sensitivity, specificity, and rate of correct classification were 65.62%, 84.87%, and 77.42% respectively. LR chi^2= 99.85. McFadden's R^2=0.30, ROC area under the curve=0.85

References for Chapter V (See Cumulative References)

Chapter VI: Discussion

Delayed or incomplete pre-kidney transplant evaluations present a serious problem for patients, particularly in light of the negative effects of prolonged time on dialysis versus the positive benefits that result from kidney transplantation (Cukor, et al., 2007; Tonelli, et al., 2009; Weng, et al., 2012). Receipt of a kidney transplant and restoration of near normal kidney function for patients with ESRD can be transformative. Moreover, delayed and incomplete evaluations can also have a negative impact on transplant center workflows resulting in inefficiencies and increased costs for transplant centers related to extended patient follow-up. It is not uncommon for barriers to the early stages of the transplant process identified in the literature to be presented in categories or "silos" that make distinctions between patient-level barriers versus healthcare-level barriers (Navantheen & Singh, 2006). Commonly reported patient-level barriers that result in delayed or failed pre-kidney transplant evaluations include biological, affective, and socioeconomic barriers (Ayanian, Cleary, Weissman, & Epstein, 1999; Kasiske et al., 1998; Weng et al., 2005). In addition, descriptions of healthcare-level barriers range from poor patient provider communication to concerns over institutionalized racism within the transplant enterprise (Ayanian, et al., 1998; Myakovski, et al., 2013; Patzer, et al., 2012b).

In recent years researchers have turned their attention to the identification of potentially modifiable barriers. Patient Reported Outcomes (PROs) have generally been underrepresented. Thus, the aims of this program of research were to: 1) describe the current state of the science related to barriers to the early stages of the kidney transplant process experienced by African American in the United States, 2) prospectively quantify patient reported barriers to completing the evaluation at an urban transplant center in the United states, and 3) conduct a technology assessment to determine which, if any, information and communication technologies may be best suited to assist in reducing or eliminating long standing barriers that result in inequities in transplant processes. Thus, identification of potentially modifiable barriers as reported from the patient's perspective may allow a more granular understanding of common barriers and may aid in the development of interventions to mitigate these barriers.

Many patient-level and healthcare-level barriers are the result of longstanding societal inequities that are deeply rooted in a system of white privilege that has been part of the fabric of the culture of the United States since its founding. The pursuit of equity in transplantation is vital to the ethical and moral framework that informs policies that guide organ procurement, distribution, and the evaluation of potential organ recipients (OPTN< 2016; UNOS, 2016). Therefore, it is imperative that all patients with ESRD should have equal access to available organs. Thus, the goal of this program of research was to identify modifiable patient reported barriers to completing the pre-kidney transplant evaluation at an urban transplant center that serves a large African American ESRD population in an effort to reduce or eliminate existing inequities.

This program of research makes a significant contribution to the existing body of knowledge on barriers and inequities related to the pre-kidney transplant evaluation in several ways. First, we were able to extend the findings of other works on barriers to the early stages of the pre-kidney transplant process for African Americans in the United States, to include additional barriers and interventions, and we proposed a new model that reduces the "silo" perspective when discussing what have been previously described as patient-level and healthcare-level barriers. Second, we prospectively quantified several patient reported barriers to the pre-kidney transplant evaluation that may reinforce existing inequities as perceived by patients navigating the evaluation. Third, we conducted a thorough "pencil and paper" technology assessment of our pre-and post-kidney transplant patients to gauge patient's level of access and comfort to information and communication technologies. Finally, we offer innovative suggestions on how the transplant community can intervene by utilizing an integrated theoretical model using Critical Race Theory (CRT) and a transplant specific socio-ecological model to mitigate existing inequities.

Implications for Practice

Furthering our understanding of barriers to the pre-kidney transplant medical evaluation by examining the PROs has important implications for nursing practice in the transplant clinical setting. First, we were able to identify and classify several modifiable patient reported barriers to the pre-kidney transplant evaluation. Trough the use of Critical Race Theory and a transplant specific socio-ecological model, researchers can begin to test interventions to address these barriers in a systematic way. In addition, inclusion of instruments that capture PROs, such as the NIH PROMIS® measures, may allow for additional variables that influence progression through the transplant evaluation that were not captured on the Subjective Barriers Questionnaire.

Second, our technology assessment provides an unbiased look at information and communication technology use in a chronically ill population. These data on technology demonstrate the complex relationship that exists between people with chronic illness and technology. As we continue to develop digital communications in healthcare we must resist the urge to be “the first” in the rapidly changing health care paradigms and be mindful not to put the technological cart before the methodological horse (Moore & Morris, 2011). The literature is overrun with technology studies that are poorly designed, and most are plagued by significant selection bias (Wooton, 2011). Given the current limitations that exist with communication technologies alternative strategies should continue to be considered, the use of informational DVDs being one example, to ensure that we avoid the unintended consequence of worsening existing health related inequities. These data suggest that an intervention utilizing text messaging may have the greatest potential for broad success given that texting is the most widely adopted of the information technologies and report of comfort of use has been high across demographics. Thus, given nursing’s unique perspective on health care, it is essential that nurses be involved in the development of communication technologies designed to reduce barriers to transplantation.

Third, from previous work we know HRQOL has been significantly correlated with patient outcomes. Given their role as educators and coordinators of care, nurses are uniquely positioned to lead and/or make significant contributions to interprofessional teams interested in uncovering the underlying mechanisms of HRQOL. Thus, nephrology and transplant nurses should be involved in the design and implementation of theory-based protocols examining the influence of HRQOL on access to transplantation, the conduct of clinical trials furthering our knowledge on barriers and potential interventions, and the dissemination of the results.

Less modifiable barriers of interest

Through this program of research we were able to identify barriers that, while less modifiable than other barriers that were described, still deserve attention due to their influence on long-standing barriers and inequities in the transplant process.

Transplant center variability a major challenge to understanding barriers

Due to variability among transplant centers it is likely disparities/inequities are underestimated. An individual center's tolerance for risk and level of resource allocation are main drivers impacting patient management at the evaluation stage. Currently, no commonly agreed upon minimum standard exists to guide centers in evaluating patients for kidney transplantation. In addition, there are no data available in national surveillance systems to aid our understanding of the many challenges related to the evaluation process. Regulatory bodies such as the United Network of Organ Sharing (UNOS), the Office of Procurement and Transplant Network (OPTN), and the Center for Medicare and Medicaid Services (CMS) offer recommendations for evaluating patients prior to wait listing, but stop short of mandating evaluation procedures or collection of evaluation specific metrics out of concern to avoid overreach by dictating clinical practice. Thus, it remains a challenge to develop interventions to improve access to transplantation that are generalizable.

While some large well-resourced transplant centers are able to complete pre-transplant evaluations in an expedited fashion (e.g. one or two day evaluation), many medium to small sized centers are unable to dedicate resources required for expedited evaluations (Weng, et al., 2005). Moreover, absolute and relative contraindications to wait listing potential patients are arbitrarily determined by individual transplant centers, making between center comparisons nearly impossible. Perhaps more troubling, anecdotal evidence suggests that some centers have resorted to mandating that patients complete a majority of screening testing (e.g. cancer screening, cardiac evaluations, rheumatology, etc.) prior to presenting for the medical evaluation at the transplant center. This practice could have the unintended consequence of increasing existing inequities by placing additional barriers to those who are already at risk of not completing the evaluation due to a variety of reasons (e.g. low health literacy, lack of resources, lack of transplant knowledge) (Gordon et al., 2001; Myaskovsky, et al., 2013; Patzer, et al., 2012b).

Are we promoting autonomy or absolving ourselves of responsibility?

Because of the limited number of kidneys available for transplant, it is imperative that patients are motivated to be actively engaged in the pursuit of the organ pre-transplant and continued maintenance required after transplantation. As previously mentioned, there is significant variability in how transplant centers evaluate patients for kidney transplantation. One significant area of variation is in the transplant center's expectations that potential patient acquire pre-evaluation testing independently (e.g. cancer screening, cardiac testing, and dental screening).

Anecdotally, transplant centers use the pre-kidney transplant evaluation as a litmus test to assess the level of motivation or compliance a potential patient possesses to receive and maintain a transplanted organ. Moreover, shifting the burden to acquire pre-transplant testing to the patient is often viewed as a matter of patient autonomy. In our prospective study, outstanding cancer screening, required specialty consults, and dental evaluations were found to be significant barriers for those who did not complete the pre-kidney transplant evaluation. Those centers that require patients to obtain prescreening testing independently prior to being evaluated are not promoting patient autonomy, nor are they getting an accurate assessment of the patient's willingness or desire to receive a transplant. This practice promotes inequity by selecting out patients who are less likely to pursue transplantation due to issues related to low health literacy, lack of resources, and lack of support to navigate the complex processes required during this stage of the transplant process (Daforge, et al., 2015; Myaskovsky, et al., 2013; Patzer, et al., 2012b; Waterman, et al., 2013). Thus, including evaluation metrics of common interest among transplant centers (e.g. number of referrals, time from referral to wait listing, number of patients deemed ineligible for transplant, reason patient deemed ineligible, etc.) in national surveillance databases would allow the transplant community to identify commonly occurring modifiable barriers by leveraging a large nationwide sample while enabling more sophisticated statistical analysis, which is currently not possible.

Eliminating the silo approach to viewing barriers

Through our systematic review and our prospective study of patients presenting for evaluation we identified several potentially modifiable barriers that occurred at the patient-level, the healthcare level, and many that could be classified as an intersection of the two (Table 6.1).

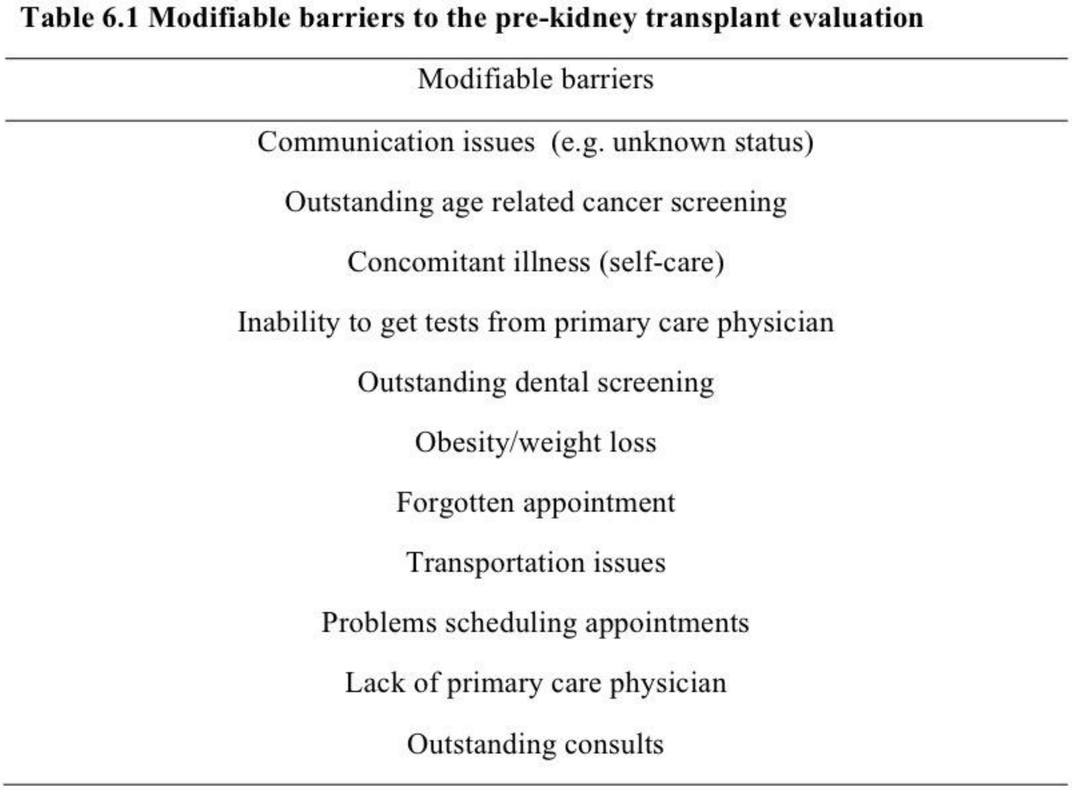


Table 6.1 Modifiable barriers to the pre-kidney transplant evaluation

Modifiable barriers
Communication issues (e.g. unknown status)
Outstanding age related cancer screening
Concomitant illness (self-care)
Inability to get tests from primary care physician
Outstanding dental screening
Obesity/weight loss
Forgotten appointment
Transportation issues
Problems scheduling appointments
Lack of primary care physician
Outstanding consults

Rather than continue to discuss barriers in siloes (e.g. patient vs. health care level barriers), we would prefer to view solutions to these challenges as a partnership between patients, their families, members of the community at-large, and members of the health care community. This approach is consistent with a socio-ecological approach where the complex interactions of internal and external factors that contribute to existing barriers are accounted for (CDC, 2016; Reifsnieder, Gallagher, & Forgione, 2005). The socio-ecological method requires an understanding that larger societal forces, such as institutionalized racism, may present barriers that are more challenging to resolve. There are, however, many opportunities to resolve barriers that result from societal pressures, such as through improved communication between patients, families, communities, and providers, and among providers. This holistic approach requires health care professionals to expand their thinking on the patient-provider relationship to include the complex relationships that occur between the individual, their social network, community resources, environmental factors, and healthcare systems. In this period of rapidly changing healthcare paradigms, health care providers must be prepared to conceptualize health issues, particularly those that sustain inequity, in a way that extends health care services beyond the walls of the hospital or clinic setting.

Health Related Quality of Life and evaluation completion

Interest in HRQOL among patients with various degrees of kidney disease and its relationship to patient outcomes has been growing over the last several decades. The transition from ESRD to transplantation allows for a unique setting to study changes in HRQOL before and after intervening with a life altering organ transplant. There are several socioeconomic, biological, and affective drivers of HRQOL that have been described in patients with kidney disease (Cameron, et al., 2000; Koudi, et al, 2004; Kimmel, 1998; Maglakelidze, Pantsulaia, Tchokhonelidze, & Chkhotua, 2011; Patel, et al., 2002; Ogutmen et al., 2006; Shayamsunder, et al., 2004; Unrun, et al., 2004;). The Dialysis Outcomes and Practice Patterns Study (DOPPS) provided evidence that HRQOL was predictive of readmission and mortality in ESRD (Mapes, et al., 2003). Moreover, there is evidence that HRQOL improves in response to transplantation among adults with ESRD (Kimmel, et al, 1998) just like it does in related transplantation scenarios such as heart, lung and liver transplantation (Ortega, et al., 2009; Wright-Pinson, Feurer, Payne, Wise, Schokley, & Speroff, 2000). What remains unknown, however, is the role HRQOL plays in progression through the pre-kidney transplant evaluation. Hence, we theorized that new insights into the role of HRQOL in the pre-kidney transplantation process might help hone interventions designed to mitigate barriers to the completion of evaluation and also eventual transplantation.

In our prospective examination of patients going through the pre-kidney transplant evaluation we included health related quality of life as a variable of interest. It should be noted, however, that the scales and subscales of the KDQOL-SF™ were dichotomized above and below the mean score to fit in a logistic regression model. Moreover, these signals related to HRQOL were only seen in the instruments subscales and not the physical and mental composite scores. Therefore, the finding that the mean score on the subscale role-emotional was a predictor of evaluation completion should be interpreted with caution. Future research examining HRQOL and the pre-kidney transplant evaluation should integrate assessments of other patient related outcomes (PROs), such as those found in the NIH sponsored Patient Related Outcomes Measurement Information System (PROMIS®), in conjunction with biomarkers, in an effort help us better understand obtained global HRQOL scores.

Theoretical foundations

Critical Race Theory

Critical Race Theory was utilized as a grand theory to support this program of research because the population under study was largely African American and from a more challenging socioeconomic situation. Several of the tenants of the CRT emerged. First, the permanence of racism was manifested in our observations that being African American continues to be an independent predictor related to incomplete evaluations despite the quest for equity in transplantation. This racial disparity is a trend that has been described for several decades (Kasiske, et al., 1991; Epstein, et al., 2000; Patzer, et al., 2012). Second, while Whiteness as property, interest in conversion, and a criticism of liberalism were not directly examined in this program of research, future work should be informed by these tenets and aid in the creation of culturally aware protocols that are supportive of oppressed peoples without being paternalistic all while considering the impact of race/ethnicity, gender, and socioeconomic status on access to transplantation (Decuir & Dixon, 2004; Delgado, 1998). Finally, we attempted to allow a space for counter-storytelling on the Subjective Barriers Questionnaire; however, the open-ended question may not have been adequate to effectively provide a platform for patients to voice their concerns. In addition, because not all patients returned to the center within the 90-day evaluation period the Subjective Barriers Questionnaire was administered over the telephone. The Subjective Barriers Questionnaire may have been better suited to be administered in an in-person interview or via the inclusion of qualitative methods through the use of a mixed methods approach. Thus, while CRT provided a broad foundation to conceptualize this program of research, future work on inequities to the early stages of the pre-kidney transplant process should consider the integration of a middle range theory.

Integration of Critical Race Theory and a socio-ecological model

The use of socio-ecological models to understand barriers to patient care has become an area of interest in the last decade (Daley, Alio, Anstey, Chandler, & Hemley, 2011; Robinson, 2008). The socio-ecological model of health promotion involves five interrelated ecological niches (individual, interpersonal, organizational, community, and policy) that are essential to our understanding of how to prevent health problems such was the inability of patients to navigate the pre-kidney transplant evaluation (CDC, 2016b; Reifsnider, Gallagher, & Forgione, 2005). The major assumption of the model is that these factors are not independent and solutions to issues related to health promotion require an understanding of the complexities of the bi-directional nature of these factors (Bronfenbrenner, 1979). Integration of a transplant specific socio-ecological model with the grand theory (CRT) allows researcher to retain the tenants the guide CRT while integrating theory and empirical evidence. An integrated CRT/socio-ecological model for barriers to the pre-kidney transplant evaluation can be found in Figure 6.1.

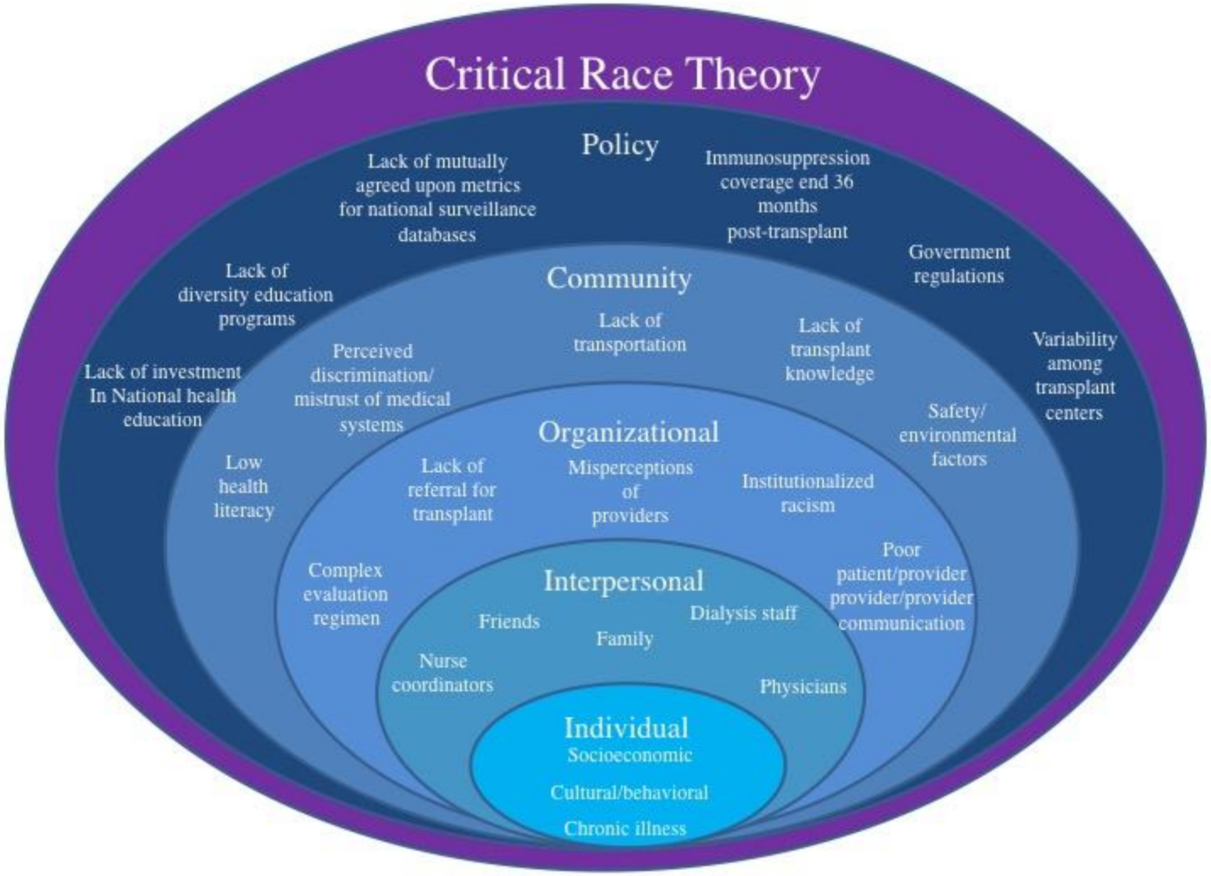


Figure 6.1 An integrated theoretical model to guide research exploring barriers to the pre-kidney transplant evaluation. The model includes Critical Race Theory as the grand theory, which allows researcher to view barriers in the context of the five tenants that guide CRT. A transplant specific socio-ecological model allows researchers to view barriers as a dynamic interaction between the individual and external forces.

Future Directions

Logical next steps (Addressing modifiable barriers)

Some of the barriers identified in this program of research are more amenable to action than other, For instance, socioeconomic barriers such as living in poverty and lack of access to quality education are more challenging to address because they require change through political action. Lobbying for change though political action is an important step in eliminating inequities in the system, but because of the lengthy process of legislating these issues, lobbying for change should be considered a continuous part of the process rather than an immediately actionable area of exploration. Additionally, progress toward finding mutually agreed upon areas of standardization in the pre-kidney transplant evaluation among transplant centers across the country that would enable collection of data related to the pre-kidney transplant evaluation in surveillance databases would likely take a considerable amount of time and perseverance. There are, however, several areas that were identified through this program of research that can be explored in the near term.

Results from this dissertation research provide a number of avenues to guide future research. Patient Reported Outcomes (PROs) have become an area of interest for many researchers interested in understanding health related problems from the patient’s perspective. Currently, there are a number of well-defined and validated instruments available through the NIH sponsored Patient Related Outcomes Measurement Information Systems (PROMIS®) study. PROs can be used alone, in conjunction with biological measures, or paired with tailored interventions in order to obtain a more precise understanding of the interactions between the patient, their environment, and their physical and mental health. In addition, PROMIS® measures could provide the foundation of future research exploring several variables identified through this program of research that require further investigation (figure 6.2).

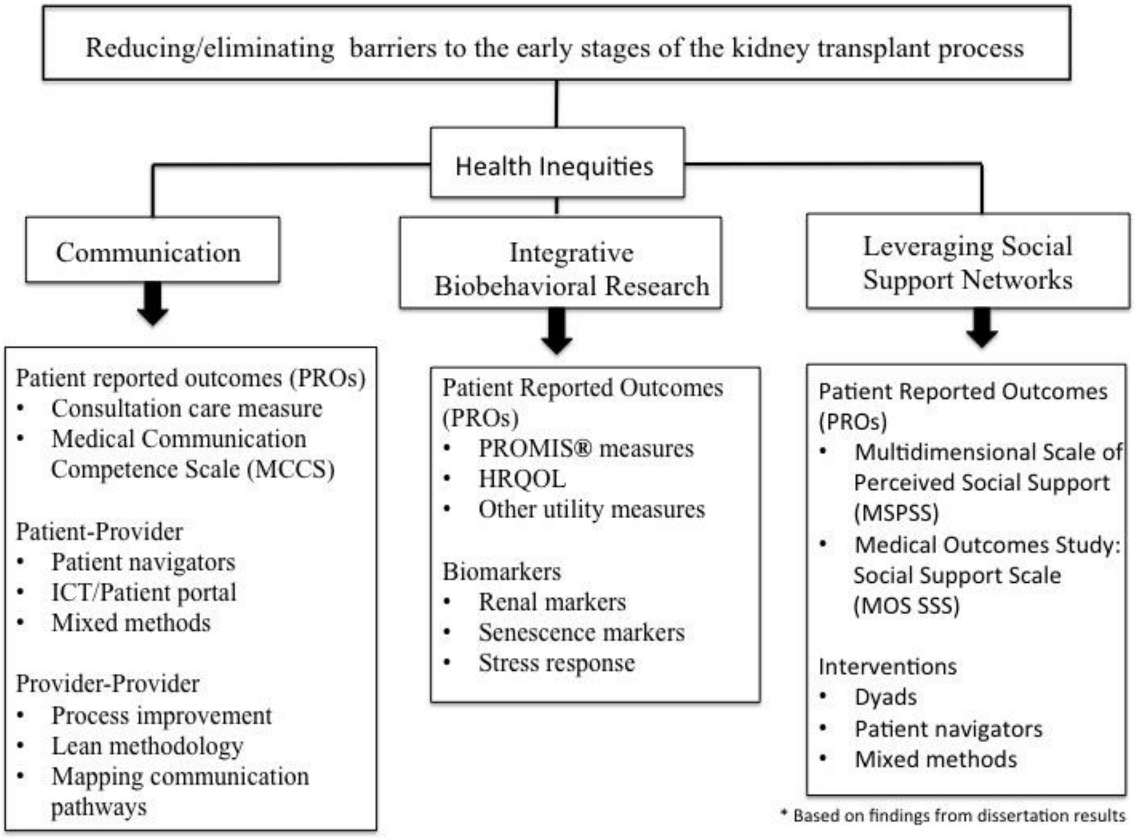


Figure 6.2 *Potential future directions for this line of inquiry include examination of biological and psychosocial factors such as health related quality of life, improving communication by leveraging social support networks in conjunction with development of ICT technologies may help to mitigate barriers and reduce inequities. Measures from the Patient Reported Outcomes Measurement Information System (PROMIS®) were funded by the National Institutes of Health

Using PROMIS® measures as the foundation of the research program

For better or worse, HRQOL has been the dominant PRO in ESRD but there are many more granular metrics of physical, mental and social health that would likely be more informative in gaining insight into the patients' perspective on the impact of transplant evaluation and even transplantation. The PROMIS® adult self-reported health framework is presented in Figure 6.4.

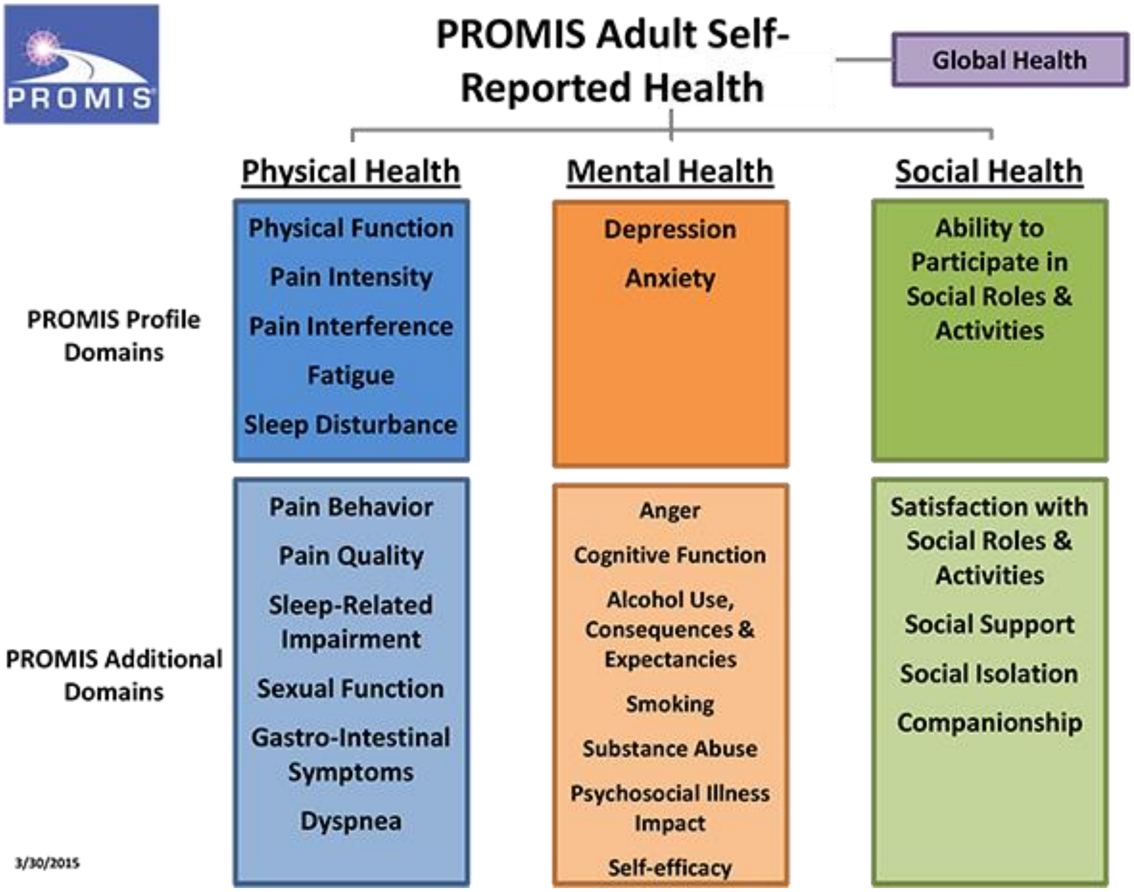


Figure 6.3 Patient reported Outcomes Measurement Information Systems (PROMIS®) adult self-reported health framework will be used to guide future work on variables identified in the early stages of this program of research

PROMIS® measures could be used in several ways to extend the findings of this research program. For example, to better understand barriers to completing the pre-kidney transplant evaluation from the patient’s perspective, researchers may decide to examine the influence self-efficacy in conjunction with psychosocial measures such as those that measure anxiety, anger or depression. One could theorize that higher scores on anxiety, anger and depression measures may result in lower self-efficacy, or vice versa, and thus a lower likelihood of successfully completing the pre-kidney transplant evaluation. The use of PROMIS® measures may aid in identifying underappreciated modifiable patient reported barriers to completing the pre-kidney transplant evaluation experienced by patients with ESRD. Thus, the use of PROMIS® instruments in conjunction with other established PRO, such as the KDQOL-SF™, may enhance our current knowledge of barriers to the early stages of the transplant evaluation.

In addition to including PROMIS® measures as a tool in future work, other logical next steps include: Leveraging social support to improve communication, gaining a better understanding of how we can leverage social support networks through the use of dyadic methods, development of a transplant specific patient navigator program, and using a mixed methods approach to obtain a more granular patient-centered understanding of barriers that patients experience to the early stages of the transplant process.

Leveraging social support to improve communication

Social support is fundamental to a patient's progression to transplantation. House, et al. (1987) described social support as the perception that one belongs to a complex network in which one can give and receive aid, affection, and obligation, in which emotional, physical and financial support are given and received. Potential kidney transplant recipients are required to demonstrate that an adequate support system is in place prior to proceeding with the pre-kidney transplant evaluation. However, there are no standardized guidelines for determining if the patient's support system is sufficient enough to support the patient's needs throughout the kidney transplant process. Higher levels of perceived social support among patients with chronic kidney disease have been correlated with better health outcomes, improved medication and treatment adherence, and lower levels of depressive affect (Clark, et al., 2008; Kutner, et al., 2010; Myakovski et al., 2012). However, the heterogeneity of data related to the effect of social support systems on successful completion of the pre-kidney transplant medical evaluation make interpretation of these data difficult. For example, in a study of 742 African American and white ESRD patients, Clark et al. found that the highest levels of perceived social support were associated with higher rates of evaluation completion among all but African American males (Clark, et al, 2008). In contrast, authors of the HEMO study, a well-designed study that evaluated outcome in ESRD patient on varying doses of hemodialysis, found there was no difference in social support among African Americans, Caucasians, Hispanics, and Asians (Unruh, et al, 2004). Many of these studies occurred in the absence of a clearly stated theoretical framework or conceptual model. Thus, framing perceived social support in the context of the theoretical or conceptual model may help with the development of more homogenous study designs that will be useful for synthesis of results across studies,

Understanding social support using a dyadic approach

Achieving a better understanding of the mechanisms that regulate social support in the context of ESRD/kidney transplantation is critical. Similar to findings on the role of perceived social support in other chronic disease conditions, Kimmel et al. (1998) demonstrated that perceived social support predicted survival in patients with ESRD. Moreover, understanding the underlying mechanisms of the patient’s support network may inform the design of novel strategies to facilitate progression through the pre-kidney transplant medical evaluation. One area that has been under appreciated in

ESRD/transplantation is the dyadic relationship that exists between patients and their caregivers. In a recent study, Pruchno, Wilson-Genderson, & Catwright studied self-rated health and depressive symptoms in married patients with ESRD and their caregivers/spouses. They found that a change in the mean score of the self-rated health of the patient was negatively associated with both the patient's and the caregiver/spouse's depressive symptoms (Pruchno, Wilson-Genderson, & Cartiwright, 2009). These findings highlight the importance of the patient-caregiver relationship. Extending the dyadic approach to the pre-kidney transplant evaluation may provide insights that are currently lacking. Thus, a better understanding of the relationship between patients and their caregivers may offer a new perspective to aid in the development of interventions designed to reduce barriers and inequities.

Developing a transplant specific patient navigator program

Patient navigators have become vital to many areas of chronic illness (Enard, et al., 2015; Freeman, 2006; Rodday, et al., 2015); however, the use of navigators in ESRD/transplant populations is limited. Patient navigators have been described in several incarnations including health care providers, laypersons, and former patients as navigators. In their 2012 study, Sullivan et al, demonstrated some success using former patients trained as patient navigators. In their study patients who were paired with a patient navigator were more likely to complete the various stages of the kidney transplant process compared to those who did not (Sullivan, et al, 2012). Despite the initial success, lack of a guiding framework in the context of kidney disease is a major concern; however, researchers at the Cleveland Clinic have recently developed a patient navigator program for patients with chronic kidney disease.

In 2015, Jolley et al proposed a patient navigator model in chronic kidney disease utilizing the Chronic Care Model as a theoretical foundation (Jolley, et al, 2015). The purpose of the model is to extend the positive results from patient navigator program in oncology and apply those techniques to the management of patients with chronic kidney disease. This model could easily be extended for use in the kidney transplant process, Thus, developing a patient navigator program in the pre-kidney transplant setting or providing patient navigator training for pre-kidney transplant nurses may be a feasible solution to mitigate barriers and inequities in the early stages of the transplant process.

Barriers related to communication

Barriers associated with deficits in communication between patients and providers, and among providers were prominent in both our systematic review and our prospective cohort study. The level of communication required for successful completion of the pre-kidney transplant evaluation is complex, particularly in the context of marginalized populations who are more at risk of low health literacy, lack of knowledge regarding the transplant process, and distrust of the medical system (Browne, 2011; Gordon, et al., 2001; Myaskovsky, et al., 2012; Waterman, et al., 2010). Despite our knowledge of poor communication during the early stages of the transplant process little attention has been given to understanding the nuances of these processes. Simply put, a more detailed understanding of these complex communication processes is required in order to develop interventions to mitigate these barriers.

Mapping communication pathways associated with the transplant evaluation

In an effort to better understand the complexity of the communication processes that occur during the pre-kidney transplant evaluation we mapped the communication pathways involved (Figure 6.4; Table 6.2). This map is a conservative estimate of the number of pathways involved in the transplant evaluation, but does not include the frequency with which the pathways are utilized. We believe that visualization of the complexity involved with communication that is required for successful navigation through the pre-kidney transplant evaluation will aid transplant centers in identifying communication pathways that may require more attention. On a practical level, the map can be used to guide quality assurance (QA) and/or continuous process improvement (CPI) projects. Ideally, the map would provide the framework for the development of a centralized transplant portal that would streamline communication between patients, their families, and providers.

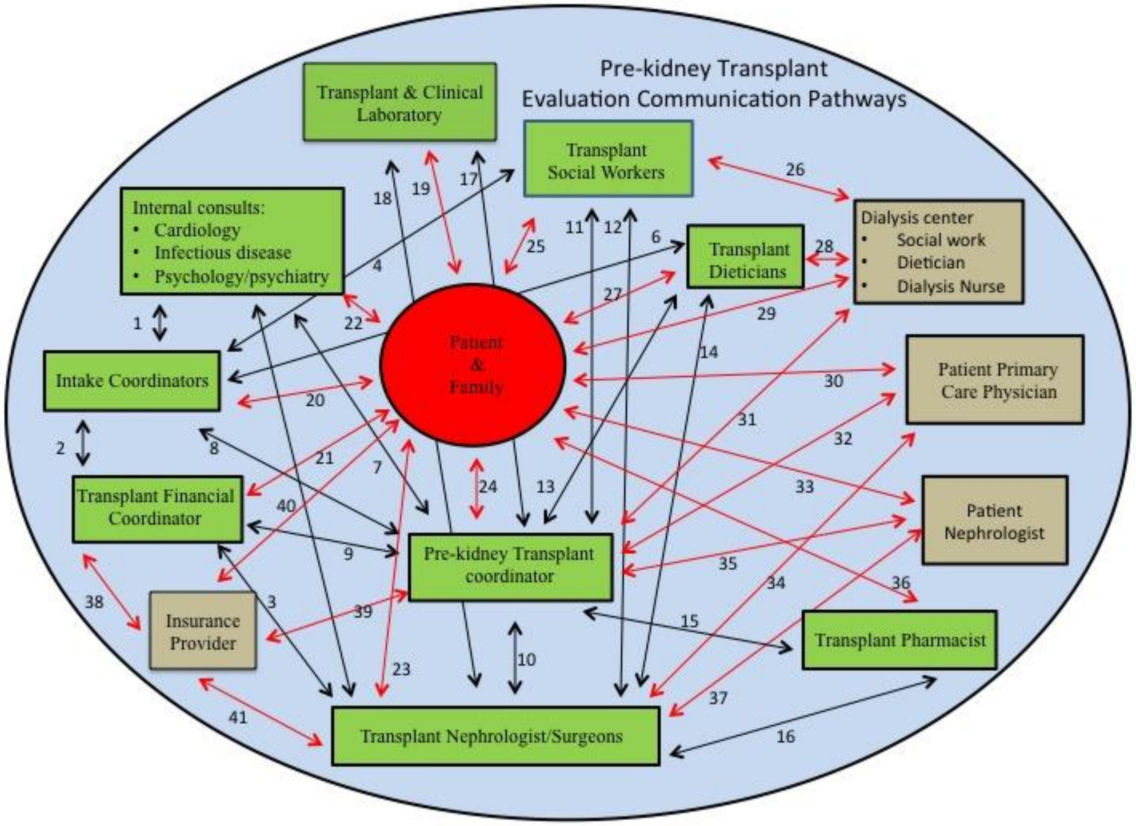


Figure 6.4 Communication pathways associated with the pre-kidney transplant evaluation. Bidirectional arrows indicated bidirectional communication pathways between providers and patients and among providers. Red arrows indicate communication that occurs with actors outside of the organization (N=19). Black arrows indicate communications that occurs between actors within the organization (N=21). In the model nurse coordinators and physicians are the most frequently involved clinicians in both internal and external communication

Table 6.2 Legend for communication pathways

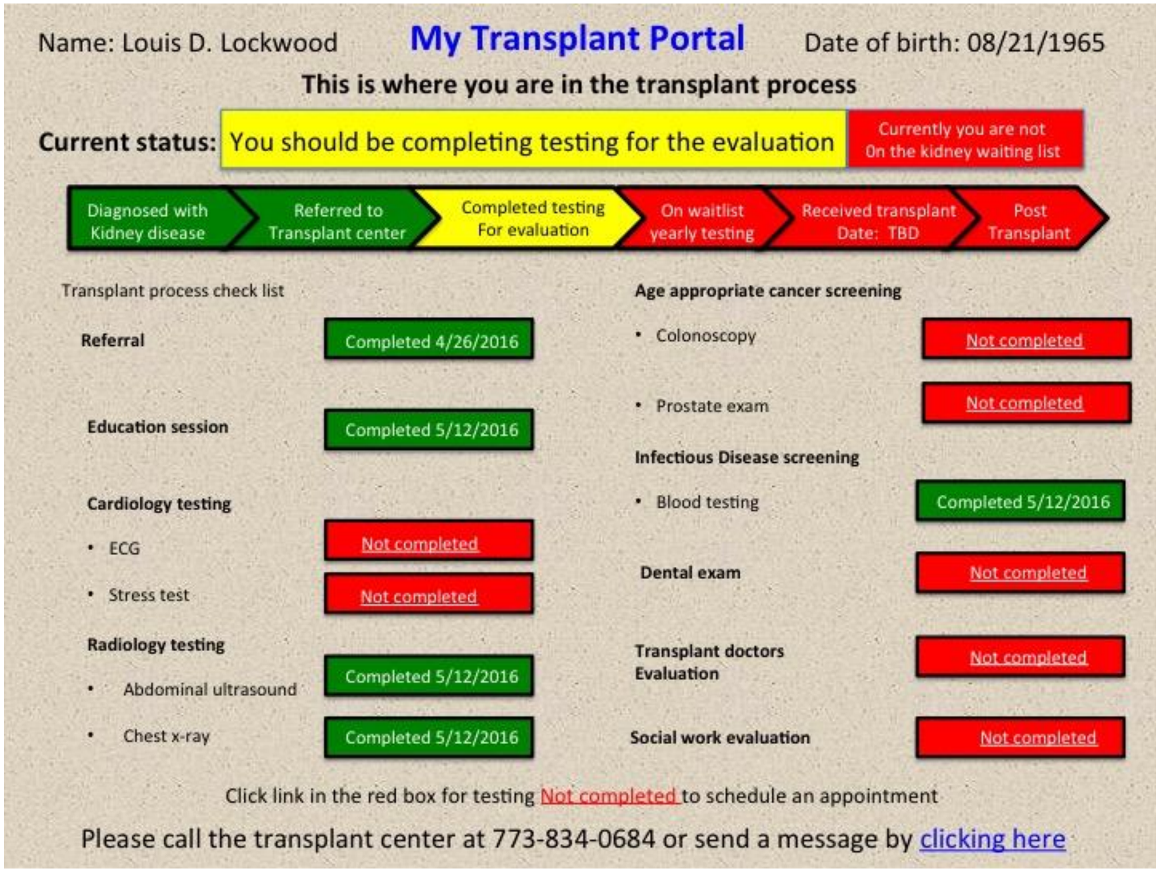
	Communication pathway	Pathway type
1	Intake coordinator-Internal consults	Within organization
2	Intake coordinator-Transplant financial coordinator	Within organization
3	Transplant financial coordinator-Transplant physicians	Within organization
4	Intake coordinator-Transplant social worker	Within organization
5	Intake coordinator-Transplant dietician	Within organization
6	Transplant physician-Internal consults	Within organization
7	Nurse coordinator-Internal consult	Within organization
8	Nurse coordinator-Intake coordinator	Within organization
9	Nurse coordinator-Transplant financial coordinator	Within organization
10	Nurse coordinator-Transplant physician	Within organization
11	Nurse coordinator-Transplant social worker	Within organization
12	Transplant social worker-Transplant physician	Within organization
13	Nurse coordinator-Transplant dietician	Within organization
14	Transplant dietician-Transplant physician	Within organization
15	Nurse coordinator-Transplant pharmacist	Within organization
16	Transplant pharmacist-Transplant physician	Within organization
17	Transplant& Clinical Laboratory-Patient	Within organization
18	Transplant & Clinical Laboratory-Nurse coordinator	Within organization
19	Transplant & Clinical Laboratory-Transplant physician	Within organization
20	Intake coordinator-Patient	Outside organization
21	Transplant financial coordinator-Patient	Outside organization
22	Internal consult-Patient	Outside organization
23	Transplant physician-Patient	Outside organization
24	Nurse coordinator-Patient	Outside organization
25	Transplant social worker-Patients	Outside organization

	Communication pathway (continued)	Pathway type
26	Transplant social worker-Dialysis center	Outside organization
27	Transplant dietician-Patient	Outside organization
28	Transplant dietician-Dialysis center	Outside organization
29	Dialysis center-Patient	Outside organization
30	Patient primary care physician-Patient	Outside organization
31	Nurse coordinator-Dialysis center	Outside organization
32	Nurse coordinator-Patient's primary care provider	Outside organization
33	Patient nephrologist-Patient	Outside organization
34	Transplant physician-Patient primary care physician	Outside organization
35	Nurse coordinator-Patient nephrologist	Outside organization
36	Transplant pharmacists-Patient	Outside organization
37	Transplant physician-Patient nephrologist	Outside organization
38	Insurance provider-Financial coordinator	Outside organization
39	Insurance provider-Nurse coordinator	Outside organization
40	Insurance provider-Patients	Outside organization
41	Insurance provider-Transplant physicians	Outside organization

Development of a centralized communication portal

As shown in our technology assessment, which included many patients from challenging socioeconomic situations, nearly all of the patients who were surveyed had access to multiple information and communication technology platforms that could be used to improve communications. Consequently, we recommend that strategies to improve communication in the pre-kidney transplant evaluation include development of transplant specific information and communication technologies, with the use of text messaging at the core of the communication strategy.

Ideally, the development of a centralized transplant portal designed to improve communication between patient and providers and among providers would provide clarity for all actors involved in the evaluation process. Moreover, once developed these systems could be easily modified to address issues across the entire spectrum of transplantation including referral, wait listing, and the post-transplant period. During the evaluation, patients and providers could log into the system to view a checklist of required testing including the status of the testing (Figure 6.2). In addition, the system clearly displays where the patient is in the transplant process. Several studies, including our prospective study have shown that many patients are not able to identify where they are in the transplant process (Gillespie, et al., 2011; Kutner, et al., 2011). By utilizing multiple communication technologies (e.g. text-messaging, email, and voice messaging) ease of communication between patients and providers is increased, while the potential for missed communication is reduced. Messaging can be configured for automated messaging, however, providers would also have the option to send personalized messages.



Name: Louis D. Lockwood

My Transplant Portal

Date of birth: 08/21/1965

This is where you are in the transplant process

Current status: You should be completing testing for the evaluation

Currently you are not
On the kidney waiting list

Transplant process check list

Referral	Completed 4/26/2016
Education session	Completed 5/12/2016
Cardiology testing	
• ECG	Not completed
• Stress test	Not completed
Radiology testing	
• Abdominal ultrasound	Completed 5/12/2016
• Chest x-ray	Completed 5/12/2016

Age appropriate cancer screening	
• Colonoscopy	Not completed
• Prostate exam	Not completed
Infectious Disease screening	
• Blood testing	Completed 5/12/2016
Dental exam	Not completed
Transplant doctors Evaluation	Not completed
Social work evaluation	Not completed

Click link in the red box for testing Not completed to schedule an appointment

Please call the transplant center at 773-834-0684 or send a message by clicking here

Figure 6.5 Wireframe of home screen for the My Transplant Portal, This screen is accessible to patient and healthcare providers and allows visualization of where the patient is in the transplant process, what tests are outstanding, and allows for easy communication between patients and providers, Green indicated the goal has been met, yellow indicates that the area is in process, read indicated the specific test or stage of the evaluation has not be completed, Portal specific training for patients and providers would be required.

Development of transplant specific technology offers a novel approach to addressing inequities by improving communications between all actors involved in the pre-kidney transplant process; however, due to the complex nature or barriers experienced by many patients additional analog strategies should be considered.

Use of mixed methods approach

Over the last several decades research into barriers to the early stages of the transplant process has moved from broad descriptions of explanatory variables to identification of specific variables that can be intervened upon. We would encourage researchers interested in this area to consider applying a mixed methods approach to identifying potential barriers to the pre-kidney transplant evaluation. A mixed methods approach allows participants to offer their lived experience through interviews using open-ended questions. The use of a mixed methods approach is harmonious with Critical Race Theory, as it would allow patients to express their counter narrative in their own words. Inclusion of qualitative data has generally been lacking in explorations of barriers to the pre-kidney transplant evaluation and would enable the transplant community to have a more in-depth understanding of the challenges our patients experience as they go through the pre-kidney transplant evaluation. Thus, inclusion of the patient’s lived experience via a mixed methods approach could provide additional modifiable barriers that may be missed through quantitative works alone.

Limitations

This program of research exploring barriers to the pre-kidney transplant evaluation and potential solutions is not without limitations. First, technology trends change at a rapid pace. At the time of our technology assessment in 2012 smartphone use was less than 50 percent for both African Americans and Caucasians. However, a recent technology assessment at the same transplant center with a similar sample found that smartphone use had increased dramatically in the four years since the initial technology assessment. This increase in smartphone adoption in no way diminishes the findings that interventions using text messaging are likely to be the most successful of any technology based intervention given the ubiquity of text messaging and the high level of comfort patients have sending and receiving text messages. However, these findings do indicate that ongoing technology assessments of patient populations are needed prior to the implementation of interventions with technology at its core.

The major challenge of studying barriers to the pre-kidney transplant medical evaluation lies in the variability of institutional resources devoted to transplant centers, and their tolerance for risk. Some large transplant centers are able to centralize services, which enables them to complete the pre-kidney transplant medical evaluation in one day (Formica, et al, 2012). In addition, centers with large patient volumes are able to take more complex patients, as their tolerance for risk is higher because poor outcomes will have less of an impact on their quality outcomes metrics. However, most small to medium sized transplant centers have fewer resources and have to proceed more cautiously when selecting patients. Moreover, our sample was an urban population, which was mainly comprised of people who identified as African American. While the results from this portion of the dissertation research may not be generalizable, it is likely that there are many centers with patient populations that may face similar barriers. Thus, by studying these barriers in a systematic way, via a prospective cohort study, we move many of these barriers from the realm of anecdote, conjecture and speculation to the realm of rigorous, empirically tested evidence.

Summary

Through a systematic review, a prospective cohort study, and a rigorous technology assessment this program of research builds on previous work in the area of barriers and inequities to transplantation, specifically the pre-kidney transplant evaluation. Variability in the evaluation process among transplant centers in the United States presents a major challenge in identifying common barriers to the pre-kidney transplant evaluation and finding solutions to address many systems based barriers. Due to the absence of nationally reported surveillance data, fractured communications, and a lack of standardization related to the evaluation process it is likely that inequities related to this stage of the transplant process, and those preceding this stage, are grossly underestimated. Therefore, addressing gaps in information and communication should be a top priority of the transplant community in addressing inequities in access to transplantation.

Equity is a key principle that is clearly articulated in the moral and ethical standards that guide the transplant enterprise. Patient autonomy should be respected; however, low health literacy, lack of transplant knowledge, and lack of resources may contribute to inequities particularly at centers that require patients to complete screening testing independently prior to being evaluated at the transplant center. Patient's inability to complete screening tests prior to being evaluated at the transplant center should not be viewed as a proxy for a patient's willingness to receive a transplant or their capability to care for the organ post operatively. Thus, consciousness raising efforts to educate patients and providers about potential barriers to the pre-kidney transplant evaluation, particularly those faced by marginalized populations, are desperately needed.

Currently, assessment of HRQOL is the primary PRO of interest in ESRD/kidney transplantation; however, HRQOL has been challenged for its lack of clarity and the absence of an instrument that is dynamic enough to fully capture the HQROL experience. The inclusion of PRO measures from the PROMIS® study provides additional data that allows researchers to capture PROs using well-established and validated instruments. Strategies designed to improve communication between patients and providers and among providers, via patient navigators and the development of information and communication technologies offer the best hope of mitigating many of these long standing barriers/inequities. Future work leveraging patient social networks including examining how dyadic relationships may be enhanced to mitigate inequities could provide another avenue to improve communication during the transplant process.

Finally, future work examining and intervening upon barriers and inequities to the pre-kidney transplant evaluation may benefit from the use of a theoretical model. We proposed an integrated model that used the tenants of Critical Race Theory as a grand theory and a transplant specific socio-ecological model as a middle range theory to help guide future research efforts. Integration of a transplant specific socio-ecological model with CRT allows researcher to retain the tenants the guide CRT while integrating theory and empirical evidence.

Cumulative References

Abdel-Kader, K., Dew, M. A., Bhatnagar, M., Argyropoulos, C., Karpov, I., Switzer, G., & Unruh, M. L. (2010). Numeracy skills in CKD: correlates and outcomes. *Clinical Journal of the American Society of Nephrology, 5*(9), 1566-1573. doi: 10.2215/cjn.08121109

Alexander, G. C., & Sehgal, A. R. (1998). Barriers to cadaveric renal transplantation among blacks, women, and the poor. *JAMA, 280*(13), 1148-1152. doi:10.1001/jama.280.13.1148

Alexander, G. C., Sehgal, A. R., & Transplant Task Force of The Renal Network, Inc. (2002). Variation in access to kidney transplantation across dialysis facilities: using process of care measures for quality improvement. *American Journal of Kidney Diseases*, *40*(4), 824-831. doi:10.1053/ajkd.2002.35695

American Psychological Society (2016). Ethnic and racial minorities & socioeconomic status. Retrieved on January 5, 2016 from: http://www.apa.org/pi/ses/resources/publications/factsheet-erm.aspx

Axelrod, D. A., Millman, D., & Abecassis, M. M. (2010). US Health Care Reform and Transplantation, Part II: impact on the public sector and novel health care delivery systems. *American Journal of Transplantation, 10*(10), 2203-2207. doi: 10.1111/j.1600-6143.2010.03247.x

Axelrod, D. A., Lentine, K. L., Xiao, H., Bubolz, T., Goodman, D., Freeman, R., . . . Schnitzler, M. A. (2014). Accountability for end-stage organ care: Implications of geographic variation in access to kidney transplantation. *Surgery, 155*(5), 734-742. doi: 10.1016/j.surg.2013.12.010

Axelrod, David A, Dzebisashvili, Nino, Schnitzler, Mark A, Salvalaggio, Paolo R, Segev, Dorry L, Gentry, Sommer E, . . . Lentine, Krista 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*, 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

Ayanian, J. Z., Cleary, P. D., Weissman, J. S., & Epstein, A. M. (1999). The effect of patients' preferences on racial differences in access to renal transplantation. *New England Journal of Medicine, 341*(22), 1661-1669. doi: 10.1056/NEJM199911253412206

Barotfi, S., Molnar, M. Z., Almasi, C., Kovacs, A. Z., Remport, A., Szeifert, L., . . . Mucsi, I. (2006). Validation of the Kidney Disease Quality of Life-Short Form questionnaire in kidney transplant patients. *Journal of Psychosomatic Research, 60*(5), 495-504. doi: 10.1016/j.jpsychores.2005.09.009

Berkman, N. D., Sheridan, S. L., Donahue, K. E, Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: an updated systematic review. *Annals of Internal Medicine, 155*(2), 97-107

Black, H., Gonzalez, R., Priolo, C., Schapira, M. M., Sonnad, S. S., Hanson, C. W., 3rd, . . . Apter, A. J. (2015). True "meaningful use": technology meets both patient and provider needs. *American Journal of Managed Care, 21*(5), e329-337.

Bramstedt, K.A., & Dave, S. (2013). The silence of Good Samaritan kidney donation in Australia: a survey of hospital websites. *Clinical Transplantation*. 27:E244-E248. Doi: 101111ctr.12067.

Bramstedt, K.A. & Young, J.B. (2006). Use of the Internet by United States heart transplant centers promote transparency in the process of patient's selection. Telemedicine and e-Health. 12(3): 359-326.

Bratton, C., Chavin, K., Baliga, P. (2011). Racial disparities in organ donation and why. Current Opinion in Organ Transplantation. 16, 243-249

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.

Browne, T. (2011). The relationship between social networks and pathways to kidney transplant parity: evidence from black Americans in Chicago. *Social Science and Medicine, 73*(5), 663-667. doi:10.1016/j.socscimed.2011.06.031

Bureau of the Census. *2010 State and Count Quickfacts Chicago (city), Illinois*. Retrieved on December 5, 2012 from: http://quickfacts.census.gov/qfd/states/17/1714000.html

Butt, Zeeshan, Yount, Susan E., Caicedo, Juan Carlos, Abecassis, Michael M., & Cella, David. (2008). Quality of life assessment in renal transplant: review and future directions. *Clinical Transplantation, 22*(3), 292-303. doi: 10.1111/j.1399-0012.2007.00784.x

Cady, R., Finkelstein, S., Lindgren, B. et al.(2009). Exploring the Translational Impact of a Home Tele-monitoring Intervention Using Time-Motion Study. *Telemedicine Journal and e-Health*. 16(5): 576-584

California Healthcare Foundation. (2010). How Smartphones are Changing Health Care for Consumers and Providers. Retrieved on November 08, 2011 from: http://www.chcf.org/publications/2010/04/how-Smartphones-are-changing-health-care-for-consumers-and-providers

Cameron, J. I., Caucasianside, C., Katz, J., & Devins, G. M. (2000). Differences in quality of life across renal replacement therapies: a meta-analytic comparison. *American Journal of Kidney Diseases, 35*(4), 629-637.

Canady, L. (2008). Implementing a Home Telemonitoring Program. *Home Health Nurse.* 26 (4):231-236

Centers for Disease Control and Prevention. (2016). Chronic kidney disease surveillance program. Retrieved on May 21, 2016, from: https://nccd.cdc.gov/ckd/

Centers for Disease Control and Prevention. (2016). Colorectal Cancer Control Program (CRCCP): Social ecological model. Retrieved on June 24, 2016, from: http://www.cdc.gov/cancer/crccp/sem.htm

Center for Medicare and Medicaid Services (2013). Eligible professional's guide to Stage 2 of the HER incentives program. Retrieved on May 1, 2016 from: https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/Downloads/Stage2_Guide_EPs_9_23_13.pdf

Cetingok, M., Hathaway, D., & Winsett, R. (2007). Contribution of post-transplant social support to the quality of life of transplant recipients. *Social Work in Health Care*, *45*(3), 39-56. doi: 10.1300/J010v45n03_03

Chandrakantan, A., de Mattos, A. M., Naftel, D., Crosswy, A., Kirklin, J., & Curtis, J. J. (2006). Increasing referral for renal transplant evaluation in recipients of nonrenal solid-organ transplants: a single-center experience. *Clinical Journal of The American Society of Nephrology: CJASN*, *1*(4), 832-836.

Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases*, *40*(5), 373-383.

Chauidry, S., Mattera, J., Curtis, et al. (2010). Telemonitoring in Patients with Heart Failure. *The New England Journal of Medicine.* 363(24):2301-2309

Chen, T. K., Choi, M. J., Kao, W. H., Astor, B. C., Scialla, J. J., Appel, L. J., . . . Crews, D. C. (2015). Examination of Potential Modifiers of the Association of APOL1 Alleles with CKD Progression. *Clinical Journal of the American Society of Nephrology, 10*(12), 2128-2135. doi: 10.2215/cjn.05220515

Chung, H., Lam, V. W., Yuen, L. P., Ryan, B. J., O'Connell, P. J., Chapman, J. R., . . . Pleass, H. C. (2015). Renal transplantation: better fat than thin. *Journal of Surgical Research, 194*(2), 644-652. doi: 10.1016/j.jss.2013.12.027

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), 1187-1193. doi: 10.1007/s11606-008-0628-7

Collins, M. G., Teo, E., Cole, S. R., Chan, C. Y., McDonald, S. P., Russ, G. R., . . . Coates, P. T. (2012). Screening for colorectal cancer and advanced colorectal neoplasia in kidney transplant recipients: cross sectional prevalence and diagnostic accuracy study of faecal immunochemical testing for haemoglobin and colonoscopy. *BMJ, 345*, e4657. doi: 10.1136/bmj.e4657

Cort, M., Cort, D. (2008). Willingness to Participate in Organ donation Among Black Seventh-Day Adventist College Students. Journal of American College Health. 56 (6), 691-697.

Cresci, M.K., Yardandi, H.N., & Morrell, R. (2010). The digital divide and urban older adults. *CIN: Computers, Informatics, Nursing*. 20(2), 88-94.

Cukor, D., Coplan, J., Brown, C., Friedman, S., Cromwell-Smith, A., Peterson, R. A., & Kimmel, P. L. (2007). Depression and anxiety in urban hemodialysis patients. *Clinical Journal of the American Society of Nephrology, 2*(3), 484-490. doi: 10.2215/cjn.00040107

Dageforde, L. A., Box, A., Feurer, I. D., & Cavanaugh, K. L. (2015). Understanding Patient Barriers to Kidney Transplant Evaluation. *Transplantation*. doi: 10.1097/tp.0000000000000543

Daley, E., Alio, A., Anstey, E. H., Chandler, R., Dyer, K., & Helmy, H. (2011). Examining barriers to cervical cancer screening and treatment in Florida through a socio-ecological lens. *Journal of Community Health, 36*(1), 121-131. doi: 10.1007/s10900-010-9289-7

Davis, C. L., & Delmonico, F. L. (2005). Living-donor kidney transplantation: a review of the current practices for the live donor. *Journal of the American Society of Nephrology, 16*(7), 2098-2110. doi: 10.1681/asn.2004100824

DeCuir, J., & Dixson, A. (2004). So When It Comes Out, They Aren't That Surprised That It Is There": Using Critical Race Theory as a Tool of Analysis of Race and Racism in Education. *Educational Researcher*, 33(5), 26-31.

Delgado, R. (1995). Critical race theory: The cutting edge. Philadelphia: Temple University Press.

Denizard-Thompson, N. M., Feiereisel, K. B., Stevens, S. F., Miller, D. P., & Wofford, J. L. (2011). The digital divide at an urban community health center: implications for quality improvement and health care access. *Journal of Community Health, 36*(3), 456-460. doi: 10.1007/s10900-010-9327-5

Dew, M.A., Goycoolea, J.M., Harris, R.C., Lee, A., Zomak, R., Dunbar-Jacob, J., Rotondi, A., Griffith, B., & Kormos, R.L. (2004). An Internet-based intervention to improve psychosocial outcomes in heart transplant recipients and family caregivers: Development and evaluation. *J Heart Lung Transplant*. 23:745-58.

DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes. *Journal of General Internal Medicine, 19*(12), 1228-1239

Dudley, R., & Harden, P. (2011). Assessment of the potential kidney transplant recipient. Retrieved on May 9, 2016 from: http://www.renal.org/guidelines/modules/assessment-of-the-potential-kidney-transplant-recipient

Edwards, T., Essman, C., & Thornton, D. (2007). Assessing Racial and Ethnic Differences in Medical Students Knowledge, Attitudes, and Behaviors Regarding Organ Donation. Journal of the National Medical Association. 99 (2), 131-137.

Egbert, N., & Nanna, K., (2009). "Health Literacy: Challenges and Strategies" *OJIN: The Online Journal of Issues in Nursing*, 14(3), Manuscript 1.

Enard, K. R., Nevarez, L., Hernandez, M., Hovick, S. R., Moguel, M. R., Hajek, R. A., . . . Torres-Vigil, I. (2015). Patient navigation to increase colorectal cancer screening among Latino Medicare enrollees: a randomized controlled trial. *Cancer Causes and Control, 26*(9), 1351-1359. doi: 10.1007/s10552-015-0620-6

Epstein, A. M., Ayanian, J. Z., Keogh, J. H., Noonan, S. J., Armistead, N., Cleary, P. D., . . . Conti, R. M. (2000). Racial disparities in access to renal transplantation--clinically appropriate or due to underuse or overuse? *New England Journal of Medicine, 343*(21), 1537-1544. doi: 10.1056/NEJM200011233432106

Farney, A. C., Doares, W., Kaczmorski, S., Rogers, J., & Stratta, R. J. (2010). Cost-effective immunosuppressive options for solid organ transplantation: a guide to lower cost for the renal transplant recipient in the USA. *Immunotherapy, 2*(6), 879-888. doi: 10.2217/imt.10.60

Feroze, U., Martin, D., Reina-Patton, A., Kalantar-Zadeh, K., & Kopple, J. D. (2010). Mental health, depression, and anxiety in patients on maintenance dialysis. *Iranian Journal of Kidney Diseases, 4*(3), 173-180.

Fischman, B., Bobo, L., Kosub, K. Womeodu, R. (1993). Cultural Issues in Serving Minority Populations: emphasis on Mexican Americans and African Americans. The American Journal of The Medical Sciences. 306 (3), 160-166.

Formica, R. N., Jr., Barrantes, F., Asch, W. S., Bia, M. J., Coca, S., Kalyesubula, R., . . . Kulkarni, S. (2012). A one-day centralized work-up for kidney transplant recipient candidates: a quality improvement report. *American Journal of Kidney Diseases, 60*(2), 288-294.

Fox S, Purcell K. Chronic Disease and the Internet. Released March 24, 2010. Retrieved on April 1, 2014 from http://www.pewinternet.org/2010/03/24/chronic-disease-and-the-internet/.

Freeman, H. P. (2006). Patient navigation: a community centered approach to reducing cancer mortality. *Journal of Cancer Education, 21*(1 Suppl), S11-14. doi: 10.1207/s15430154jce2101s_4

Gallop (2014). U.S. views on honesty and ethical standards in professions. Retrived on January 5, 2016 from: http://www.gallup.com/poll/180260/americans-rate-nurses-highest-honesty-ethical-standards.aspx

Gautam, N. R., Gautam, N. S., Rao, T. H., Koganti, R., Agarwal, R., & Alamanda, M. (2014). Effect of end-stage renal disease on oral health in patients undergoing renal dialysis: A cross-sectional study. *J Int Soc Prev Community Dent, 4*(3), 164-169. doi: 10.4103/2231-0762.142006

Gibney, E., King, A., Maluf, D., Garg, A., Parikh, C. (2007). Living Kidney Donors Requiring Transplantation: Focus on African Americans. Transplantation. 84 (8), 647-649.

Gill, J. S., Hendren, E., Dong, J., Johnston, O., & Gill, J. (2014). Differential association of body mass index with access to kidney transplantation in men and women. *Clinical Journal of the American Society of Nephrology, 9*(5), 951-959. doi: 10.2215/cjn.08310813

Gillespie, A., Hammer, H., Lee, J., Nnewihe, 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), 1522-1526. doi: 10.1111/j.1600-6143.2011.03524.x

Glover, C., Banks, P., Carson, A., Martin, C. R., & Duffy, T. (2011). Understanding and assessing the impact of end-stage renal disease on quality of life: a systematic review of the content validity of self-administered instruments used to assess health-related quality of life in end-stage renal disease. *Patient, 4*(1), 19-30. doi: 10.2165/11584650-000000000-00000

Goldfarb-Rumyantzev, A. S., Koford, J. K., Baird, B. C., Chelamcharla, M., Habib, A. N., Wang, B. J., . . . Isaacs, R. B. (2006). Role of socioeconomic status in kidney transplant outcome. *Clinical Journal of the American Society of Nephrology, 1*(2), 313-322. doi: 10.2215/CJN.00630805

Gordon, Elisa J. (2001). Patients' decisions for treatment of end-stage renal disease and their implications for access to transplantation. *Social Science and Medicine, 53*(8), 971-987.

Gordon, E. J., Prohaska, T. R., & Sehgal, A. R. (2008). The financial impact of immunosuppressant expenses on new kidney transplant recipients. *Clinical Transplantation, 22*(6), 738-748. doi: 10.1111/j.1399-0012.2008.00869.x

Gracia, E. & Herrero, J. (2009). Internet use and self-rated health among older people: a national survey. *Journal of Medical Internet Research*. 11(4), e49. Doi:10.2196/jmir.1311.

Greer, Raquel, & Boulware, Ebony. (2015). Reducing CKD risks among vulnerable populations in primary care. *Advances in Chronic Kidney Disease*, *22*(1), 74-80. doi: 10.1053/j.ackd.2014.06.003

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

Guay, A. H. (2004). Access to dental care: solving the problem for underserved populations. *Journal of the American Dental Association, 135*(11), 1599-1605; quiz 1623.

Halafax, N., Caffazzo, J., DPhil, MJ., et al. (2007). Tele-management of hypertension: A qualitative assessment of patient a physician preferences. *Canadian Journal of Cardiology*. 23 (7): 591-594

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), 743-751. doi: 10.1681/ASN.2010080819

Hanif, F., Abayasekara, K., Willcocks, L., Jolly, E.C., Jamieson, N.V., Praseedom, R.K., Goodcare, J.A., Read, J.C., Chaudhry, A., & Gibbs, P. (2007). The quality of information about kidney transplantation on the World Wide Web. *Clinical Transplantation*. 21: 371-376. doi: 10.111|j.1399-0012.2006.00652.x.

Hanif, F., Read, J.C., & Clancy. (2012). A snapshot of renal transplant patients using medical web browsing. *Exp Clin Transplant*. 10(3): 219-23.

Hardwick, M., Pulido, P., Adelson, W. (2007). The use of Handheld Technology in Nursing Research and Practice. *Orthopaedic Nursing*. 26(4): 251-255

Harris, L., Tulfano, J., Le, T. (2010). Designing Mobile Support for Glycemic Control in Patients with Diabetes. *Journal of Biomedical Informatics*. 43(2010): 537-540

Hays, Ron D., Joel Kallich, Donna Mapes, Stephen Coons, Naseen Amin, William B. Carter and Caren Kamberg. (1997). Kidney Disease Quality of Life Short Form (KDQOL-SF ™), Version 1.3: A Manual for Use and Scoring. Santa Monica, CA: RAND Corporation.

Hemmelgarn, B. R., Manns, B. J., Quan, H., & Ghali, W. A. (2003). Adapting the Charlson Comorbidity Index for use in patients with ESRD. *American Journal of Kidney Diseases, 42*(1), 125-132.

Huang, Y., & Samaniego, M. (2012). Preemptive kidney transplantation: has it come of age? *Nephrologie & Therapeutique*, *8*(6), 428-432. doi: 10.1016/j.nephro.2012.06.004

International Telecommunications Union. (2012). The World in 2009: Facts and Figures. A Decode of Growth Driven by Mobile Technology. Retrieved on June 25, 2012 from: http://www.itu.int/ITU-D/ict/statistics/

International Telecommunications Union. World Telecommunication/ICT indicators database 2013 (17th edition). Released December 2013. Retrieved April 13, 2014 from http://www.itu.int/en/ITU-D/Statistics/Pages/publications/wtid.aspx.

Institute of Medicine (2003). Unequal treatment: Confronting racial and ethnic disparities in health care. Retrived on January 4, 2016 from: http://iom.nationalacademies.org/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx

Irving, M. J., Tong, A., Jan, S., Cass, A., Rose, J., Chadban, S., . . . Howard, K. (2012). Factors that influence the decision to be an organ donor: a systematic review of the qualitative literature. *Nephrology Dialysis Transplantation, 27*(6), 2526-2533

Johansen, K. L., Zhang, R., Huang, Y., Patzer, R. E., & Kutner, N. G. (2012). Association of race and insurance type with delayed assessment for kidney transplantation among patients initiating dialysis in the United States. *Clinical Journal of the American Society of Nephrology, 7*(9), 1490-1497. doi: 10.2215/CJN.13151211

Jolly, S. E., Navaneethan, S. D., Schold, J. D., Arrigain, S., Konig, V., Burrucker, Y. K., . . . Nally, J. V. (2015). Development of a chronic kidney disease patient navigator program. *BMC Nephrology, 16*, 69. doi: 10.1186/s12882-015-0060-2

Joshi, S., Gaynor, J. J., Bayers, S., Guerra, G., Eldefrawy, A., Chediak, Z., . . . Kupin, W. (2013). Disparities among blacks, Hispanics, and Caucasians in time from starting dialysis to kidney transplant waitlisting. *Transplantation, 95*(2), 309-318. doi: 10.1097/TP.0b013e31827191d4

Kahwaji, J., Bunnapradist, S., Hsu, J. W., Idroos, M. L., & Dudek, R. (2011). Cause of death with graft function among renal transplant recipients in an integrated healthcare system. *Transplantation, 91*(2), 225-230. doi: 10.1097/TP.0b013e3181ff8754

Kasiske, B. L., London, W., & Ellison, M. D. (1998). Race and socioeconomic factors influencing early placement on the kidney transplant waiting list. *Journal of the American Society of Nephrology, 9*(11), 2142-2147.

Kasiske, B. L., Neylan, J. F., III, Riggio, R. R., Danovitch, G. M., Kahana, L., Alexander, S. R., & White, M. G. (1991). The effect of race on access and outcome in transplantation. *New England Journal of Medicine, 324*(5), 302-307. doi: 10.1056/NEJM199101313240505

Kazley, A. S., Simpson, K. N., Chavin, K. D., & Baliga, P. (2012). Barriers facing patients referred for kidney transplant cause loss to follow-up. *Kidney International, 82*(9), 1018-1023. doi: 10.1038/ki.2012.255

Kazley, A. S., Johnson, E. E., Simpson, K. N., Chavin, K. D., & Baliga, P. (2014a). Health care provider perception of chronic kidney disease: knowledge and behavior among African American patients. *BMC Nephrology, 15*, 112. doi: 10.1186/1471-2369-15-112

Kazley, A. S., Johnson, E., Simpson, K., Chavin, K., & Baliga, P. (2014b). African American patient knowledge of kidney disease: A qualitative study of those with advanced chronic kidney disease. *Chronic Illness*. doi: 10.1177/1742395314556658

Kimmel, P. L., & Patel, S. S. (2006). Quality of life in patients with chronic kidney disease: focus on end-stage renal disease treated with hemodialysis. *Seminars in Nephrology, 26*(1), 68-79. doi: 10.1016/j.semnephrol.2005.06.015

Klop, K. W., Kok, N. F., Dols, L. F., d'Ancona, F. C., Adang, E. M., Grutters, J. P., & JN, I. Jzermans. (2013). Cost-effectiveness of hand-assisted retroperitoneoscopic versus standard laparoscopic donor nephrectomy: a randomized study. *Transplantation, 96*(2), 170-175. doi: 10.1097/TP.0b013e318296ca25

Koivusilta, L., Lintonen, T., & Rimpela, Arja. (2007). Orientations in adolescent use of information and communication technology: A digital divide by sociodemographic background, education career, and health. *Scandinavian Journal of Public Health*. 35: 95-103.

Kouidi, E., Grekas, D., Deligiannis, A., & Tourkantonis, A. (2004). Outcomes of long-term exercise training in dialysis patients: comparison of two training programs. *Clinical Nephrology, 61 Suppl 1,* S31-38.

Kruse, R.L., Kooperman, R.J., Wakefield, B.J., Wakefield, D.S., Keplinger, L.E., Canfield, S.M., & Mehr, D.R.(2012). Internet use by primary care patients: Where is the digital divide? *Family Medicine*. 44(5), 342-347.

Kruse, C. S., Argueta, D. A., Lopez, L., & Nair, A. (2015). Patient and provider attitudes toward the use of patient portals for the management of chronic disease: a systematic review. *Journal of Medical Internet Research, 17*(2), e40. doi: 10.2196/jmir.3703

Kruse, C. S., Bolton, K., & Freriks, G. (2015). The effect of patient portals on quality outcomes and its implications to meaningful use: a systematic review. *Journal of Medical Internet Research, 17*(2), e44. doi: 10.2196/jmir.3171

Kucirka, L. M., Grams, M. E., Balhara, K. S., Jaar, B. G., & Segev, D. L. (2012). Disparities in provision of transplant information affect access to kidney transplantation. *American Journal of Transplantation, 12*(2), 351-357. doi: 10.1111/j.1600-6143.2011.03865.x

Kutner, N. G., Zhang, R., Huang, Y., & Johansen, K. L. (2012). Impact of race on predialysis discussions and kidney transplant preemptive wait-listing. *American Journal of Nephrology, 35*(4), 305-311. doi: 10.1159/000336891

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), 669-674. doi: 10.1111/j.1600-6143.2009.02561.x

Leaf, D. E., & Goldfarb, D. S. (2009). Interpretation and review of health-related quality of life data in CKD patients receiving treatment for anemia. *Kidney International, 75*(1), 15-24. doi: 10.1038/ki.2008.414

Lockwood, M. B., Saunders, M. R., Lee, C. S., Becker, Y. T., Josephson, M. A., & Chon, W. J. (2013). Kidney transplant and the digital divide: Is information and communication technology a barrier or a bridge to transplant for African Americans? *Progress in Transplantation, 23*(4), 302-309. doi: 10.7182/pit2013869

Lockwood, M., Saunders, M., Josephson, M. A., Becker, Y. T., & Lee, C. (2015). Determinants of frequent Internet use in an urban kidney transplant population in the United States: characterizing the digital divide. *Prog Transplant*, *25*(1), 9-17. doi: 10.7182/pit2015957

Lopes, A. A., Bragg-Gresham, J. L., Goodkin, D. A., Fukuhara, S., Mapes, D. L., Young, E. W., . . . Port, F. K. (2007). Factors associated with health-related quality of life among hemodialysis patients in the DOPPS. *Quality of Life Research, 16*(4), 545-557. doi: 10.1007/s11136-006-9143-7

Lu, J. L., Kalantar-Zadeh, K., Ma, J. Z., Quarles, L. D., & Kovesdy, C. P. (2014). Association of body mass index with outcomes in patients with CKD. *Journal of the American Society of Nephrology*, *25*(9), 2088-2096. doi: 10.1681/asn.2013070754

Lunsford, S., Simpson, K., Chavin, K., et al. (2006). Racial Disparities in Living Donation: Is there a Lack of Willing Donors or an Excess of Medically Unsuitable Candidates? Clinical Transplantation. 82 (7), 876-881.

Lustria, M.L., Smith, S.A., & Hinnant, C.C.(2011). Exploring digital divides: An examination of eHeath technology use in health information seeking, communication and personal health information management. *Health Informatics Journal*. 17(3):224-243.

Maglakelidze, N., Pantsulaia, T., Tchokhonelidze, I., Managadze, L., & Chkhotua, A. (2011). Assessment of health-related quality of life in renal transplant recipients and dialysis patients. *Transplantation Proceedings, 43*(1), 376-379. doi: 10.1016/j.transproceed.2010.12.015

Mapes, D. L., Lopes, A. A., Satayathum, S., McCullough, K. P., Goodkin, D. A., Locatelli, F., . . . Port, F. K. (2003). Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney International*, *64*(1), 339-349. doi: 10.1046/j.1523-1755.2003.00072.x

Matas, A. J., Smith, J. M., Skeans, M. A., Thompson, B., Gustafson, S. K., Stewart, D. E., . . . Kasiske, B. L. (2015). OPTN/SRTR 2013 Annual Data Report: kidney. *American Journal of Transplantation, 15 Suppl 2*, 1-34. doi: 10.1111/ajt.13195

Mauch, Teri Jo, & Bratton, Susan L. (2014). Organ Transplantation and Donation: Why Minority Groups Need More Organs But Donate Less—It’s Complex!*. *Critical Care Medicine, 42*(6), 1546-1548

Mayberry, L.S., Kripalani, S., Rothman, R.L., & Osborn, C.Y. (2011). Bridging the digital divide in diabetes: Family support and implications for health literacy. *Diabetes Technology and Therapeutics*. 13(10), 1005-1012. Doi: 10.1089/dia.2011.0055.

McDonald, M. V., Pezzin, L. E., Peng, T. R., & Feldman, P. H. (2009). Understanding the complexity of hypertensive African American home care patients: challenges to intervention. *Ethnicity and Disease, 19*(2), 148-153.

Midtvedt, K., & Hartmann, A. (2002). Hypertension after kidney transplantation: are treatment guidelines emerging? *Nephrology, Dialysis, Transplantation, 17*(7), 1166-1169.

Merkus, M. P., Jager, K. J., Dekker, F. W., Boeschoten, E. W., Stevens, P., & Krediet, R. T. (1997). Quality of life in patients on chronic dialysis: self-assessment 3 months after the start of treatment. The Necosad Study Group. *American Journal of Kidney Diseases, 29*(4), 584-592.

Merkus, M. P., Jager, K. J., Dekker, F. W., de Haan, R. J., Boeschoten, E. W., & Krediet, R. T. (1999). Physical symptoms and quality of life in patients on chronic dialysis: results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). *Nephrology, Dialysis, Transplantation, 14*(5), 1163-1170.

Miller, B. W., Cress, C. L., Johnson, M. E., Nichols, D. H., & Schnitzler, M. A. (2002). Exercise during hemodialysis decreases the use of antihypertensive medications. *American Journal of Kidney Diseases, 39*(4), 828-833. doi: 10.1053/ajkd.2002.32004

Miller, E. & West, D. (2009). Where's the revolution? Digital technology and health care in the Internet age. Journal of Health Politics. Policies, and Law. 34(2), 261-284.

Miloh, T., Annunziato, R., Aaron, R., et al. (2009). Improved Adhereance and Outcomes for Pediatric Liver Transplant Recipients by Using Text Messaging. *Pediatrics*. 124(5); 843-850

Monson, R. S., Kemerley, P., Walczak, D., Benedetti, E., Oberholzer, J., & Danielson, K. K. (2015). Disparities in completion rates of the medical prerenal transplant evaluation by race or ethnicity and gender. *Transplantation, 99*(1), 236-242. doi: 10.1097/tp.0000000000000271

Moore, D.R., Feurer, I.D., Zavala, E.Y., Schaffer, D., Karp S., Hoy, H., & Moore, D.E. (2013). A web-based application for initial screening of living kidney donors: development, implementation and evaluation. *American Journal of Transplantation*. 13: 450-457.

Morgan, S. (2006). Many Facets of Reluctance: African Americans and the Decision (Not) to Donate Organs. Journal of The National Medical Association. 98 (50) 695-703.

Morrow, D., Clark, D., Tu, W., Wu, J., Weiner, M., Steinley, D., & Murray, M.D. (2006). Correlates of health literacy in patients with chronic heart failure. *The Gerontologist, 46*(5), 669-676

Myaskovsky, L., Almario Doebler, D., Posluszny, D. M., Dew, M. A., Unruh, M., Fried, L. F., . . . Shapiro, R. (2012). Perceived discrimination predicts longer time to be accepted for kidney transplant. *Transplantation*, *93*(4), 423-429. doi: 10.1097/TP.0b013e318241d0cd

National Institute of Diabetes and Digestive and Kidney Diseases. (2016). Chronic Kidney Disease and Kidney Failure. Retrieved on April 15, 2016 from: https://report.nih.gov/NIHfactsheets/ViewFactSheet.aspx?csid=34&key=C#C

National Kidney Foundation. (2016). Kidney disease. Retrieved on Arpil 24, 2016 from: https://www.kidney.org/kidneydisease

National Organ Transplant Act of 1984. (1984). Public Law. 98-507, 98 Stat. 2339-2348

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), 769-775. doi: 10.1111/j.1399-0012.2006.00568.x

Neter, E. & Brainin, E. (2012). Ehealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research*. 4(1), e49. Doi: 10.2196/jmir.1619.

Neuner, J., Fedders, M., Caravella, M., Bradford, L., & Schapira, M. (2015). Meaningful use and the patient portal: patient enrollment, use, and satisfaction with patient portals at a later-adopting center. *American Journal of Medical Quality, 30*(2), 105-113. doi: 10.1177/1062860614523488

Neyhart, C. (2008). Education of patient's pre and post-transplant: improving outcomes by overcoming the barriers. *Nephrology Nursing Journal*. 35(4): 409-410.

Ogutmen, B., Yildirim, A., Sever, M. S., Bozfakioglu, S., Ataman, R., Erek, E., . . . Emel, A. (2006). Health-related quality of life after kidney transplantation in comparison intermittent hemodialysis, peritoneal dialysis, and normal controls. *Transplantation Proceedings, 38*(2), 419-421. doi: 10.1016/j.transproceed.2006.01.016

Ohlstein, J. F., Brody-Camp, S., Friedman, S., Levy, J. M., Buell, J. F., & Friedlander, P. (2015). Initial Experience of a Patient Navigation Model for Head and Neck Cancer. *JAMA Otolaryngol Head Neck Surg, 141*(9), 804-809. doi: 10.1001/jamaoto.2015.1467

OPTN, (2011). Center data report. University of Chicago Medical Center: Transplants in the US by Recipient Ethnicity. Retrieved on August 1, 2012 from: http://optn.transplant.hrsa.gov/latestData/rptData.asp

OPTN. (2015). Center Data. Retrieved May 10, 2015, from http://optn.transplant.hrsa.gov/converge/latestData/step2.asp

OPTN (2016). Final Rule. Retrieved on May 31, 2016 from: https://optn.transplant.hrsa.gov/governance/about-the-optn/final-rule/

OPTN, (2011). National data report. Transplants in the US by recipient ethnicity (National). Retrieved on August 1, 2012 from: http://optn.transplant.hrsa.gov/latestData/rptData.asp

The Organization for Economic Co-operation and Development (OECD). Understanding the Digital Divide, Released January 1, 2001.retrived on April 1, 2014 from http://www.oecd-ilibrary.org/science-and-technology/understanding-the-digital-divide_236405667766. Doi: 10.1787/236405667766.

Parsa, A., Kao, W. H., Xie, D., Astor, B. C., Li, M., Hsu, C. Y., . . . Appel, L. J. (2013). APOL1 risk variants, race, and progression of chronic kidney disease. *New England Journal of Medicine, 369*(23), 2183-2196. doi: 10.1056/NEJMoa1310345

Parsons, T. L., Toffelmire, E. B., & King-VanVlack, C. E. (2004). The effect of an exercise program during hemodialysis on dialysis efficacy, blood pressure and quality of life in end-stage renal disease (ESRD) patients. *Clinical Nephrology, 61*(4), 261-274.

Patel, S. S., Shah, V. S., Peterson, R. A., & Kimmel, P. L. (2002). Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. *American Journal of Kidney Diseases, 40*(5), 1013-1022. doi: 10.1053/ajkd.2002.36336

Patrick, K., Griswold, W., Rash, F., Intile, S. (2008). Health and the Mobile Phone. *American Journal of Preventative Medicine*. 35(2): 177-181

Patzer, R. E., Perryman, J. P., Pastan, S., Amaral, S., Gazmararian, J. A., Klein, M., . . . McClellan, W. M. (2012). Impact of a patient education program on disparities in kidney transplant evaluation. *Clinical Journal of The American Society of Nephrology: CJASN, 7*(4), 648-655. doi: 10.2215/CJN.10071011

Patzer, R. E., Perryman, J. P., Schrager, J. D., Pastan, S., Amaral, S., Gazmararian, J. A., . . . McClellan, W. M. (2012b). The role of race and poverty on steps to kidney transplantation in the Southeastern United States. *American Journal of Transplantation, 12*(2), 358-368. doi: 10.1111/j.1600-6143.2011.03927.x

Pew Research Center's Internet and American Life 2000-2009. (2011). Retrieved on November 02, 2011 from: http://pewinternet.org/

Pinson, C. W., Feurer, I. D., Payne, J. L., Wise, P. E., Shockley, S., & Speroff, T. (2000). Health-related quality of life after different types of solid organ transplantation. *Annals of Surgery, 232*(4), 597-607.

Plaza, I., Martin, L., Martin, S., Medrano, C. (2011). Mobile Applications in an Aging Society: Status and Trends. *The Journal of Systems and Software*. 84: 1977-1988

Possemato, A.K. & Geller, P.A. (2007). Web resources for transplant candidates, recipients, and donors. *Progress in Transplantation*.17(2): 161-166.

Pruchno, R., Wilson-Genderson, M., & Cartwright, F. (2009). Self-rated health and depressive symptoms in patients with end-stage renal disease and their spouses: a longitudinal dyadic analysis of late-life marriages. *Journals of Gerontology. Series B: Psychological Sciences and Social Sciences, 64*(2), 212-221. doi: 10.1093/geronb/gbp006

Rayner, H. C., Zepel, L., Fuller, D. S., Morgenstern, H., Karaboyas, A., Culleton, B. F., . . . Robinson, B. M. (2014). Recovery time, quality of life, and mortality in hemodialysis patients: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Kidney Diseases, 64*(1), 86-94. doi: 10.1053/j.ajkd.2014.01.014

Rebollo, P., Ortega, F., Valdes, C., Fernandez-Vega, F., Ortega, T., Garcia-Mendoza, M., & Gomez, E. (2004). Influence of erectile dysfunction on health related quality of life of male kidney transplant patients. *International Journal of Impotence Research, 16*(3), 282-287. doi: 10.1038/sj.ijir.3901159

Reese, P., Shea, J., Bloom, R. (2009). Predictors of Having a Potential Live Donor: A Prospective Cohort Study of Kidney Transplant Candidates. American Journal of Transplantation. 9, 1-8.

Reeves-Daniel, A., Adams, P., Daniel, K., et al. (2009). Impact of Race and Gender on Live Kidney donation. Clinical Transplantation. 23, 39-46.

Reifsnider, E., Gallagher, M., & Forgione, B. (2005). Using ecological models in research on health disparities. *Journal of Professional Nursing, 21*(4), 216-222. doi: 10.1016/j.profnurs.2005.05.006

Rice, R. & Katz, J. (2003). Comparing Internet and Mobile Phone Usage: Digital Divides of Usage, Adoption, and Dropouts. *Telecommunications Policy*. 27(2003); 597-623

Rigo, D. H., Ziraldo, L., Di Monte, L., Jimenez, M. P., Giotto, A. P., Gutierrez, L., . . . Novoa, P. A. (2011). Preemptive kidney transplantation: experience in two centers. *Transplantation Proceedings, 43*(9), 3355-3358. doi: 10.1016/j.transproceed.2011.09.083

Rizk, C. S., & Singh, S. N. (2012). Implications of the Affordable Care Act for kidney transplantation. *Virtual Mentor, 14*(3), 250-255. doi: 10.1001/virtualmentor.2012.14.3.pfor3-1203

Roark, D. (1999). The need for Increasing Organ donation among African Americans and Hispanic Americans: An Overview. Journal of emergency Nursing. February 1999, 21-27.

Robinson, D., Borba, C., Thompson, N., Perryman, J., Arriola, K. (2009). Correlates of Support for Living Donation among African American Adults. Progress in Transplantation. 19 (3), 244-251.

Robinson, T. (2008). Applying the socio-ecological model to improving fruit and vegetable intake among low-income African Americans. *Journal of Community Health, 33*(6), 395-406. doi: 10.1007/s10900-008-9109-5

Rodday, A. M., Parsons, S. K., Snyder, F., Simon, M. A., Llanos, A. A., Warren-Mears, V., . . . Freund, K. M. (2015). Impact of patient navigation in eliminating economic disparities in cancer care. *Cancer*. doi: 10.1002/cncr.29612

Russell, Emily, Robinson, Dana HZ, Thompson, Nancy J, Perryman, Jennie P, & Arriola, Kimberly R Jacob. (2012). Distrust in the healthcare system and organ donation intentions among African Americans. *Journal of Community Health, 37*(1), 40-47

Sakhuja, A., Naik, A., Amer, H., Cibrik, D., Eikstadt, R., Schold, J. D., & Stegall, M. D. (2016). Underutilization of Timely Kidney Transplants in Those With Living Donors. *American Journal of Transplantation, 16*(3), 1007-1014. doi: 10.1111/ajt.13592

Saunders, M. R., Lee, H., Alexander, G. C., Tak, H. J., Thistlethwaite, J. R., Jr., & Ross, L. F. (2015). Racial disparities in reaching the renal transplant waitlist: is geography as important as race? *Clinical Transplantation 29*(6), 531-538. doi: 10.1111/ctr.12547

Sarkar, U., Karter, A. J., Liu, J. Y., Adler, N. E., Nguyen, R., Lopez, A., & Schillinger, D. (2011). Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association, 18*(3), 318-321. doi: 10.1136/jamia.2010.006015

Sawant, A., House, A. A., & Overend, T. J. (2014). Anabolic Effect of Exercise Training in People with End-Stage Renal Disease on Hemodialysis: A Systematic Review with Meta-analysis. *Physiotherapy Canada, 66*(1), 44-53. doi: 10.3138/ptc.2012-59

Schold, J. D., Gregg, J. A., Harman, J. S., Hall, A. G., Patton, P. R., & Meier-Kriesche, H. U. (2011). Barriers to evaluation and wait listing for kidney transplantation. *Clinical Journal of The American Society of Nephrology: CJASN, 6*(7), 1760-1767. doi: 10.2215/CJN.08620910

Segelnick, S. L., & Weinberg, M. A. (2009). The periodontist's role in obtaining clearance prior to patients undergoing a kidney transplant. *Journal of Periodontology, 80*(6), 874-877. doi: 10.1902/jop.2009.080515

Shaqman, M., Ioannidou, E., Burleson, J., Hull, D., & Dongari-Bagtzoglou, A. (2010). Periodontitis and inflammatory markers in transplant recipients. *Journal of Periodontology, 81*(5), 666-672. doi: 10.1902/jop.2010.090570

Slakey, D., & Nowfar, S. (2013). Internet use by a multidisciplinary transplant clinic population. *Transplantation*. 75(1): 155-157.

Smith, S. G., O'Conor, R., Aitken, W., Curtis, L. M., Wolf, M. S., & Goel, M. S. (2015). Disparities in registration and use of an online patient portal among older adults: findings from the LitCog cohort. *Journal of the American Medical Informatics Association, 22*(4), 888-895. doi: 10.1093/jamia/ocv025

Stojanova, J., Caillard, S., Rousseau, A., & Marquet, P. (2011). Post-transplant lymphoproliferative disease (PTLD): Pharmacological, virological and other determinants. *Pharmacological Research, 63*(1), 1-7. doi: 10.1016/j.phrs.2010.10.016

Stolzmann, K. L., Bautista, L. E., Gangnon, R. E., McElroy, J. A., Becker, B. N., & Remington, P. L. (2007). Trends in kidney transplantation rates and disparities. *Journal of the National Medical Association, 99*(8), 923-932.

Stepnowski, C., Palau, J., Marler, BA., Gifford, A. (2007). Pilot Randomized Trial of the Effect of Wireless Tele-Monitoring on Compliance and Treatment Efficacy in Obstructive Sleep Apnea. *Journal of Medical Internet Research*. 9(2): 1-15

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: CJASN, 7*(10), 1639-1645. doi: 10.2215/CJN.11731111

Sun, G. (2012). The digital divide in Internet-based patient education materials. *Otolaryngology-Head and Neck Surgery*. 147(5), 855-857. Doi: 10.1177/0194599812456153.

Swendeman, D., Rotheram-Borus, MJ. (2010). Innovation in Sexually Transmitted Disease and HIV Prevention: Internet and Mobile Phone Delivery Vehicles for Global Diffusion. *Current Opinion in Psychiatry*. 23: 139-144

Taha, J., Sharit, J., & Czaja, S. J. (2014). The impact of numeracy ability and technology skills on older adults' performance of health management tasks using a patient portal. *Journal of Applied Gerontology, 33*(4), 416-436. doi: 10.1177/0733464812447283

Takhreem, M. (2008). The effectiveness of intradialytic exercise prescription on quality of life in patients with chronic kidney disease. *Medscape Journal of Medicine, 10*(10), 226.

Tedla, F. M., Brar, A., Browne, R., & Brown, C. (2011). Hypertension in chronic kidney disease: navigating the evidence. *International Journal of Hypertension, 2011*, 132405. doi: 10.4061/2011/132405

Therrien, A., Giard, J. M., Hebert, M. J., & Bouin, M. (2014). Importance of pre-transplant colonoscopy in renal transplant recipients. *Journal of Clinical Medicine Research, 6*(6), 414-421. doi: 10.14740/jocmr1934w

Tonelli, M., Klarenbach, S., Rose, C., Wiebe, N., & Gill, J. (2009). Access to kidney transplantation among remote-and rural-dwelling patients with kidney failure in the United States. *JAMA, 301*(16), 1681-1690. doi: 10.1001/jama.2009.545

Trisolini, M., Roussel, A., Zerhusen, E., Schatell, D., Harris, S., Bandel, K., … Klicko, K. (2004). Activating chronic kidney disease patients and family members through the Internet to promote integration of care. *International Journal of Integrated Care, 4,* e17.

Turk, S., Guney, I., Altintepe, L., Tonbul, Z., Yildiz, A., & Yeksan, M. (2004). Quality of life in male hemodialysis patients. Role of erectile dysfunction. *Nephron: Clinical Practice, 96*(1), c21-27. doi: 10.1159/000075568

United States. (1978). *The Belmont report: Ethical principles and guidelines for the protection of human subjects of research*. Bethesda, Md.: The Commission.

U.S. Department of Commerce, National Telecommunications and Information Administration (NTIA). 1995. Falling through the net: A survey of the "have nots" in rural and urban America. Retrieved from http://www.ntia.doc.gov/ntiahome/fallingthru.html

U.S. Department of Health and Human Services, Office of Minority Health. (2016). Minority Health. Retrieved on May 1, 2016 from: https://www.unos.org/data/

United Network of Organ Sharing. (2016). Data. Retrieved on May 1, 2016 from: https://www.unos.org/data/

United States Renal Data System. (2016a). 2014 Annual Data Report. Retrieved May 10, 2015 http://www.usrds.org/adr.aspx

United States Renal Data Sytem (2016b). Incidence, Previlance, patient characteristics, and treatment modalities. Retrived on January 5. 2016 from: http://www.usrds.org/2014/view/v2_01.aspx

United States Renal Data System (2016c). Mortality. Retrived on Aprol 3. 2016 from: http://www.usrds.org/2012/view/v2_05.aspx

Unruh, M., Benz, R., Greene, T., Yan, G., Beddhu, S., DeVita, M., . . . Meyer, K. B. (2004). Effects of hemodialysis dose and membrane flux on health-related quality of life in the HEMO Study. *Kidney International, 66*(1), 355-366. doi: 10.1111/j.1523-1755.2004.00738.x

Valderrabano, F., Jofre, R., & Lopez-Gomez, J. M. (2001). Quality of life in end-stage renal disease patients. *American Journal of Kidney Diseases, 38*(3), 443-464.

Vamos, Eszter Panna, Novak, Marta, & Mucsi, Istvan. (2009). Non-medical factors influencing access to renal transplantation. *International Urology and Nephrology, 41*(3), 607-616.

Van Deursen, A.J., & Van Dijk, J.A. (2011). Internet skills and performance tests: are people ready for eHealth? *Journal of Medical Internet Research*. 12(2) e35. Doi: 10.2196/jmir.1581.

Walters, B. A., Hays, R. D., Spritzer, K. L., Fridman, M., & Carter, W. B. (2002). Health-related quality of life, depressive symptoms, anemia, and malnutrition at hemodialysis initiation. *American Journal of Kidney Diseases*, *40*(6), 1185-1194. doi: 10.1053/ajkd.2002.36879

Wang, J.Y. Bennet, K., & Probst, J. (2011). Subdividing the digital divide: differences in Internet access and use among rural residents with medical limitations. *Journal of Medical Internet Research*.13(1), e25. Doi: 10.2196/jmir.1534.

Waterman, A. D., Peipert, J. D., Hyland, S. S., McCabe, M. S., Schenk, E. A., & Liu, J. (2013). Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant. *Clinical Journal of the American Society of Nephrology 8*(6), 995-1002. doi: 10.2215/CJN.08880812

Waterman, A. D., Robbins, M. L., Paiva, A. L., & Hyland, S. S. (2010). Kidney patients' intention to receive a deceased donor transplant development of stage of change, decisional balance and self-efficacy measures. *Journal of Health Psychology, 15*(3), 436-445. doi: 10.1177/1359105309351248

Weinberg, M. A., Segelnick, S. L., Kay, L. B., & Nair, V. (2013). Medical and dental standardization for solid organ transplant recipients. *New York State Dental Journal, 79*(6), 35-40.

Weng, F. L., Brown, D. R., Peipert, J. D., Holland, B., & Waterman, A. D. (2013). Protocol of a cluster randomized trial of an educational intervention to increase knowledge of living donor kidney transplant among potential transplant candidates. *BMC Nephrology, 14*, 256. doi: 10.1186/1471-2369-14-256

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), 734-745. doi:10.1053/j.ajkd.2005.06.011

Wilczynska-Borawska, M., Baginska, J., & Malyszko, J. (2010). Dental problems in a potential kidney transplant recipient: case report and literature review. *Annales Academiae Medicae Stetinensis, 56*(2), 51-54.

Wong, Germaine, Howard, Kirsten, Chapman, Jeremy R, Chadban, Steven, Cross, Nicholas, Tong, Allison, . . . Craig, Jonathan C. (2012). Comparative survival and economic benefits of deceased donor kidney transplantation and dialysis in people with varying ages and co-morbidities. *PloS One, 7*(1), e29591

Wootton, R., Bahaadinbeigy, K., & Hailey, D. (2011). Estimating travel reduction associated with the use of telemedicine by patients and healthcare professionals: proposal for quantitative synthesis in a systematic review. *BMC Health Services Research, 11*, 185. doi: 10.1186/1472-6963-11-185

Wyld, M., Morton, R. L., Hayen, A., Howard, K., & Webster, A. C. (2012). A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. *PLoS Medicine, 9*(9), e1001307. doi: 10.1371/journal.pmed.1001307

Yen, E. F., Hardinger, K., Brennan, D. C., Woodward, R. S., Desai, N. M., Crippin, J. S., . . . Schnitzler, M. A. (2004). Cost- effectiveness of extending Medicare coverage of immunosuppressive medications to the life of a kidney transplant. *American Journal of Transplantation, 4*(10), 1703-1708. doi: 10.1111/j.1600-6143.2004.00565.x

Yoo, S. W., Kwon, O. J., & Kang, C. M. (2009). Preemptive living-donor renal transplantation: outcome and clinical advantages. *Transplantation Proceedings, 41*(1), 117-120. doi: 10.1016/j.transproceed.2008.09.063

Young, C. J., & Gaston, R. S. (2002). African Americans and renal transplantation: disproportionate need, limited access, and impaired outcomes. *American Journal of the Medical Sciences*, *323*(2), 94-99.

Zach, L., Dalrymple, P.W., Rogers, M., & Williver-Farr, H. (2011). Assessing Internet access and use in a medically underserved population: implications for providing enhanced health information services. *Health Information and Libraries Journal*. 29, 61-71. Doi:10.1111/j.1471-1842.2011.00971.x.

Zickuhr, K. (2013). Who's not online and why. Released September 25, 2013. Retrieved on April 1, 2014 from http://www.pewinternet.org/2013/09/25/whos-not-online-and-why/.