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Identifying Potential Predictors of Health Literacy and Steps Taken to Pursue Kidney Transplant Among African-Americans on Dialysis

Stacy Skelton
slskelton@charter.net

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Identifying Potential Predictors of Health Literacy and Steps Taken to Pursue Kidney Transplant Among African-Americans on Dialysis

Stacy L. Skelton
MSN, Nursing Education, University of Missouri-St. Louis, 2002
BSN, Nursing, Barnes College St. Louis Missouri 1993

A Dissertation Submitted to The Graduate School at the University of Missouri-St. Louis in partial fulfillment of the requirements for the degree Doctor of Philosophy in Nursing

May 2019

Advisory Committee

Dr. Kuei-Hsiang Hsueh
Chairperson

Dr. Anne F. Fish

Dr. Wilma Calvert

Dr. Rick Zimmerman
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## Table of Contents

*Chapter 1 Introduction*  
Abstract ................................................................................................................................. 4  
Introduction ............................................................................................................................. 6  
Aims & Research Questions .................................................................................................... 10  
Overview of the 3 manuscripts ............................................................................................... 10  

*Chapter 2 First manuscript*  
Abstract ................................................................................................................................. 15  
Introduction ............................................................................................................................. 16  
Literature Review .................................................................................................................... 17  
Conclusion ................................................................................................................................. 32  
References (Manuscript One) ................................................................................................. 35  

*Chapter 3 Second manuscript*  
Abstract ................................................................................................................................. 45  
Introduction ............................................................................................................................. 46  
Methods .................................................................................................................................. 47  
Results ..................................................................................................................................... 49  
Discussion ................................................................................................................................ 61  
Conclusion .................................................................................................................................. 63  
References (Manuscript Two) ................................................................................................. 65  

*Chapter 4 Third manuscript*  
Abstract ................................................................................................................................. 71  
Introduction ............................................................................................................................. 73  
Conceptual Framework ............................................................................................................ 75  
Methods .................................................................................................................................. 79  
Results ..................................................................................................................................... 82  
Discussion ................................................................................................................................ 90  
Conclusion .................................................................................................................................. 95  
References (Manuscript Three) ............................................................................................... 96  

*Chapter 5 Summary*  
Implications .............................................................................................................................. 109  
Conclusion .................................................................................................................................. 110
Chapter 1 Introduction

Abstract
This dissertation attempts to address the disparity seen in all transplant centers today, the low number of African-American end-stage renal disease (ESRD) patients pursuing kidney transplant as renal replacement therapy. Currently, there are two renal replacement options, dialysis or a kidney transplant. Research has shown that kidney transplant provides the best health care outcomes in terms of quality of life and decrease mortality. While African-Americans carry the burden of the disease by being four times more likely to have ESRD they only represent 1/3 of the kidney transplants done in the United States. There have been three attempts to increase access to kidney transplant for all minorities, including African-Americans. The first was in 2005 by The Centers for Medicare and Medicaid Services, mandating all patients be informed of their transplant options within 45 days of initiating dialysis. The second was in 2010 requiring the use of clear communication through the Plain Writing Act. The third change was in 2014 by changing point allocation for patients listed for a deceased donor kidney, by giving harder to match patients, points for their length of time being on the transplant waitlist. Yet, African-Americans transplant rates remain low. Many studies have focused on barriers to transplant, for example, transplant knowledge, with significant results but effects are not large compared to standard education. This dissertation attempts to address this gap by broadly reviewing the evidence of best practices in designing educational material, examining the educational preparation interventions for kidney transplant, and identify any associations and predictors of personal factors and health literacy.
skills in African-Americans pursuing kidney transplant, all to aid in reducing this disparity.

*Keywords*: Blacks, African-Americans, end-stage renal disease, kidney transplant, education, health literacy
Identifying Potential Predictors of Health Literacy and Steps Taken to Pursue Kidney Transplant among African-Americans on Dialysis

Introduction

There is a disparity in the number of African-Americans pursuing kidney transplant – a widely recognized effective therapy in reducing mortality and morbidity for patients with ESRD (Waterman, & Peipert, 2018). African-Americans have almost four times higher rate of ESRD (ESRD), yet the rate for kidney transplant is less than 30%. Kidney transplant has been shown to be the gold standard of renal replacement therapies, related to improve quality of life, and decrease mortality and morbidity (Boulware et al., 2011, Lockwood, Bidwell, Werner, & Lee 2016, Waterman et al., 2018). Additionally, ESRD care is costly. In 2016 over $35 billion was spent on ESRD care, accounting for 7% of Medicare claims (USRDA, 2016). Comparing costs of dialysis to kidney transplant, dialysis is more expensive, costing $28 billion per year versus $3.4 billion for kidney transplant (USRDA, 2016).

Research has shown that a lack of knowledge is a barrier to transplant for African-Americans living with ESRD pursuing kidney transplant (Boulware et al., 2011, Lockwood et al., 2016, Waterman, & Peipert, 2018). To help improve access the Centers for Medicare and Medicaid services (CMS) mandated all patients to be informed of kidney transplant as an option to renal replacement therapy with 45 days of initiation dialysis in order to be paid for dialysis care provided to Medicare and Medicaid recipients (Hall, et al., 2012, Waterman, Peipert, Goalby, Dinkel, Ziao, & Lentine, 2015). Another government mandate
that hoped to improve access to care, including kidney transplant was the Plain Language Act of 2010 ("plain language", n.d). This act is to improve access by ensuring patient educational materials were easy to read, and understand by eliminating irrelevant information, and including pictures where applicable. However, even with these two mandates the rates of kidney transplant in African-Americans remain low (Hall et al., 2012; Waterman et al. 2015). The next change was made in 2014 by the United Network for Organ Sharing. A new point allocation system was adopted to aid in reducing the disparity seen in minorities waiting for kidney transplant, by giving points for time on dialysis prior to initiating the evaluation. Patients must still complete the evaluation and be approved for a kidney transplant; however, they will be waitlist with points award for time on dialysis. While this improved access to kidney transplant and the rate of African-Americans receiving a kidney transplant (Massie et al., 2016), overall the rate remains low when compared to the burden of disease on the African-American population.

The research has shown there are at least two categories for barriers related to kidney transplant, health care provider barriers and patient related barriers, this dissertation will focus on patient related barriers. Patient related barriers include worry about the costs, issues with transportation, lack of medical trust, and a lack of transplant benefits, fear of the surgery, and complexity of the evaluation process (Lockwood et al., 2016; Waterman et al. 2018). These barriers may delay and even prevent a patient from pursuing kidney transplant as treatment option.
The purpose of this dissertation work, as reflected in the following three manuscripts, was to address the low rates of kidney transplant in African-Americans by broadly reviewing the evidence of best of practices in designing educational material, examining the educational preparation interventions for kidney transplant, and identifying any associations and predictors of personal factors and health literacy skills in African-Americans pursuing kidney transplant, all to aid in reducing this disparity.

**Scientific Underpinnings**

The instances of newly reported ESRD cases continues to rise by approximately 20,000 cases annually in the United States (USRDS, 2016). In 2015, 124,111 new cases were reported, bringing the total number of people living with ESRD on either dialysis or living with a kidney transplant to over 700,000. When looking at the demographics of patients living with ESRD, African Americans account for 35% of the patients living with ESRD in United States (USRDS, 2016).

Research has shown that kidney transplant is the optimal treatment for ESRD and displays better patient outcomes such as higher quality of life, and lower mortality and morbidity rates (Harding et al., 2017; Waterman, 2015). The mortality rates for dialysis patients are two to three times higher for dialysis than that for transplant patients (USRDS, 2016); three-year survival rates for kidney transplant recipients are as high as 87% versus 54% for those on dialysis.

There is a considerable amount of literature devoted to investigating barriers related to this health disparity in kidney transplantation among African-
Americans (Betancourt et al., 2014; Harding et al., 2017). Common barriers that prevent to access kidney transplantation among African-Americans include lower socioeconomic status (SES) (Monson et al., 2015), limited access to transplant education (Waterman, Peipert, Hyland, McCabe, Schenk, & Liu, 2013), issues with reliable transportation for evaluation (Chenitz, Fernando, & Shea, 2014), concerns over cost (Hardinger, Hutcherson, Preston, & Murillo, 2012), lack of psychological and emotional support, medical mistrust (LaVeist, Isaac, & Williams, 2009; Doescher, Saver, Franks, & Fiscella 2000; LaVeist, Nickerson, & Bowie, 2000), and limited health literacy (Grubbs, Gregorich, Perez-Stable, & Hsu, 2009).

Substantial evidence indicates that limited health literacy is common in patients living with ESRD (Green & Cavanaugh, 2013, Jain & Green, 2016). Those patients with limited health literacy may see the length of the transplant evaluation form (health-related questionnaires and educational materials) as a barrier to transplantation. Adequate health literacy is needed for persons living with ESRD to comprehend information, effectively self-manage their disease process, function in the healthcare setting, and act on information provided to make an informed decision (Green & Cavanaugh, 2015; Jain & Green, 2016). Studies have identified demographics to be mediators of health literacy; however, there is a lack of consensus on which demographics are strongest predictors. A study by Marks, Schectman, Groninger, and Plews-Ogan (2010) found that age, sex, and education combined could provide another method to infer limited health literacy that is as effective as utilizing reliable and valid health literacy
instruments. Another study found that patients older than 65 and did not complete high school had greater difficulty identifying prescription medication and had an increased rate of limited health literacy (Kripalani et al., 2006). A review of the literature found that relatively few studies on ESRD focused on what the predictors of limited health literacy are and how limited health literacy affects dialysis patients pursuing transplant.

Aims & Research Questions

The overall aim of this dissertation work was to examine the best evidence for designing education materials and identify effective educational interventions shown to be effective in African-Americans on dialysis to improve rates of pursuing kidney transplant (in the two reviews) and study the associations and predictors of health literacy skills among low-income African-Americans living with ESRD. The dissertation work consisted of two integrative reviews and one research study. Three manuscripts were included as dissertation chapters two, three, and four, respectively. The three manuscripts completed for this dissertation were to address the overarching research question: What are the predictors of health literacy and the individualized needs of African-Americans on dialysis to pursue transplant. Table 1 presents the specific aim and research question for each manuscript.

Overview of the 3 manuscripts

The first integrative review was conducted through database searches in MEDLINE, Cumulative Index of Nursing and Allied Health Literature, PsycINFO, and Academic Comprehensive results from the first integrative review
are presented in the manuscript that is inserted for chapter two. In summary, multiple studies in chronic disease have shown that the best educational intervention should be individually tailored, understandable for patients with limited health literacy, and culturally sensitive. Additionally, some studies have shown that health literacy and navigational skills are not assessed.

Table 1.

Aims and Research Questions

<table>
<thead>
<tr>
<th>Specific Aim</th>
<th>Research Question</th>
<th>Manuscript</th>
</tr>
</thead>
<tbody>
<tr>
<td>An integrative review was conducted to identify the best practices in designing patient education.</td>
<td>What are the best educational interventions, from the broader literature that can be applied to patients with ESRD to aid in pursuit of kidney transplant?</td>
<td>One (Chapter Two) Progress to Transplantation</td>
</tr>
<tr>
<td>An integrative review was conducted to explore the effectiveness of educational trials in facilitating progress to kidney transplant in African-Americans.</td>
<td>What are the most significantly effective educational interventions that help African-Americans on dialysis to overcome the barriers to kidney Transplant</td>
<td>Two (Chapter Three) Progress to Transplantation</td>
</tr>
<tr>
<td>A secondary analysis of baseline data was conducted to identify potential predictors of general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation in low-income African-Americans living with ESRD on dialysis</td>
<td>What is the association of factors (age, sex, educational attainment, number of health insurance policies, neighborhood safety, social support, and medical trust) and preparation for kidney (general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation)?</td>
<td>Three (Chapter Four) Archives of Transplantation</td>
</tr>
</tbody>
</table>

The second integrative review was conducted through database searches in CINAHL, Medline, and PubMed using were black, black-American or African-American patients, dialysis or kidney transplant, and education. The literature search included the years 2006-2019. Results from the second integrative review were presented in the manuscript that was inserted for chapter three. In summary, studies with samples of 100% African American and four with samples
at least 51% African-American have shown that there are at least five important aspects of educational preparation that emerged from the literature review were transplant readiness, transplant knowledge, willingness to communicate about transplant, benefits and concerns, and family involvement and support. While the results are low in number, they are significant. Refining educational practices and interventions may help in reducing the transplant disparity that exists in all transplant centers.

The dissertation research project used a data driven approach to conduct a secondary analysis of data obtained from "Explore Transplant at Home" (ETH) project developed and implemented by Dr. Amy Waterman. The ETH project was funded by the Human Resources and Services Administration (4R39OT26843-01-02) and the UCLA Clinical and Translational Science Institute grant (UL1TR000124).

Overall, 25.6% of the participants had limited health literacy. Results of the multiple regression analysis indicated that sex ($\beta=.10$), education attainment ($\beta=.20$), and neighborhood safety ($\beta=.21$) predicted general health literacy. Age($=-.18$), educational attainment ($\beta=.17$), and the number of health insurance policies ($\beta=.13$ predicted making efforts to learn educations materials. Age ($\beta=-.16$) and educational attainment ($\beta=.19$) predicted taking steps to pursue transplant.
Chapter 2 First manuscript

Chapter Two is the first of three manuscripts. Applying best practices to designing patient education for patient with end-stage renal disease pursuing kidney transplant. The manuscript was submitted April 2014 to Progress in Transplantation and was accepted in May 25, 2014.

Applying best practices to designing patient education for patients with end-stage renal disease pursuing kidney transplant.

List of Authors

Stacy L Skelton PhDc, RN, Amy D. Waterman PhD, LaShara A. Davis PhD, John D. Peipert MA, Anne F. Fish PhD, RN

Authors’ Affiliations:
University of Missouri, St. Louis, Missouri student (SLS), David Geffen School of Medicine at UCLA Los Angeles, California (ADW, JDP), Saint Barnabas Medical Center, Livingston, New Jersey (LAD), University of Missouri, St. Louis, Missouri (AFF)

The authors declare no conflict of interest.
Abstract
Despite the known benefits of kidney transplant, less than 30% of the 614,000 patients living with end-stage renal disease (ESRD) in the United States have received a transplant. More than 100,000 people are presently on the transplant waiting list. Although the shortage of kidneys for transplant remains a critical factor in explaining lower transplant rates, another important and modifiable factor is patient’s lack of comprehensive education about transplant. The purpose of this article is to provide an overview of known best practices from the broader literature that can be used as an evidence base to design improved education for ESRD patients pursuing a kidney transplant. Best practices in chronic disease education generally reveal that education that is individually tailored, understandable for patients with low health literacy, and culturally complete is most beneficial. Effective education helps patients navigate the complex health care process successfully. Recommendations for how to incorporate these best practices into transplant education design are described. Providing more ESRD patients with transplant education that encompasses these best practices may improve their ability to make informed health care decisions and increase the numbers of patient interested in pursuing transplant.

Keywords: kidney transplant, pretransplant education, end-stage renal disease treatment options, patient education, tailored education, low health literacy, cultural competence, and patient navigation.
Introduction

Kidney transplantation is one of the treatment options for end-stage renal disease (ESRD) patients needing renal replacement therapy (RRT). Compared to remaining on dialysis or receiving no therapy, kidney transplantation is associated with decreased mortality and morbidity from ESRD\(^1\) and enhanced quality of life.\(^2\) Despite these benefits, less than 30% of the 615,000 patients living with ESRD in the United States have received a transplant,\(^1\) and over 100,000 people are presently on the transplant waiting list (OPTN data as of 3/28/2014).\(^1\) Patients newly diagnosed with ESRD have very little time to decide which RRT they want to pursue, and they often do not receive sufficient information to make an informed decision.\(^3\) While the United States government mandates that all ESRD patients receive education about kidney transplant,\(^4\) current research suggests that at least 30% of them are uninformed about this option.\(^5\) Further, research has shown that health care providers are often unable to educate patients about transplant due to their own lack of knowledge or time constraints.\(^6\)

Recently emerging studies indicate that high quality transplant education may improve ESRD patients’ access to transplant\(^7\)–\(^9\) and even increase transplantation rates.\(^10\)–\(^12\) Yet, there is presently no consensus on the most effective ways to educate patients about transplant. In order to further this research direction, a clear understanding of “best practices” for transplant education is required. Best practices for education are defined as “practices which lead to superior performance, achieving consistent quality in what is
To meet the requirements of best practice, transplant education needs to be clear, comprehensive, understandable, and motivating to facilitate patients successfully completing the clinical steps necessary to be evaluated for transplant. After a comprehensive literature review, relatively few research studies were found that specifically define best practices in education specifically for ESRD patients. Thus, the narrative review was expanded to identify best practices in the broader literature including strategies and key recommendations that can be directly applied to designing education for ESRD patients pursuing kidney transplantation.

A comprehensive review of the CINAHL and PubMed electronic databases was completed. Keywords included kidney transplant, pre-transplant education, end-stage renal disease treatment options, patient education, tailored education, low health literacy, cultural competence, and patient navigation. This narrative review of literature includes research and expert opinion from the social work, psychology, health education, and nursing literature. A limitation of this review is that it excludes literature on the educational needs and recommendations for the post-transplant patient.

**Literature Review**

From this review and synthesis of the broader literature, four strategies emerged as best practices for education for ESRD patients pursuing transplant - designing education that is: 1) individually tailored; 2) understandable for patients with low health literacy; 3) culturally competent; and 4) helpful in showing patients how to navigate the complex health care process. For each strategy, a review of the broader literature, the benefits of the strategy in general and for
ESRD patients pursuing transplant specifically are discussed. Table 1 presents a summary of the strategies and key recommendations for best practices in education that can be translated to the education of ESRD patients pursuing transplant.

Individually Tailored Education

One educational strategy that has been shown to be effective is individually tailoring materials based on patients’ specific knowledge levels, fears, or barriers regarding the desired behavior.\textsuperscript{14,15} According to Kreuter and Skinner, tailoring is “any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment”.\textsuperscript{16(p5)} To tailor educational efforts effectively, time must be taken to actively listen to the obstacles the patient is facing and to assess the patient’s preferred learning styles. Key recommendations for tailoring education for individual patients are presented in Table 1.

\textbf{A review of the broader literature.}

A meta-analysis of 57 print interventions for health behavior change found that, across all studies, interventions with tailored health messages had a small, but significantly greater effect on health behaviors than non-tailored health messages (sample-size weighted effect size $r = 0.074$, 95% confidence interval: 0.066-0.082).\textsuperscript{17} This meta-analysis included interventions in physical inactivity, diet, and tobacco use. Compared to letters, manuals, and booklets, the types of tailoring materials that resulted in the greatest impact on health behavior change
were pamphlets, brochures, and newsletters.\textsuperscript{17} This effect could be related to the information in pamphlets, brochures and newsletters being presented in smaller easy to read amounts. Giving smaller amounts of information plus increasing the number of sessions was shown to have a greater effect on behavior change compared with other strategies.\textsuperscript{17} Tailored materials can be provided in many different learning formats, for example, through face-to-face, written, or video presentations, allowing for the material to be presented in the patient’s preferred learning style. The use of pictures and graphics and overall attractiveness keeps the reader’s attention, helping them retain information. While tailored materials require more time in preparation, evolving technology provides greater ease and flexibility in creating and changing education materials to fit the unique characteristics of the population being seen in the clinic setting.\textsuperscript{15}

\textit{Overall benefits of tailored education.} Tailoring education to the unique needs of an individual has been shown to be more effective than using a standardized one-size-fits-all educational approach.\textsuperscript{15} The benefits of tailoring seem to result from the patient’s ability to better identify with the material, which increases thoughtful consideration, self-reflection, and self-assessment, thereby improving the patient’s intent.\textsuperscript{15} Compared to a standard message condition, Campbell et al. found that patients, receiving the messages tailored to their level of readiness to change, were twice as likely to remember receiving the message, to read the information, and to make a significant change in health promoting behaviors such as improving nutrition.\textsuperscript{14} Another important benefit of tailored education is an increase in the patient’s self-confidence.\textsuperscript{14} For example, one
study found that including personalized feedback materials in a smoking cessation program improved self-confidence in quitting at twice the rate of groups receiving standard care. When the patient’s name is printed on the pamphlets, the patient is more likely to read the materials, view the materials as being unique and specific to his/her situation, and reflect on the benefits of applying the information provided. Through tailoring, understanding of the materials is increased.

*Potential benefits of tailored education for ESRD patients pursuing transplant.* There is a large amount of complex educational content given to patients pursuing transplant that must be learned by the patient including information about surgical risks and benefits, a complex medication regimen, and details of follow-up care. Transplant education tailored to the patients’ disease stage, level of readiness to get a transplant, or life circumstances may more successfully assist ESRD patients in making an informed decision about their treatment. One study compared the implementation of a home-based kidney transplant education program to standard education at a transplant center. This study used a roundtable discussion that encouraged the patient and support persons to ask questions tailored to their unique life circumstances. In this study, discussion of and knowledge about living donor kidney transplant increased and the patients’ concerns about transplant decreased significantly ($p < 0.0001$). Tailored programs with small amounts of education provided in different sessions may particularly help improve the education of ESRD patients who are living with mental fatigue and cloudiness that are associated with higher serum creatinine
levels. Explore Transplant, a transplant education program based on the Transtheoretical Model of Behavior Change, was designed to provide information to patients tailored to their level of readiness to get a transplant. Explore Transplant was found to increase dialysis patients' knowledge of transplant, positive attitudes towards transplant, and calling a transplant center to begin transplant evaluation. More research is needed to determine the type of tailored strategies and the number of sessions that are most effective in this specific population.

Understandable Education for Patients with Low Health Literacy

The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Health literacy entails more than a patient being able to read written instructions; it requires the ability to comprehend and apply the information ascertained. In 2003, the United States Department of Education conducted the National Assessment of Adult Literacy (NAAL), which measured the health literacy of English speaking adults ages 16 and older living in the United States. According to this survey, only 12% of adults have sufficient health literacy. According to the American Medical Association, “poor health literacy is a stronger predictor of a person’s health than age, income, employment status, education level, and race.” Patients with low health literacy are often not able to understand and follow their health provider’s care instructions appropriately, especially given the time constraint providers have to spend in discussion with any one patient,
stressing the need for simple, easy-to-understand health education. Key recommendations for providing education for patients with low health literacy are presented in Table 1.

**A review of the broader literature.** Populations at highest risk for low health literacy are older adults, immigrants, minorities, and low-income individuals. A systematic review of health literacy research conducted by the Agency for Health Care Research and Quality (AHRQ) found that lower health literacy is associated with increased use of the emergency department, increased number of hospitalizations, and less use of preventive screenings like mammography. In addition, those with low health literacy often have poorer control of their disease process. The literature illustrates many recommendations for the design of educational interventions to improve or accommodate low health literacy. Those interventions include creative approaches to communication such as designing brochures with large font including easy-to-understand pictures or graphs, developing culturally competent video materials, presenting only information that will directly help patients with their immediate problem while eliminating background information, and writing materials at a sixth-seventh grade reading level. Another strategy is to infuse the patient into the message by using active voice and pictures of people similar to or identifiable by the patient in age or race. At times specialized medical terms related to specific health diseases must be identified and defined for patients. The photonovela, a comic book that uses photographs combined with easy to read captions to tell an educational story, utilizes many of methods of
intervention and is gaining popularity among health education programs. The story and photos can be tailored to the setting and culture of the population, aiding the patient to identify with the informational message provided\textsuperscript{30}. Affecting a patient’s understanding and comprehension of health education has been associated with patients’ overall health status and outcomes, including reduced hospitalizations, disease severity, and mortality\textsuperscript{29}.

**Overall benefits of understandable education for low literacy.** If educational materials are written at an understandable level, patients may be more likely to read the material. Increasing the exposure the patient has to the material may increase the patient’s knowledge. With knowledge, the patient is better able to problem solve specific symptoms they are having or contact the appropriate health care professional for assistance, thus reducing unnecessary emergency room department visits, hospitalizations, and mortality\textsuperscript{29}. Another benefit may be increased health prevention screenings\textsuperscript{29}. Finally, communicating health information in a more understandable way may be more cost effective reducing, potentially unnecessary use of health care, e.g. extra hospital visits\textsuperscript{28}.

**Potential benefits of understandable education for low literacy ESRD Patients Pursuing transplant.** The health literacy studies conducted with the ESRD population revealed that the rate of low health literacy in kidney patients is similar to the rate of the United States population\textsuperscript{31,32}. Green et al. found that ESRD patients with low health literacy were more likely to miss dialysis treatments, to utilize the emergency department, and to be hospitalized resulting in inadequate disease management\textsuperscript{33}. This can impact a patient’s pursuit of
transplant evaluation in many ways. The patients who have poorer control of their
diseases, in addition to low health literacy, are less likely to pursue
transplant.\textsuperscript{34,35} Another example is the ESRD patient who decides to pursue
transplant but cannot read or write. These patients are less likely to complete and
return the packet of forms to begin the evaluation process, which in reality may
block them from ever receiving a transplant.\textsuperscript{36} Despite recommendations for
multi-media education, a recent review found that most transplant centers in the
United States utilize only written transplant educational materials\textsuperscript{37}. Utilizing
many different learning formats such as brochures, videos, and patient stories
may enhance comprehension.\textsuperscript{29} This increase in comprehension may aid ESRD
patients pursuing transplant in making informed decisions about whether
transplant fits their lifestyle. Further research is needed in this population to see
how well an educational program for patients with low health literacy impacts
completing the transplant evaluation process.

Culturally Competent Education

Cultural competence is defined as “the ability to understand and work
effectively with patients whose beliefs, values and histories differ from one’s
own”.\textsuperscript{38(p299)} The lack of culturally competent care is associated with alienation,
inadequate treatment (Betacourt, Corbett & Bondaryk, 2014), misdiagnosis,
increased malpractice, and decreased patient satisfaction.\textsuperscript{40}. The disparities in
health care have been well researched in the United States and has shown to
cost near $1.24 trillion between 2003-2006. (LaVeist, Gaskin, & Richard, 2009)
Cost is acquired through prolonged hospitalizations(Ash, & Brandt, 2006),
improper utilization of service (Sack 2008; Jha, Orav, Zheng, & Epstein 2008; Jha, Orav, Li, & Epstein, 2007), and medical errors (Divi, Koss, Schmaltz, Loeb, 2007; Schyve 2007; Flores 2006). With the passage of health-care reform, cultural competence is receiving more attention and is being seen as one tool to reduce health care disparities (Betacourt, Corbett & Bondaryk, 2014). Patients who are of lower economic status, a minority race, non-insured, and those of lower health literacy may all be in need of culturally competent care and education.³⁹ Key recommendations for providing culturally competent care for patients are presented in Table 1.

Table 1 Applying strategies and key recommendations to designing patient education on end-stage renal disease

<table>
<thead>
<tr>
<th>Strategies to improve education</th>
<th>Key recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tailor education for individual patients</td>
<td>• Fit the format to the preferred way of learning (e.g., face-to-face, written, or video presentation)</td>
</tr>
<tr>
<td></td>
<td>• Acknowledge what is known and build on that knowledge</td>
</tr>
<tr>
<td></td>
<td>• Print the patient’s name on the information</td>
</tr>
<tr>
<td></td>
<td>• Tailor videos, images, pictures, and stories that relate to patients’ experiences</td>
</tr>
<tr>
<td></td>
<td>• Provide more information in areas in which patients show an interest</td>
</tr>
<tr>
<td></td>
<td>• Create individualized goals, discussing how the patient will meet them, and what the patient will do when faced with a problem situation</td>
</tr>
<tr>
<td></td>
<td>• Limit the length: newsletters, bullet points, short sentences, and paragraphs</td>
</tr>
</tbody>
</table>
| Make education understandable for patients with low health literacy | • Use of photonovela, comic book  
• Use several teaching formats (eg, written, verbal, and teach back)  
• Focus on immediate, practical topics and eliminate background information  
• Introduce no more than 3 topics at once, with the most important topic first  
• Explain complex issues in easy-to-understand language  
• Use white space  
• Use large font and easy-to-read font (e.g., sans serif typeface) |
|---|
| Provide culturally competent education for patients | • Show care and empathy: “walk in their shoes”  
• Assess the patient’s cultural needs, sources of strength, and communication norms (e.g., personal space, touch, eye contact, and taboo subjects)  
• Meet patients where they are in regard to treatment options, knowledge, and definition of health beliefs  
• Assess the economic resources that are available to the patient through their community/family  
• Acknowledge own biases (eg, stereotypes or assumptions related to a patient’s weight, skin color, accent, alternative remedies, and appearance)  
• Keep an open about each patient’s thoughts, feelings decision making, and values |
Help patients navigate the health care process

- Use reminders for upcoming appointments (e.g., post cards and phone calls)
- Use navigating headings on materials to orient the reader
- Mail maps and forms to be completed before appointments, asking only for essential information
- Use patient advocates to call and assist with any barriers to accessing health care (e.g., a lack of transportation)

A review of the broader literature. Evidence indicates that training, in how best to deliver culturally competent care, advances professionals’ skills in asking patients questions about beliefs concerning their illness and provides strategies to bridge differing communication styles, leading to higher patient satisfaction in their overall health care.\(^{41}\) However, research also has shown that care must be taken when delivering cultural competence training not to merely teach a list of traits or a set of categories that could lead to cultural stereotyping.\(^{42}\) Culture is fluid, not static; therefore, the overall aim of this type of training is for health care providers to have an open mind and treat patients as individuals.

DeRosa and Kochurka proposed six steps in the provision of culturally competent care. In the first step, the provider must develop attitudes associated with culturally competent care, such as caring, empathy, openness, and flexibility.\(^{43}\) Incorporating these behaviors in the fast-paced health care environment, with many health care providers presenting information quickly with
minimal discussion and little time for questions is challenging. Slowing down, asking patients what they expect from the treatment, and taking time to ask patients what questions they have are vital to being open and flexible to patients’ needs. The second step is for the health care provider to assess how values and health care beliefs influence each person’s health differently. Some health care decisions require family discussion, while others are individual decisions.

The third step is to obtain information about the patient’s preferences regarding communication, both in how it should be done and in what type of environment and timeframe. Some patients may need more time at home with family and friends to process health information and may require another visit to the health care provider to ensure comprehension. The fourth step is a cultural assessment to learn patients’ native language and health beliefs about, for example, medications. Patients who speak English as a second language may over estimate their ability to comprehend English fluently, which leads to misunderstandings of instructions leading to medication errors. The fifth step is the preserve-accommodate-restructure framework. This framework is based on preserving the cultural aspects that improve health care outcomes while accommodating cultural practices that do not harm the situation and restructuring those practices that may interfere with treatment. This type of partnership is a win-win situation. The patient becomes an active member in their health care by collaborating with the health care provider to devise a plan that honors the patient’s own beliefs while promoting good outcomes. The sixth and final step is for the health care provider to avoid being defensive and to apologize for
mistakes.\textsuperscript{43} When meeting a person whose culture is different from one’s own, a provider may make mistakes like invading personal space. Health care providers should take ownership and apologize. These six steps may help produce a culturally competent and individualized plan of care that respects the patient as an individual and increases the patient’s sense of wellbeing.

\textit{Overall benefits of culturally competent education.} Most culturally competent studies have focused on outcomes such as improving provider sensitivity, knowledge, or communication skills, not on patient outcomes.\textsuperscript{44} However, important patient benefits have been identified when culturally competent education is present, including increased patient satisfaction (Beach, Robinson, Price et al. 2004) scores which includes trustworthiness, empathy, and respect.\textsuperscript{44} and (Betacourt, Corbett & Bondaryk, 2014). Increases in patient satisfaction and trust may lead to better follow up and less loss to follow up, thereby giving the health care provider additional opportunities to educate patients. To date, studies have not shown an association between providing culturally competent care and reductions in mortality and morbidity.\textsuperscript{44} In order to improve the quality of health care in diverse populations cultural competence is critical. (Betacourt, Corbett & Bondaryk, 2014)

\textit{Potential benefits of culturally competent education for ESRD patients pursuing transplant.} Culturally competent education is one important step in reducing disparities in the pursuit and rates of transplantation for minorities.\textsuperscript{45} Racial disparities have been associated with delaying referrals to the kidney transplant center, slowing transplant evaluation process, and in some
cases preventing access to transplantation. Research suggests that the demographic disparities in kidney transplant may be getting worse due to physician bias in referring patients to the transplant center and patient misconceptions about their eligibility for transplant. A review of transplant centers throughout the United States found that a majority of centers relied on interpreters to communicate with non-English speaking patients (78%) and that a minority of centers have bicultural staff (43%) or provide cultural competency training (34%). Another national analysis revealed that Black patients may not be benefiting from transplant education as much as White patients.

Research has focused on ways to address this problem, with one important recommendation being to improve health care providers’ ability to deliver culturally competent education and care. Among extant culturally competent transplant educational interventions, a good example is found in the Talking About Live Donation (TALK) intervention. This is a culturally-competent educational program that has not only been shown to help pre-ESRD patients and their family members consider living donor kidney transplantation, but equally acceptable to Black and White patients. A second intervention that provided transplant education to patients and their families in the settings of their homes actually demonstrated a greater effect in Black patients compared to Whites, while increasing the ability of patients of both races to discuss living donor kidney transplantation with potential donors.

Navigation of the Health Care Process
Health care systems and processes are very complex especially for those who have limited experience with health care or low health literacy. Patients may have difficulties in knowing when and where to seek medical help or information. Health care processes shown to be most important include having patients arrive at their scheduled appointments and following the health care provider’s recommendations. Patients who are confused or disempowered may appear to be noncompliant or make unintentional errors by misunderstanding instructions related to medical advice. Health care systems use a number of ways to assist patients in navigating: automated phone call reminders of appointments, mailing of maps and forms prior to the first appointment, and concierge service. Even with these approaches, there is still a heavy burden placed on the patient to understand and follow complex health care recommendations. Key recommendations for helping patients navigate the health care process are presented in Table 1.

**A review of the broader literature.** The use of patient navigators is gaining more attention as health care systems are trying to be seen as more user-friendly. These navigators are either peers or educated professionals who assist patients in moving through the health care process. Koh, Nelson, and Cook studied the use of a patient navigation system in cancer patients. Their study showed that over 71% of the barriers to care such as fear, lack of financial resources, transportation, and childcare were resolved at the first treatment visit due to intervention by patient navigators.
**Overall benefits of being able to navigate the health care process.**

The benefits of helping the patient through the health care process include increased attendance at scheduled appointments, increased ability to ask specific questions related to individual barriers to care, and decreased feelings of fear. An added health-related benefit is decreased loss to follow up, which offers the health care provider more opportunities for assessment, management, and education.

**Potential benefits of being able to navigate the complex transplant evaluation process for ESRD patients.** Several barriers were identified that slow or prevent the patient from completing the transplant evaluation, including lack of financial resources, lack of knowledge about transplant, fear of medical tests, and fear of surgery. For example if patients do not understand medical terminology, they are unlikely to be able to navigate through the multi-step transplant evaluation process well. Sullivan et al. conducted a randomized control trial to test the impact of a tailored patient navigator on dialysis patients’ completion of 8 steps toward receiving a kidney transplant (e.g. deemed suitable for transplant, expresses interest in transplant) with the 8th, ultimate step being receipt of a kidney transplant. Patients who received the patient navigator completed significantly more steps toward transplant than patients in the control condition (3.5 vs. 1.6, 95% confidence interval: 1.3-2.5). Additional efficacy and effectiveness trials examining the impact of patient navigators in larger samples would add significant evidence to the field.

**Conclusion**
Kidney transplants have been performed since the 1950s. Since that time, many research studies have demonstrated transplant benefits over dialysis, yet the rates of transplant remain low. Although organ shortage is a major factor in low transplantation rates, may patients; lack of access to comprehensive education about transplant is a barrier to considering or pursuing transplant.\textsuperscript{11} A recent study of transplant patients’ experience with the education they received at a transplant center revealed difficulties in retaining information provided, unclear expectations and confusion around the evaluation process, and a lack of discussion of living donor transplant.\textsuperscript{59} Other recent research has emphasized the benefit of using optimal education approaches in aiding ESRD patients to make an informed decision about transplant.\textsuperscript{60}

Health literacy remains a major barrier to transplantation\textsuperscript{36} and demands greater attention in transplant education research. Reasons for the lack of focus on health literacy may include the length of health literacy assessment tools, the lack of training in administering a tool, or the difficulty in identifying a tool that both fits this population and is easy to administer in the clinical setting. More user-friendly, precise, and unbiased assessments of health literacy\textsuperscript{61,62} will enable transplant educators to understand which of their patients have low health literacy, and are, therefore, at higher risk for adverse outcomes. Further, such assessment will enhance the ability of the educator to tailor education to the individual patient.\textsuperscript{35}

The current practice of educating ESRD patients pursuing transplant often consists of delivering the same educational packet to each patient, sometimes
before ever meeting the patient in the clinic setting. For the most part, due to time constraints and a weak research base, assessment of the patient’s health literacy, cultural beliefs, and navigational skills is not being conducted in a systematic way. For changes to occur in the education process, resources must be allocated in the form of materials and culturally competent staff to guide the ESRD patient through the process, beginning from their initial request for information. Theoretically consistent, adequate educational preparation, and a guide to help navigate through the initial process may facilitate patients’ understanding of the process, as well as expected outcomes post-transplant.

Finally, while strategies from the broader literature about education can be applied to this population to try to reduce barriers and improve the rate of transplantation, more evidence-based practice projects and well-controlled research studies are needed to assess the efficacy of various education strategies for ESRD patients pursuing transplant. In the future, through research studying the efficacy of different educational approaches for patients with ESRD, we can build a knowledge base of the best education practices for ESRD patients. For now, providing more ESRD patients with kidney transplant education that encompasses best practices may improve their ability to make informed health care decisions.
References (Manuscript One)


Chapter 3 Second manuscript

The topic for the second manuscript was an integrative review on the Educational Preparation of African-Americans in Regard to Kidney Transplant. The manuscript will be submitted to Progress to Transplantation the end of April 2019.

An Integrative Review on the Effectiveness of Educational Interventions in Facilitating Progress to Kidney Transplant in African-Americans

List of Authors

Stacy L. Skelton, PhD(c), Amy Waterman, PhD, Anne F. Fish, PhD, Kuei-Hsiang Hsueh, PhD, and Wilma J. Calvert PhD, MPE, MS(N), RN

Authors’ Affiliations:

University of Missouri, St. Louis, Missouri student (SLS), David Geffen School of Medicine at UCLA Los Angeles, California (ADW), University of Missouri, St. Louis, Missouri (AFF, WJC, KHH)

The authors declare no conflict of interest.
Abstract

Background: Kidney transplant has benefits over dialysis such as reduced mortality, yet fewer African-Americans pursue transplant. One likely cause is insufficient educational preparation for end-stage renal patients to consider a move from dialysis to transplant, a complex process.

Objective: The purpose of this review is to explore the effectiveness of educational trials in facilitating progress to kidney transplant in African-Americans.

Methods: An integrative review was conducted using CINAHL, Medline, and PubMed databases including the years 2006-2019. Study quality was evaluated using the Cochrane Criteria or the Consolidated Criteria for Reporting Qualitative research. Results: Six articles met the eligibility criteria: four with samples that were 100% African-Americans and two with samples that were at least 51% African-American. Sample sizes ranged from 92-268 participants, with as few as 30 per group. Educational interventions significantly improved transplant readiness, knowledge, willingness to communicate, and living donor inquiries, as well as reduced concerns compared to controls. In some studies, benefits were significantly improved compared to controls. No significant differences were found for family discussion or completing transplant evaluation.

Discussion: Based on the small number of trials, the interpretation must be viewed with caution. Further research is needed in 100% African-American samples using ethnocentric materials and larger sample sizes.

Keywords: Black patients, black-American patients, African-American patients, dialysis, kidney transplant, education
Introduction

Kidney transplant is the preferred treatment option for patients with end-stage renal disease (ESRD), based on the evidence of improved quality of life and lower mortality compared to dialysis. The fact that the prevalence of ESRD is 3.5 times higher in African-Americans and they have a higher burden living with the disease is a serious situation in healthcare today. Moreover, African-Americans have a 35% to 75% lower probability receiving a kidney transplant.\(^1\)

Efforts have already been made to remedy this situation by The Centers for Medicare & Medicaid Services (CMS) and the Organ Procurement and Transplantation Network (OPTN), which is operated under contract with the United States Department of Health and Human Services by the United Network for Organ Sharing (UNOS). In 2005, CMS mandated that clinicians inform new patients of their transplant options within 45 days of starting dialysis\(^1\) and, in 2014, UNOS created a new kidney allocation system\(^2\)-\(^6\). However, the quality of the information given to dialysis patients because of the CMS mandate does not meet any standard as a formal education program; thus, leaving a very real gap between what is mandated and what patients actually need to progress to transplant. Even though these major policy changes resulted in some improvement in rates of kidney transplants, the number of African-Americans pursuing a kidney transplant remains low\(^2\)-\(^6\).

Evidence indicates that there is a lack of education on kidney transplant that focuses on African-American patients on dialysis\(^7\)-\(^13\). In order for African-Americans to pursue kidney transplant, knowledge about transplant must be provided to patients so they can have discussions with health care providers to
start the process to transplant. Jones, You, and Kendrick found only 31.7% of African-Americans on dialysis reported having any discussion about kidney transplant with a doctor. This lack of education results in relatively small numbers of African American patients knowing the benefits and how to progress to transplant.\textsuperscript{14,15}

The purpose of this review is to explore the effectiveness of educational trials in facilitating progress to kidney transplant in African-Americans. Exploring effective educational interventions is imperative regarding African-Americans living with ESRD because they need to be adequately prepared to pursue kidney transplant.

\textbf{Methods}

This integrative review was conducted using the process outlined by Whittemore and Knafl. The keywords used during a comprehensive review of CINAHL, Medline, and PubMed electronic databases were Black, Black-American or African-American patients, dialysis or kidney transplant, and education. The literature search included the years 2006-2019. The inclusion criteria were articles written in English, contained an educational intervention, and included at least 51% African-American ESRD participants. The cut off of 51% was used because too few studies were found with only African-Americans participants. The assumption was made that findings of studies using a majority of African-Americans would be strong enough, and generalizable to African-Americans. Additionally, samples of participants ranged from those before transplant evaluation to post-transplant. We included patients post-transplant
because it is likely that they would provide valuable insight into how they overcame fears and barriers of transplant through completion of the transplant process. The exclusion criterion was articles conducted in pediatric patients. Articles from reference lists were obtained.

The search resulted in 127 articles. Abstracts and titles were reviewed, resulting in the elimination of 115 articles. At the conclusion of the search, six articles were included (Figure 1).

Figure 1

Types of articles included were randomized controlled trials (n=5) and a qualitative study (n=1). In four RCTs, an intervention or interventions were compared to controls that received standard of care transplant education. In contrast, one study compared three interventions (home visits, group education,
and individual counseling). The qualitative study used focus groups. Two quasi-experimental were found; however, one had a small sample size and the other lacked a detailed description of the intervention, and therefore both were excluded. No published articles were found outside of the United States.

**Data Evaluation**

The quality of quantitative studies was evaluated using the Cochrane criteria whereas qualitative research studies were evaluated using the Consolidated Criteria for Reporting Qualitative research (COREQ). Studies not meeting these standards were excluded from the review.

**Data Analysis**

Data were extracted from the articles using standard forms if the study was about the effectiveness of educational interventions and any of the eight key outcomes: transplant readiness, transplant knowledge, willingness to communicate about transplant, benefits, concerns, discussion with family, transplant evaluation, and living donor inquiries. For quantitative studies, design and sample, characteristics of interventions, outcomes measured, and key results were considered. For the qualitative study, we reported characteristics of the sample and themes obtained from focus groups.

**Results**

**African-American ESRD Patient Samples**

Table 1 presents a summary of six studies included in the review. Of the six studies, sample sizes ranged from 26 to 268 participants. Most participants were middle-aged; the ages ranged from 37 to 69 years.
Table 1. Studies Included in the Review (n=6).

<table>
<thead>
<tr>
<th>Authors</th>
<th>Design and Sample</th>
<th>Intervention/ Focus Groups</th>
<th>Results/Themes</th>
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<tbody>
<tr>
<td>Arriola et al. 2014&lt;sup&gt;16&lt;/sup&gt;</td>
<td>-RCT n=136</td>
<td>Intervention: About Choices in Transplantation and Sharing (Living ACTS)</td>
<td>Knowledge</td>
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<tr>
<td></td>
<td>intervention 100%</td>
<td>• One individual session</td>
<td>Intervention</td>
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<tr>
<td></td>
<td>African-Americans</td>
<td>• Printed materials/videos</td>
<td>Control</td>
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<tr>
<td></td>
<td>n=132 control 100%</td>
<td>• Culturally sensitive</td>
<td>Pre 14.41</td>
</tr>
<tr>
<td></td>
<td>African-Americans</td>
<td>• Emphasize role of the family</td>
<td>6 mths 14.83*</td>
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<tr>
<td></td>
<td>-Evaluated for transplant</td>
<td>• Benefits of live donor</td>
<td>Knowledge Intervention 14.30</td>
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<td></td>
<td></td>
<td>• Process for donor and recipient</td>
<td>Control 14.09</td>
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<td></td>
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<td>• Preventing rejection</td>
<td>Willingness</td>
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<td>• Resources</td>
<td>Intervention</td>
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<td>Control 34.41</td>
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<td></td>
<td>Pre 36.12*</td>
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<td></td>
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<td>6 mths 34.30</td>
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<td>Benefits</td>
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<td>Intervention 33.25</td>
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<td></td>
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<td></td>
<td>Pre 35.05</td>
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<td></td>
<td></td>
<td></td>
<td>6 mths 33.23</td>
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<tr>
<td>Boulware et al. 2018&lt;sup&gt;17&lt;/sup&gt;</td>
<td>-RCT n=30</td>
<td>Intervention 1: Providing Resources to Enhance African American Patients’ Readiness</td>
<td>Family Discussion</td>
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<td>Intervention 1</td>
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<td>Intervention 2 Control 3</td>
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*Significant difference at p<0.05
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<tbody>
<tr>
<td>Rodrigue et al. 2014</td>
<td>-n=54 intervention 1</td>
<td>Intervention 1: Home-Based Education (HOUSE CALLS)</td>
<td>Pre</td>
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<tr>
<td>-n=49 intervention 2</td>
<td>-n=49 intervention 3</td>
<td></td>
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<tr>
<td>-n=54 intervention 1</td>
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<td>Readiness</td>
<td>Intervention 1</td>
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<td>-n=49 intervention 2</td>
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<td>Intervention 2</td>
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<td>Knowledge</td>
<td>Intervention 1</td>
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<td></td>
<td></td>
<td>Willingness</td>
<td>Intervention 1</td>
</tr>
</tbody>
</table>
### 100% African-Americans - Not yet started the transplant process

- Types of transplant/donor
- Average waiting times to transplant
- Living donor education, donor recovery, risks, benefits, concerns
- Recipient concerns
- Indirect costs and resources
- Transplant evaluation

**Intervention 2: Group-Based Education**
- One 60-90-minute group session at the transplant center
- Printed materials with discussion
- Patients with invited guests

**Intervention 3: Individual Counseling Education**

<table>
<thead>
<tr>
<th>Concerns</th>
<th>Intervention 1</th>
<th>Intervention 2</th>
<th>Intervention 3</th>
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<tbody>
<tr>
<td></td>
<td>38.9</td>
<td>38.9</td>
<td>39.9</td>
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<td>31.5*</td>
<td>34.5</td>
<td>38.6</td>
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<thead>
<tr>
<th>Living Donor Inquiries</th>
<th>Intervention 1</th>
<th>Intervention 2</th>
<th>Intervention 3</th>
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<tr>
<td></td>
<td>82%*</td>
<td>61%*</td>
<td>47%*</td>
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</table>
Rodrigue et al. 2007\textsuperscript{19} - RCT  
- n=63 intervention  
51% African-Americans  
n=69 control  
58% African-Americans  
- Approved for transplant  

<table>
<thead>
<tr>
<th>Intervention: Home-based Education</th>
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<tbody>
<tr>
<td>One 60-90-minute group session</td>
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<td>Printed materials with discussion</td>
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<td>Patients with invited guests</td>
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<td>Average waiting times to transplant</td>
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<td>Living donor education, donor recovery, risks, benefits, concerns</td>
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<td>Recipient concerns</td>
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<tr>
<th>Knowledge</th>
<th>Pre</th>
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<tr>
<td>Intervention</td>
<td>8.8</td>
<td>13.4*</td>
</tr>
<tr>
<td>Control</td>
<td>8.8</td>
<td>10.3</td>
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<tr>
<th>Willingness</th>
<th>Pre</th>
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<tr>
<td>Intervention</td>
<td>3.8</td>
<td>6.1*</td>
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<tr>
<td>Control</td>
<td>4.0</td>
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<tr>
<th>Concerns</th>
<th>Pre</th>
<th>1 mth</th>
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<tr>
<td>Intervention</td>
<td>9.3</td>
<td>9.5*</td>
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<tr>
<td>Control</td>
<td>9.9</td>
<td>9.9</td>
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</table>

Living donor inquiries were 72.7%, reported overall not by group.
| Waterman et al. 2018<sup>20</sup> | -RCT -n=133 intervention 71% African-Americans n=120 control 82% African-Americans -Not yet in the transplant process | Intervention: Explore Transplant Education program (EXPLORE Transplant)  - Four 30-minute one-on-one sessions  - Printed materials and videos, featuring various ethnicities and socioeconomic groups  - Benefits  - Communication skills  - Post-transplant stories | | | | Readiness | Intervention Control | 55.6 | 73.6* | 62.5 | 57.5 | | Knowledge | Intervention Control | 8.5 | 12.3* | 8.8 | 9.4 | | Benefits | Intervention Control | 23.4 | 24.8* | 23.5 | 23.5 | | 1 year | | | | | | | Transplant Evaluation Completed | Intervention Control | - | 3.1% | | 3.3% | | 6 mths | | | | | | | Living Donors Inquiries | Intervention Control | - | 17* | | 5 | |
| 100% African-American Referred, listed, or transplanted | • What was your concerns about getting a transplant?  
• What are some of the reasons you think that people do not get a transplant?  
• What made it easier for you to learn about kidney transplant? | Themes about concerns and reluctance to pursue a transplant: fears of transplant surgery, transplant rejection, and being eligible or offered a transplant.  
Important themes about strategies to make it easier to pursue transplant: high quality health care provider communication (repetitive, optimistic, and comforting), exposure to peer success, and encouragement during family discussion. |

Abbreviations: pre=pre-intervention; month=mth

* ≤ p 0.05
The percentages of male participants ranged from 39% to 78%. Four studies contained all African-American participants, and two studies contained 51-82% African-Americans. Most of the participants had a high school education or higher. The number of African-American participants in all studies totaled 923, specifically 897 in randomized control trials. The studies included participants at different points in the transplant process: three studies where the participants had not started the transplant process,\textsuperscript{17,18,20} one study where the participants were in the evaluation process,\textsuperscript{16} one study where the participants had been approved for transplantation,\textsuperscript{17} and one study where the participants had been referred, listed, or transplanted.\textsuperscript{21} The control groups in the interventional studies received standard of care treatment.

**Components of the Educational Interventions Including African-Americans**

Regarding the intervention studies, three articles included materials and interactions that had culturally sensitive aspects.\textsuperscript{16,18,20} In the studies that provided materials, all three videos and pamphlets had diverse people represented. Four of the studies first conducted either pilot studies or focus groups that evaluated the cultural sensitivity intervention materials and methods with transplant recipients, donors, and health care professionals with diverse backgrounds and ethnicities.\textsuperscript{16,18} In two studies, the face-to-face educators went through training to ensure content knowledge and how to field patient and family questions in a sensitive manner.\textsuperscript{18,20} Only the qualitative study identified the ethnicity of the research coordinator, an African-American who led the focus groups.\textsuperscript{21}
All studies provided detailed protocols about the educational interventions. In the five RCTs, the settings for the intervention varied and ranged from formal in a health care facility to informal in patients’ homes. Additionally, the program length varied considerably from one 90-minute session to four 30-minute sessions. Finally, the delivery methods varied widely. The RCTs with educational interventions with the lowest level of interaction was viewing a video with handouts in one session with no interaction, or with individual face-to-face scripted communication with all questions being directed to the healthcare provider. The RCTs with interventions with moderate interaction was viewing a video with handouts with individual face-to-face discussion, or face-to-face discussion with the participant and invited guests. The RCT with an educational intervention with the highest level of interaction included group lecture with dialogue, role-play, and question and answer discussion. None of the studies included internet websites or computer-based education as a learning strategy.

**Effectiveness of the Interventions**

Outcomes related to progress to kidney transplant and the number of studies found per outcome were transplant readiness (n=2), transplant knowledge (n=4), willingness to communicate about transplant (n=3), benefits (n=2), concerns (n=2), discussion with family (n=2), transplant evaluation (n=2), and living donor inquiries (n=3).

**Transplant Readiness.** Two studies included measurements of readiness. Readiness was significantly improved in the home-based education group compared to the group based or individual counseling at the transplant
center. This was also true in the Explore Transplant trial. In these studies, Prochaska’s Transtheoretical Model of Behavioral Change was used, specifically five stages of readiness. The five stages are: precontemplation not considering or not ready to pursue transplant, contemplation considering pursuing transplant, preparation planning to pursue transplant, action having contacted the transplant center, and maintenance have been approved for transplant. The individually tailored teaching sessions were based on their stage of change.

**Transplant Knowledge.** Adequate knowledge is critical for patients to make an informed decision to pursue transplant. In the studies that included transplant education as an intervention, the results showed that transplant knowledge was significantly improved compared to the standard education. Regarding the educational interventions, several patterns were seen. In the four studies that had face-to-face educational sessions, repetition was provided through question and answer sessions to allow clarification of information. Repetition was also used in those studies that provided videos and pamphlets given to the patients for review again at home. Exposure to peer success stories may aid participants in overcoming reluctance to pursue transplant.

**Willingness to Communicate About Transplant.** The willingness of a patient to talk about transplant is essential in gaining the support of family and healthcare providers. In three studies, willingness to communicate or communication self-efficacy was significantly improved in the intervention versus the control group and, in one study, it was significantly improved in the home-
based versus the group-based or individual counseling interventions.\textsuperscript{18} Additionally, those patients with frequent discussions with health care providers felt that the information was useful and emotionally comforting.\textsuperscript{21} Other studies focused on the willingness to talk about transplant in terms of living donor transplant. Many ESRD patients are reluctant to broach this subject due to concerns of imposing their need for a kidney on others.\textsuperscript{17-21} The willingness to talk about transplant may lead to a patient discussing with family members about the kidney transplant options, for example, living versus deceased donor transplant.

\textbf{Benefits Regarding Transplant.} Benefits of both donors and recipients were reviewed.\textsuperscript{16,18-20,21} This allowed ESRD patients to hear donors’ and recipients’ real-life stories of the benefits of transplant.\textsuperscript{16,18-20,21} Mixed results were found in the improvement of benefits regarding transplant. Waterman reported significantly increased benefits in the intervention versus the control group, whereas Arriola did not.

\textbf{Concerns Regarding Transplant.} Concerns were significantly reduced in the home-based versus the group-based or individual counseling intervention. Being willing to accept a deceased donor kidney transplant may weigh heavily on an ESRD patient because someone lost their life; this is particularly true in cases where the donor was young or healthy.\textsuperscript{8,22,25-27} ESRD patients may have concerns about the potential harm for donors’ welling being and future health. Additionally, patients may then have the added fear of losing the kidney transplant to rejection.\textsuperscript{8,16,17,23-25} Due to these concerns, some patients may
refuse to allow other people to donate.\textsuperscript{24,25} A synthesis from a recent review of the literature indicated that a discussion of benefits to the kidney donor and benefits of kidney transplant may help to overcome concerns.\textsuperscript{27}

\textbf{Discussion with Family.} In reviewing the qualitative study that included only African-Americans in conversations about transplant education barriers and facilitators, the role of family support and encouragement played a significant part in the decision process to pursue kidney transplant.\textsuperscript{25} Many of the studies found having friends and family attend educational interventions aided in clarifying misinformation about transplant, reducing fears of surgery, and increasing knowledge related to the benefits of kidney transplant.\textsuperscript{14,20-22} Two studies included family and friends in the intervention, which was the home-based educational intervention that was effective in reaching the African-American patients and their extended friends and family; the intervention significantly increased living donor transplant in the intervention group compared to the control group.\textsuperscript{18-21,27}

\textbf{Transplant Evaluation Completed.} For two of the intervention studies, transplant evaluation completion was reported. Only in one study, completing transplant evaluations was significantly higher in the intervention versus control group.

\textbf{Living Donor Inquiries.} The more living donors willing to undergo the donor evaluation, the more chance a participant may be able to have a living donor kidney transplant. The number of living donors presenting to the transplant center was significantly higher in the intervention versus the control group.
Rodrigue (2014) reported that living donor inquiries were significantly higher in the home-based compared to the group-based or individual counseling intervention. In the literature living donor, education is viewed from the perspective of the donor in regard to evaluation, eligibility, surgery, recovery, and risks, which helps to clarify and resolve misinformation.\textsuperscript{16-20} Additionally, studies review the benefits to the donor such as saving a life and improving the life for the recipient.\textsuperscript{18} Two of the studies provide content on how to approach the discussion of transplant as well as living donor kidney transplant with friends and family.\textsuperscript{18,21}

\textbf{Discussion}

The purpose of this review is to explore the effectiveness of educational trials in facilitating progress to kidney transplant in African-Americans. Pursing transplant is a complex process, beginning with the patient completing a packet of health history forms, undergoing several medical procedures and tests, and sharing their wishes on treatment. Many of the studies in this review had one educational session and had significant results in improved knowledge, willingness, readiness, and reduction in concerns. While the results for starting and completing the transplant evaluations were mixed, in some cases, participants had living donors come forward to be evaluated.

Due to the complexity of the transplant evaluation process, one formal session may not be enough for patients to process all the information. Including the family in the educational session may offer the patient more support. Utilizing all the health care members may provide opportunities for repetition of content.
These include nephrologists and personnel at dialysis and transplant centers. The one study that had no significant findings had only scripted interaction and all questions were diverted back to the health care provider -- essentially missing the vital time for patients to receive answers on their specific questions.\(^{17}\) A well-informed staff who are able to answer patients' questions is critical in overcoming patients' reluctance and fears, thereby, potentially moving patients into actively pursuing kidney transplant.\(^{27}\)

Other studies are looking at using navigators to aid patients in completing steps to transplant. One study, researchers examined the effects of having a personal social support person or navigator to assist in facilitating the transplant education intervention by guiding the participant through the logistics of a large health center, and completing the complicated forms to improve pursuit of living kidney transplant, thereby, increasing the number of steps ESRD patients completed. This study found the group with navigators completed twice as many steps and more were placed on the transplant waitlist.\(^{28}\)

Another study examined the effects and preferences of digital education. That study found significantly more African Americans (77\%) preferred to acquire knowledge in the classroom settings than Whites (60\%). In the same study, significantly more African Americans (66\%) preferred educational DVDs than Whites (46\%). Both studies found that the use of cell phone technology, specifically text messaging, could be a way to connect with African-Americans.\(^{21,29}\) In the one qualitative study, exposure to peers was a common theme heard, for example one participant who said, “These people were looking good after
their surgery. They are looking at us and laughing and answering our questions and giving us hugs.”

Further qualitative work is needed to focus on lived experiences or ethnography to expand and refine educational interventions to provide the essential knowledge required for African-Americans to consider kidney transplant. Perspectives of African-Americans post-transplantation may identify themes that need to be addressed in educational sessions. Past experiences with family or health care professionals, either negative or positive, may weigh heavily in whether a patient will pursue transplant.

Many studies were careful to limit the possibility of harm coming to the participants during the intervention by choosing research staff with strong communication skills and educating them on crisis management and content delivery.

Generalizability of the findings of this review is limited; no studies were found on Blacks pursuing transplant outside the US. Also, only two of the studies had exclusively African-American participants. In those studies with many races, the specific effects in African-American participants could not be determined. Yet, when all results were reviewed, they seemed similar between those studies with 100% African Americans and those with a majority of African Americans. There is a need for more RCTs with Black participants globally.

**Conclusion**

To our knowledge, this is the first integrative review on patient education about kidney transplant in regard to African-Americans. The interventions were of
high quality and rigorous. All RCTs but one showed some benefit of the educational intervention. The goal of educational interventions is to motivate participants to pursue transplant by examining the following outcomes: starting or completing the evaluation and having a living donor contact the transplant center. Future research studies need to be conducted with large samples that are all African-Americans to discover effective interventions in overcoming the complex process of pursuing and improving treatment outcomes in this population.

Author Roles

All authors made contributions to this article from the concept through revision.

Declaration of Conflicting interests

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References (Manuscript Two)


27. Agerskov H, Bistrup C, Ludvigsen MS, Pedersen BD. Experiences of


Chapter 4 Third manuscript

The topic of this third manuscript was to a quantitative research study on Predictors of Health Literacy and Steps Taken to Pursue Kidney Transplant among African-Americans on Dialysis. This manuscript presents the problem of interest, the design, recruitment, data collection, data analysis procedures, and findings. The manuscript will be submitted to Archives of Transplantation in April 2019.

Predictors of General Health Literacy, Making Efforts to Learn Educational Materials, and Taking Steps to Pursue Kidney Transplant Among Low-Income African-Americans

List of Authors

Stacy L. Skelton, PhD(c), Amy D. Waterman, PhD, Kuei-Hsiang Hsueh, PhD, Anne F. Fish, PhD, and Wilma J. Calvert PhD, MPE, MS(N), RN

Authors’ Affiliations:

University of Missouri, St. Louis, Missouri student (SLS), David Geffen School of Medicine at UCLA Los Angeles, California (ADW), University of Missouri, St. Louis, Missouri (KHH, AFF, WJC)

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Abstract

Objective: To identify potential predictors of health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation in low-income African-Americans living with end-stage renal disease on dialysis.

Methods: A secondary analysis was conducted using an existing database from 399 low-income African-American dialysis patients obtained from an NIH-funded multi-site study entitled "Explore Transplant at Home." All participants completed measures on neighborhood safety, social support received, medical trust, general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant.

Results: Overall, 25.6% of the participants had limited health literacy. Results of multiple regression analysis indicated that sex (β=10), educational attainment (β=20), and neighborhood safety (β=.21) predicted general health literacy. Age (β=-.18), educational attainment (β=.17), and the number of health insurance policies (β=.13) predicted making efforts to learn educational materials. Age (β=-.16) and educational attainment (β=.19) predicted taking steps to pursue transplant.

Conclusions: For African-Americans who live below the poverty level, their general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant are essential in preparation for kidney transplant. Making efforts to learn kidney transplant educational materials should be encouraged as this is associated with taking steps to pursue kidney transplant.
Keywords: Blacks, African-Americans, end-stage renal disease, kidney transplant, education, health literacy
Introduction

The incidence of end-stage renal disease (ESRD) cases continues to rise by approximately 20,000 cases annually in the United States (United States Renal Data System; USRDS, 2016). In 2015, there were 124,111 new cases of ESRD, bringing the total number of people living on dialysis or with a kidney transplant to over 700,000. The number of African-Americans living ESRD is more than 3.7 times higher than any other ethnic group.

Research has shown that kidney transplant is the optimal treatment for ESRD, reporting higher quality of life and lower mortality and morbidity rates (Harding et al., 2017; Waterman et al., 2015). When comparing the three-year survival rates for kidney transplant recipients to dialysis, transplant survival rates are 74% versus 40% for those on dialysis (USRDS, 2016; Waterman et al. 2019). However, the rate of kidney transplant in African-Americans remains low (Waterman & Piepert, 2018). The low kidney transplant rate among African-American has been recognized as a healthcare disparity related to inadequate access to or use of quality care (USRDS, 2016).

Healthcare disparity refers to people who have a poor health outcome related to obstacles to health care due to social, economic, and/or environmental disadvantages (Healthy People, 2020). Healthcare disparities are costly and often closely associated with limited health literacy (Baker 2006; Squiers et al., 2012); both are linked to poor health outcomes (Betancourt, Corbett, & Bondaryk, 2014; Harding et al., 2017). Health literacy refers to the ability to attain, understand, and comprehend basic health information and services required to
make informed health decisions (Institute of Medicine, 2004). People with limited health literacy often have insufficient knowledge and skills to make informed medical decisions such as pursuing kidney transplant (McPherson et al., 2017).

Limited general health literacy (i.e., self-confident to understand, and perceived difficulty of provided health information) is one of the most serious disparities in ESRD for African-Americans. A number of studies reported that being older, male, socioeconomically disadvantaged, and a minority increase the risk for limited general health literacy (Chenitz et al., 2014; Hardinger et al., 2012; Kripalani et al., 2006; Monson et al., 2015; Waterman et al., 2013). Salter et al. found that African-American females and older males were less likely to pursue transplants than younger males, but there is no age and sex difference in the lack of knowledge about kidney transplant (2015). For African-Americans living with ESRD, the lack of general health literacy in preparation for kidney transplant has been recognized as the primary reason for the low-referral rate by health care providers (Cavanaugh et al., 2010; Fraser et al., 2013; Harding et al., 2017, Jain & Green, 2016). Historically, these patients have been socioeconomically disadvantaged minorities who are more likely to be poor, less educated, and less likely to have adequate health insurance policies (Harding et al.2017; Kripalani et al., 2006; Waterman et al., 2013). Further, this vulnerable group often live in poor neighborhoods that have a lack of resources, safety, social support, and medical trust (Cohen et al., 2003; Doescher et al., 2000; LaVeist, Isaac, & Williams, 2009; LaVeist, Nickerson, & Bowie, 2000). Pursuit of kidney transplant in low income African-Americans requires further study.
The purpose of the current study was to identify potential predictors of general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation in low-income African-Americans living with ESRD on dialysis by examining the following the research questions:

1. What is the association among the personal-psychosocial factors (age, sex, educational attainment, number of health insurance policies, neighborhood safety, social support, and medical trust) and preparation for kidney transplant (general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant)?

2. Do personal-psychosocial factors predict general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant?

**Conceptual Framework**

The overarching framework for the current study was proposed by Squiers, Peinado, Berman, Boudewyns, & McCormack (2012). This work focused on factors related to general health literacy in preparation for kidney transplant.

**Personal-Psychosocial Factors**

**Demographics.** Researchers have identified that demographics of age, sex, educational attainment, and adequate health insurance policies are closely linked to health disparities in low-income African-Americans living with ESRD (Harding et al., 2017; King, 2008; Squiers et al., 2012). For example, age is significantly and negatively correlated with general health literacy; sex (female) is correlated with general health literacy; and educational attainment is significantly
and positively correlated with general health literacy. Those factors are associated with the development of general health literacy that impacts the ability to learn educational materials and take steps leading to positive health outcomes (Harding et al., 2017; Squiers et al., 2012). Yet, there is a paucity of research relating these variables together.

**Social support received.** Having adequate social support, such as a person to attend medical appointments with the patient, can provide the patient with an extra set of ears and eyes to obtain the information and improve health outcomes. Receiving adequate social support has a positive impact on the actions of a patient after the health care visit such as retaining, retrieving, using, and seeking health information (Squiers et al., 2012). One study found that having friends and family attend a transplant education session increased the rate of evaluation completion in ESRD patients (Patzer et al., 2012). Another study found that African-American ESRD patients and post-kidney transplant patients preferred receiving social support throughout the transplant evaluation process (Lewis, Dolph, Said, Feeley, & Kayler, 2018).

**Neighborhood safety.** Some researchers suggest that neighborhood safety in low-income areas is an important contributor to health disparity (Cohen et al., 2003). These authors propose that people who live in the lower socioeconomic neighborhoods that have safe areas for exercise (e.g., walking) are more likely to have opportunities to interact and involve participation of physical activities and exchange of health information leading to positive health outcomes among people living with chronic disease (Cohen et al., 2003).
Exchanging health information with others plays an important role in general health literacy. No articles in African-Americans on dialysis were found that include neighborhood safety and its relationship to general health literacy, making efforts to learn educational materials, or taking steps to kidney transplant.

**Medical trust.** Studies have shown that African-Americans reported lower medical trust than White-Americans (Doescher et al., 200; Isaac & Williams 2009; Saver, Franks, & Fiscella, 2000; LaVeist et al., 2001; Nickerson, & Bowie 2000). Lower medical trust is associated with poor medical adherence such as decreased medication compliance, fewer self-care behaviors, and lower patient satisfaction with care (White et al., 2016). In transplant, lower medical trust has been attributed to reluctance to donate organs, which may lead to a larger number of the African-Americans waiting on the deceased donor transplant list due to the shortage of histocompatible donors (LaVeist et al., 2000; Robinson et al., 2015). History has documented the exploitation of African-Americans in medical research, and two well-known examples are the Tuskegee study and the story of Henrietta Lacks. One modifiable aspect of medical trust is the interpersonal interactions with patients. Communication with patients, who are vulnerable by having limited general health literacy, limited resources, and a negative post experience in healthcare, may influence perceived quality of care and provider communication (White et al., 2016).

**Preparation for Kidney Transplant**

**General health literacy.** Researchers have identified three key concepts for preparation for kidney transplant that include general health literacy, the
ability to learn educational materials, and the ability to take steps to pursue kidney transplant (Lipford et al. 2018). Limited general health literacy in ESRD patients has been linked to poor health behaviors and outcomes, and an even higher risk of death (Cavanaugh et al. 2010). Another study suggests general health literacy may be associated with the ability of ESRD patient to learn educational materials and take actions leading to positive health outcomes (Wong et al. 2018).

**Making Efforts to Learn Educational Materials**

Multiple research studies have shown there is a lack of knowledge about kidney transplant in ESRD patients (Boulware et al. 2018, Patzer et al. 2012, Rodrigue et al. 2006, Traino et al. 2017, Waterman & Piepert, 2018). Most health care providers offer printed materials as a way to educate patients. Efforts to learn educational materials about transplant include reading brochures, watching videos, talking with health care providers, letting friends and family know about interest in deceased and living kidney transplant. Patients making efforts to learn is critical. Without this effort, patients will likely not even consider kidney transplant as a treatment option.

**Taking Steps to Pursue Kidney Transplant**

After reading educational materials to learn about kidney transplant, thinking about taking steps to pursue transplant is essential. From the beginning of the transplant evaluation through approval of getting a transplant, the process is complicated and extensive, requiring a patient to complete many calls, lengthy
forms, medical tests, and appointments. This process is understandably
overwhelming for those with limited general health literacy.

In summary, demographics, and medical trust have been associated with
general health literacy (White et al., 2013) but social support received has not
(Geboers, Reijneveld, Janson, & Winter 2016). The factors that are associated
with making efforts to learn educational materials, and taking steps toward kidney
transplant are unknown.

**Methods**

The current study used a data-driven approach to analyze secondary data
obtained from "Explore Transplant at Home" (ETH) project developed and
implemented (Waterman et al. 2018). The original data were obtained from
patients in the Missouri Kidney Program (MoKP). This program provides
education and subsidized dialysis and transplant medications expenses for
approximately 1,200 low-income, English-speaking patients, aged 18 and older in
the state of Missouri. Exclusion criteria of the original project were patients who
had been previously transplanted or told they were not a transplant candidate.
The baseline data from the original project was used for secondary analysis in
the current study. All eligible participants completed a 45-minute phone survey.
The current study focused on African Americans (n=399) living in Missouri, aged
18-74 years old, with a confirmed diagnosis of ESRD, on dialysis, with a
household income at or below 250% of the federal poverty level, and were able
to speak and read English (Waterman et al., 2015). The sample size of 399
exceeded the minimum requirement of 55 participants needed to achieve a
statistical power of 0.80, a reasonable effect size of 0.5, and an alpha of 0.05, based on the G*Power program (Faul et al., 2009). The sample size requirements of at least ten to twenty participants per independent variable was met for regression analysis (Faul et al., 2009; Tabachnick & Fidell, 2007).

**Measurements**

**Neighborhood safety.** One single question was asked to measure the degree to which the participants felt safe in their neighborhoods. The question has three response options: 1=not safe, 2=somewhat safe, and 3=very safe. Higher scores indicate a greater sense of safety in their neighborhoods.

**Social support received.** One single question was asked to measure how much help or support the participants received related to their kidney disease in the past six months. The question response options: 1=none, 2=a little, 3=some, and 4=a great deal. Higher scores indicate greater social support received in the past six months.

**Medical trust.** Seven questions were asked to measure the levels of mistrust of healthcare organizations using the Medical Mistrust Index (MMI), which is a 7-item, 4-point Likert-type scale. Each question has four response options: 1=strongly agree, 2=agree, 3=disagree, and 4=strongly disagree (Laveist, Isaac, & Williams, 2009). The possible range of scores was 6-28. Higher scores indicate greater medical trust in healthcare organizations. The MMI is a robust indicator of medical trust, has reasonable test-retest reliability, and is correlated with the Trust in Physicians Scale (TIPs), reflecting good construct validity (LaVeist et al., 2009). The MMI has been widely used in
multiple studies including diverse populations such as those with low income and African-American (Artinian et al., Lange, Templin, Stallwood, & Hermann, 2003; Wolf, Feinglass, Thompson & Gazmararian, 2007; Beers et al., 2003; McDonald, Quistberg, Ravenell, Asch & Shea, 2003; Hammond, 2011; Kirsch, 1993; Paaschel-Orlow et al., 2005).

**General health literacy.** Two questions were asked to measure general health literacy using the Brief Health Literacy Screen (BHLS), which is a 5-point, Likert-type scale (Cavanaugh et al. 2015; Chew et al., 2008). One question asked, “How confident are you filling out forms by yourself?” Each item scored from 1=none of the time, 2=a little of the time, 3=some of the time, 4=most of the time, and 5=all of the time. The other question asked, “How often do you have someone help you read hospital materials?” Each item was reversed scored as follows: 1=all of the time, 2=most of the time, 3=some of the time, 4=a little of the time, and 5=none of the time.

A total score for the BHLS of 2 through 6 indicates limited general health literacy, 7 through 8 indicates marginal general health literacy, and 9 through 10 indicates adequate general health literacy. Both items were useful in detecting limited general health literacy in patients with the Veterans Affair (VA) outpatient population (Chew et al., 2008). The internal consistency reliability in patients cared for in clinic or hospital settings were good with a Cronbach alpha of .80 (Wallston et al., 2014). Construct validity was demonstrated, given strong correlations with the S-TOFHLA and REALM (Cavanaugh et al., 2015; Wallston et al., 2014).
Efforts to learn educational materials. Six yes/no questions were asked to measure what efforts participants made to learn about kidney transplant. The number of efforts ranged from 0–6. One example question was, “Have you watched videos on deceased or living donation?”

Steps taken to pursue kidney transplant. Four yes/no questions were asked to measure steps taken to pursue kidney transplant. There is no relative order among the four steps. The number of steps taken ranged from 0-4. One example question was, “Have you called the transplant center to begin evaluation?”

Statistical Analyses

Data were analyzed using SPSS 25. With less than 1% of data missing, listwise deletion was used to exclude cases with incomplete data (Belin, 2009). Descriptive statistics were used to describe the characteristics of the participants and the distribution of variables. Cronbach’s alpha was used to determine the internal consistency reliability of the medical trust and general health literacy instruments. Pearson’s correlation was used to answer Research Question 1. Multiple linear regression analysis was used to answer Research Question 2.

Results

Participant Characteristics

The mean age of the sample (n=399) was 52.9 years (SD=10). The sample was made up of 50.6% males and 49.4% females (Table 1). The majority of participants (54.2%) had less than some college or vocation school. Almost all participants (97.8%) had one or more health insurance policies, with 84.5%
receiving Medicare and Medicaid. Over half of the participants (68.4%) felt very safe in their neighborhood, 29.8% felt somewhat safe, and 1.5% did not feel safe. Over one-third of participants (35.8%) received a great deal of social support. About 74.4% of the participants had marginal or adequate general health literacy, and 25.6% had limited general health literacy.

Regarding confidence in filling out forms by themselves, 82.2% of participants were confidence ranging from some to none of the time. In addition, 86.3% needed someone to help them read hospital materials at least some of the time. An overall mean score of 8.04 (SD=2.04) indicates marginal general health literacy. Specifically in participants with limited general health literacy with a score of less than seven, 19.98% felt no confidence in filling out the forms by themselves and 19.6% did not have help from family members, friends, hospital/clinic workers, or caregivers to read hospital materials.

For efforts to learn educational materials, the majority had talked to medical staff about transplant (84.0%), spoken to their family members or friends about getting on the transplant waiting list (77.2%), read brochures about transplant (72.9%), and/or spoken to their family members or friends about getting a living donor transplant (55.6%). On average, participants used about half of these types of educational materials.

Regarding taking steps to pursue transplant, 37.1% of the participants had called the transplant office to begin the evaluation. The numbers of participants, who had completed and mailed back the transplant office’s new patient medical forms (28.6%), was similar to the number that had completed medical tests
(25.8%). Only 18.3% had completed the transplant evaluation process by following-up with the transplant coordinator. On average, participants took few steps to pursue kidney transplant. Overall the participants reported a mean medical trust score of 19.63 (SD=4.59), reflecting a mid to somewhat high range.

Table 1

**Participant Characteristics**

<table>
<thead>
<tr>
<th>Variables</th>
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<th>%</th>
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</thead>
<tbody>
<tr>
<td><strong>Sex (n=399)</strong></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>202</td>
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<tr>
<td>Female</td>
<td>197</td>
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<tr>
<td>8th grade or less</td>
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<td>Some high school</td>
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<td>High school diploma or GED</td>
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<td>Some college or vocational school</td>
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<td>33.6</td>
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<td>College degree and above</td>
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<tr>
<td>Other government (VA)</td>
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<td>1.8</td>
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<tr>
<td>No or not listed or unknown</td>
<td>10</td>
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<tr>
<td><strong>Neighborhood Safety (n=398)</strong></td>
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<tr>
<td>Very safe</td>
<td>273</td>
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<td><strong>Social Support Received (n=397)</strong></td>
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<td>Some</td>
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<td>A little</td>
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<td>20.3</td>
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<tr>
<td>None</td>
<td>63</td>
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</table>

**General Health Literacy (n=398)**

Confident filling out forms
- All of the time: 5 (5.0)
- Most of the time: 13 (12.9)
- Some of the time: 40 (39.6)
- A little of the time: 23 (22.8)
- None of the time: 20 (19.8)

Help with hospital materials
- All of the time: 20 (19.6)
- Most of the time: 26 (25.5)
- Some of the time: 42 (41.2)
- A little of the time: 8 (7.8)
- None of the time: 6 (5.9)

**General Health Literacy Level (n=399)**

- Adequate health literacy: 201 (50.4)
- Marginal health literacy: 96 (24.0)
- Limited health literacy: 102 (25.6)

**Making Efforts to Learn Educational Materials (n=399)**

- Talked to medical staff: 335 (84.0)
- Spoken about getting on waitlist: 308 (77.2)
- Read brochures: 291 (72.9)
- Spoken about living donor: 222 (55.6)
- Browsed the internet: 114 (28.6)
- Watched videos: 104 (26.1)

**Taking Steps to Pursue Kidney Transplant (n=399)**

- Called the transplant office: 148 (37.1)
- Completed and mailed back packet: 114 (28.6)
- Completed the medical tests: 103 (25.8)
- Completed transplant process: 73 (18.3)
Results of Research Question 1

Correlations are presented in Table 2. Findings suggest that older participants were significantly less likely to make efforts to learn educational materials \( r = -0.17 \) and take steps to pursue kidney transplant \( r = -0.17 \).

Table 2

<table>
<thead>
<tr>
<th>Variable</th>
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<td>1. Age</td>
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<td>-.17**</td>
<td>-.17**</td>
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<tr>
<td>2. Sex</td>
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<td>.02</td>
<td>.04</td>
</tr>
<tr>
<td>3. Educational Attainment</td>
<td>.20**</td>
<td>.21**</td>
<td>.20**</td>
</tr>
<tr>
<td>4. Number of Health Insurance Policies</td>
<td>.06</td>
<td>.13*</td>
<td>.10*</td>
</tr>
<tr>
<td>5. Neighborhood Safety</td>
<td>.19**</td>
<td>.00</td>
<td>-.02</td>
</tr>
<tr>
<td>6. Social Support Received</td>
<td>-.01</td>
<td>.06</td>
<td>.04</td>
</tr>
<tr>
<td>7. Medical Trust</td>
<td>-.04</td>
<td>-.08</td>
<td>-.09</td>
</tr>
<tr>
<td>8. General Health Literacy</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>9. Making Efforts to Learn Educational Materials</td>
<td>.03</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>10. Taking Steps to Pursue Kidney Transplant</td>
<td>.11*</td>
<td>.39**</td>
<td>1</td>
</tr>
</tbody>
</table>

Note. *\( p \leq .05 \), **\( p \leq .01 \)
Females ($r=0.10$) had higher general health literacy than males. Higher educational attainment ($r=0.20$) was associated with higher general health literacy, with making more efforts to learn educational materials ($r=0.21$), and with taking more steps to pursue kidney transplant ($r=0.20$). Participants who had more health insurance policies made more efforts to learn educational materials ($r=0.13$) and took more steps to pursue kidney transplant ($r=0.10$). Furthermore, participants feeling safer in their neighborhood ($r=0.19$) reported higher general health literacy. Higher general health literacy ($r=0.11$) and making more efforts to learn educational materials ($r=0.39$) were associated with taking more steps to pursue kidney transplant (Figure 1).

Results of Research Question 2

**Predictors of general health literacy.** Neighborhood safety ($\beta=0.21$) had the strongest predictive power, followed by educational attainment ($\beta=0.20$), and
sex ($\beta=.10$; Table 3; Figure 1). Those who perceived their neighborhoods to be safe, had more education, and were female were more likely to have higher general health literacy. The overall model [$F(7, 388)=5.74$, $p<.001$, $R^2=.09$] explained 9% of the variance in general health literacy.

Table 3

Predictors of General Health Literacy

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE</th>
<th>ST $\beta$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
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<td>.01</td>
<td>-.03</td>
<td>.61</td>
</tr>
<tr>
<td>Sex</td>
<td>.42</td>
<td>.20</td>
<td>.10*</td>
<td>.04</td>
</tr>
<tr>
<td>Educational Attainment</td>
<td>.37</td>
<td>.09</td>
<td>.20**</td>
<td>.001</td>
</tr>
<tr>
<td>Number of Health Insurance Policies</td>
<td>.18</td>
<td>.19</td>
<td>.05</td>
<td>.35</td>
</tr>
<tr>
<td>Neighborhood Safety</td>
<td>.86</td>
<td>.20</td>
<td>.21**</td>
<td>.001</td>
</tr>
<tr>
<td>Social Support Received</td>
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<td>.09</td>
<td>-.05</td>
<td>.35</td>
</tr>
<tr>
<td>Medical Trust</td>
<td>-.01</td>
<td>.02</td>
<td>-.02</td>
<td>.71</td>
</tr>
</tbody>
</table>

$F(7, 388)=5.74$

$R^2=.09$

*Note. SE=Standard Error; ST $\beta=$Standardized $\beta$; *$p<.05$, **$p<.01$*

**Predictors of making efforts to learn educational materials.** Age ($\beta=-.18$) had the strongest predictive power, followed by educational attainment ($\beta=.17$), and the number of health insurance policies ($\beta=.13$; Table 4; Figure 1). Those who were younger in age, had more education, and had more insurance policies made more efforts to learn educational materials. The overall model [$F(7,
388) = 5.28, p ≤ .001, $R^2 = .09$] explained 9% of the variance in making efforts to learn educational materials.

Table 4

**Predictors of Making Efforts to Learn Educational Materials**

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE</th>
<th>ST β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.03</td>
<td>.01</td>
<td>-.18**</td>
<td>.001</td>
</tr>
<tr>
<td>Sex</td>
<td>.001</td>
<td>.16</td>
<td>.001</td>
<td>.10</td>
</tr>
<tr>
<td>Educational Attainment</td>
<td>.25</td>
<td>.07</td>
<td>.17**</td>
<td>.001</td>
</tr>
<tr>
<td>Number of Health Insurance Policies</td>
<td>.40</td>
<td>.15</td>
<td>.13*</td>
<td>.01</td>
</tr>
<tr>
<td>Neighborhood Safety</td>
<td>.06</td>
<td>.16</td>
<td>.02</td>
<td>.71</td>
</tr>
<tr>
<td>Social Support Received</td>
<td>.04</td>
<td>.07</td>
<td>.03</td>
<td>.63</td>
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<tr>
<td>Medical Trust</td>
<td>-.02</td>
<td>.02</td>
<td>-.06</td>
<td>.24</td>
</tr>
</tbody>
</table>

$F(7, 388) = 5.28$

$R^2 = .09$

**Note.** SE = Standard Error; ST β = Standardized β; *p ≤ .05, **p ≤ .01

**Predictors of taking steps to pursue kidney transplant.** Educational attainment (β = .19) had stronger predictive power than age (β = -.16; Table 5; Figure 1). Those who were more educated, younger, and had a higher number of insurance plans took more steps to pursue kidney transplant. The overall model \[F(7, 388) = 4.04, p < .001, R^2 = .07\] explained 7% of the variance in taking steps to pursue kidney transplant.
Table 5

Predictors of Taking Steps to Pursue Kidney Transplant

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B</th>
<th>SE</th>
<th>ST β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.02</td>
<td>.007</td>
<td>-.16**</td>
<td>.002</td>
</tr>
<tr>
<td>Sex</td>
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<td>.15</td>
<td>.02</td>
<td>.85</td>
</tr>
<tr>
<td>Educational Attainment</td>
<td>.25</td>
<td>.07</td>
<td>.19**</td>
<td>.001</td>
</tr>
<tr>
<td>Number of Health Insurance Policies</td>
<td>.09</td>
<td>.14</td>
<td>.03</td>
<td>.60</td>
</tr>
<tr>
<td>Neighborhood Safety</td>
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<td>.15</td>
<td>-.02</td>
<td>.70</td>
</tr>
<tr>
<td>Social Support Received</td>
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<td>.07</td>
<td>-.03</td>
<td>.50</td>
</tr>
<tr>
<td>Medical Trust</td>
<td>-.21</td>
<td>.02</td>
<td>-.06</td>
<td>.20</td>
</tr>
</tbody>
</table>

$F(7, 388)=4.04$

$R^2=.07$

Note. SE=Standard Error; ST β=Standardized β; *$p<.05$, **$p<.01$

Discussion

The purpose was to identify potential predictors of general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation in low-income African-Americans living with ESRD on dialysis. The current study found that several personal-psychosocial factors are associated with, and some are predictors of the general health literacy needed in preparation for kidney transplant.

Sample Characteristics

The percentage of females in the current study was comparable to previous studies. Most participants in the current study had less than a college degree and had both Medicare and Medicaid like the literature, findings in agreement with other studies (Boulware et al. 2018, Patzer et al. 2012, Rodrigue et al. 2006, Traino et al. 2017, Waterman & Piepert, 2018). One explanation for
why many participants had Medicare and Medicaid is that the participants in the current study had a household income at or below 250% of federal poverty level and were on dialysis, which is a disability.

**Associations Among Personal-Psychosocial Factors, General Health Literacy, Making Efforts to Learn Educational Materials, and Taking Steps to Pursue Kidney Transplant**

In the current study, age was correlated with making efforts to learn educational materials as well as taking steps to pursue kidney transplant. This finding is in agreement with previous studies, where aging impacts cognition and the ability to be able to retain information (Levinthal et al., 2008). While the current study did not measure cognition, higher age was associated with lower total scores for making efforts to learn educational materials and taking steps to pursue kidney transplant. The literature supports the move from dialysis to kidney transplant regardless of age so patients of all ages should be educated about the move to transplant.

Educational attainment was correlated with general health literacy, efforts to learn educational materials, and steps taken to pursue kidney transplant. These findings are consistent with previous studies in African-Americans ESRD patients on dialysis (Boulware et al. 2018; Rodrigue et al. 2006). Higher educational attainment is associated with higher general health literacy (Zimmerman et al. 2014). It is important that health care providers take the relationship between education and general health literacy, as to identify those at
risk and utilize evidence-based education methods to aid African-American patients to make efforts to learn and take steps to pursue kidney transplant.

**Predictors of General Health Literacy**

Consistent with previous studies, sex and educational attainment were found to be significant predictors of general health literacy (U.S. Department of Education, 2003). The current study supports the finding of previous studies by Cavanaugh et al. (2010) and Green et al. (2011) that limited general health literacy is common in African-American patients living with ESRD; many participants were in poverty. While many studies examined prevalence and correlations of general health literacy in ESRD, few are multivariant.

The current study found that participants’ perception of living in an unsafe neighborhood predicted general health literacy. While there are studies that focus on neighborhood safety related to health care outcomes, none was found that focused on general health literacy and neighborhood safety in African-Americans with ESRD. Consistent with previous studies (DeJesus et al. 2010, Robinette, Charles, & Gruenewald, 2016), participants in the current study with higher general health literacy perceived their neighborhood safe, were females and had more educational attainment. In a previous study comparing African American to white-American participants, African-Americans who had less than a college degree had significantly lower general health literacy (Shea et al., 2004). A household income at or below the 250% federal poverty level could influence the residual neighborhoods of the participants (Wilson, Kirtland, Ainsworth & Addy, 2004). Another reason could be higher educational attainment and being
younger; the education materials were easier to understand and apply. Also, older participants may hesitate to pursue kidney transplant due to viewing the process as too complicated with numerous appointments, medical testing, lengthy evaluation, and follow-up (Lipford et al. 2018). Furthermore, older participants were more likely to have more insurance policies but lower general health literacy. This finding suggests that an individual’s drive and ability to keep learning play a role in shaping general health literacy (Lipford et al. 2018).

As with the literature (van der Heide et al. 2013), the more educated participants had higher levels of self-confidence to fill out forms by themselves and required less help reading hospital materials. One explanation is that educational attainment influences the ability to read, comprehend, and apply health information. Feeling confident about being able to understand and answer all questions provides a drive for completing forms by themselves (Zimmerman, Woolf, & Haley 2014). Consistent with previous studies (Paaschel-Orlow et al., 2005; Shea et al., 2004, van der Heide et al. 2013), higher educational attainment was associated with higher general health literacy.

**Predictors of Making Efforts to Learn Educational Materials**

The current study found that age, educational attainment and the number of health insurance policies predicts making efforts to learn the educational materials. This is consistent with a study with previous findings by Boulware et al. 2018, Lipford et al., 2018, Rodrigue et al. 2006, Traino et al. 2017, and Waterman & Piepert, 2018.
Predictors of Taking Steps to Pursue Kidney Transplant

There are many interventional studies providing findings that increasing transplant knowledge improves the probability of participants starting and even completing the transplant evaluation (Arriola et al. 2014; Patzer et al., 2012; Rodrigue et al., 2014; Traino, West, Nonterah, Russell, & Yuen 2017; Waterman, & Piper, 2018). However, there were no studies found that identified personal-psychosocial factors as predictors of steps taken to pursue kidney transplant.

Limitations

One limitation of the study was that it was a secondary analysis in which the data were collected for a related purpose. Another is that all participants were from the state of Missouri. The strength of this research is that new knowledge was generated about the correlations of general health literacy and making efforts to learn educational materials with taking steps to pursue kidney transplant in African-Americans.

Implications

The findings have several implications. For practice, it is helpful to screen for limited general health literacy on all patients living with ESRD on dialysis before initiating referrals for kidney transplant. A more thorough evaluation is necessary for individuals with limited health literacy who answer no confidence in filling out the forms by themselves or need help from family members, friends, hospital/clinic workers, or caregivers to read hospital materials. The results of the thorough evaluation should be considered when designing individually-tailored kidney transplant educational plans for those with limited general health literacy.
The plan must match the learning style of the patient. Using the type of educational material that patients prefer is important. For research, using qualitative interviewing with African-Americans at or below the poverty level should be considered before designing educational strategies for this population. It is essential to study how to effectively encourage patients to start making efforts to learn educational materials because, if that can be accomplished, then patients can be helped to start taking steps toward kidney transplant.

Regarding policy, findings provide useful informational implications for policy makers to develop health service programs that could benefit African-Americans at or below the poverty level who need assistance with health insurance coverage, help with filling out forms needed, and help reading kidney transplant materials. Policy makers should pay attention to address various ethnic perspectives when providing additional social resources for patients who are unable to afford aspects of essential care for kidney transplant.

Conclusion

For African-Americans who live below the poverty level, their general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant are essential in preparation for kidney transplant. Making efforts to learn kidney transplant educational materials should be encouraged as this is associated with taking steps to pursue kidney transplant.
References (Manuscript Three)


Caucasian adults: disparities in rapid estimate of adult literacy in medicine (REALM) scores. *Family Medicine, 36*(8), 575-581.


Chapter 5 Summary

An integrative approach was used to provide an overview of known best practices from the broader literature that can be used as an evidence base to design improved education for ESRD patients pursuing a kidney transplant. The population was then narrowed to explore the state of the science on the effectiveness of educational trials in facilitating progress to kidney transplant in African-Americans. A secondary analysis of data was used to identify potential predictors of health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplantation in low-income African-Americans living with ESRD on dialysis.

The best educational practices in patients living with chronic disease include tailored education to the patient’s health literacy skills, cultural beliefs, and experiences, as well having patient navigators to help guide the patient through the process of transplant as well as the logistics of large health center. All of these aspects are important the ESRD patient pursuing transplant due to the complex evaluation required. However, there were specific interventions for the ESRD patients that were found in the integrative review those included transplant readiness, transplant knowledge, willingness to communicate about transplant, benefits, concerns, discussion with family, transplant evaluation, and living donor inquiries. Utilizing best practices to designing the key concepts of transplant education that emerged from the integrative review, may reduce barriers and improve the rate of African-Americans pursuing transplant.
The research completed in the transplant educational preparation of African Americans pursuing transplant is small. While the studies completed are of high quality and rigorous, results increasing the number of patients pursuing transplant remained small.

The cost of health literacy is high in both in money spent but also in the decreasing quality of life and increased morbidity. Assessing health literacy is not a standard of care.

A secondary analysis of data showed the following findings. General health literacy is associated with educational attainment, sex and neighborhood safety; for example, higher educational level, being female and perceiving your neighborhood as safe is associated with higher health literacy. In reviewing the associations for efforts made to learn educational materials, age, educational attainment and number of health insurance policies were significant. Therefore, younger participants who had higher educational attainment, and more health insurance policies made more efforts to learn educational materials. When examining the associations for steps taken to pursuing transplant, age, educational attainment and number of health insurance policies were significant. Those participants who were younger, had higher educational attainment, and more health insurance policies had taken more steps in pursuing kidney transplant.

Multiple regression was used to identify potential predictors of general health literacy, making efforts to learn educational materials and taking steps to pursue transplant. The current study found sex, educational attainment and
neighborhood safety to be predictors of general health literacy. The strongest predictor was neighborhood safety. There were no previous studies found by this author where neighborhood safety was a predictor for health literacy. Predictors of making an effort to learn educational materials were age, and educational attainment. The strongest predictor was educational attainment.

When examining predictors of steps taken to pursue kidney transplant age and educational attainment were significant. The strongest predictor was education attainment. The number of those with limited health literacy were comparable to results found in other studies. Additionally, the findings showed that limited health literacy reduced the number of steps a patient took to pursue transplant.

**Implications**

In order to make a difference in African Americans with ESRD pursuing transplant, change is necessary. Health care providers must review the current educational practices and adapt effective education interventions to reduce this disparity. The preferred setting would be in a classroom with support people present. The focus of the material should be on the improve transplant knowledge including risks, benefits, enabling conversations and resources. All materials should be culturally sensitive showing a diverse ethnicity in photos and stories of success. The availability of material and health care providers who are diverse will add the patient being able to see peer successes. Care must be taken to avoid disadvantaging patients who have limited access or comfort in using technology.
Identification of limited health literacy can be as simple as asking two questions. However, going further to assess neighborhood safety and education obtained can provide more information on the individual's needs pertaining to the understanding and applying the educational information provided. This can lead to tailored education where the frequency of the education needed can be based upon the individual patient's understanding and questions.

Future research should include phenomenology and ethnography approach in qualitative research to expand preferred educational methods and requirements that African-American ESRD patients need to pursue kidney transplant. Another area of research needs to address is the number and frequency of education interventions needed in this population. Finally, future studies on the development of effective interventions for promoting health literacy among those who live in a less safe neighborhood and less educated patients who are on dialysis to the pursuit of a kidney transplant.

Conclusion

For African-Americans who live below the poverty level, their general health literacy, making efforts to learn educational materials, and taking steps to pursue kidney transplant are essential in preparation for kidney transplant. Making efforts to learn kidney transplant educational materials should be encouraged as this is associated with taking steps to pursue kidney transplant.
References (not in manuscripts)


Comparing educator reported and medicare data. *Clinical Journal of the American Society of Nephrology, 10*(9), 1617-1625.