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The Journal of Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 1,000 social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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ISSN 1532-0863

THE JOURNAL OF
NEPHROLOGY SOCIAL WORK

Volume 37
Summer 2013

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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

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The Journal of Nephrology Social Work (*JNSW*) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. The *Journal* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics, (**http://www.socialworkers.org/pubs/code/code.asp** ; see clause 5.02 (a)-(p) focused on research). This portion of the code pertains to conflicts of interest, research with human participants, and informed consent. Per the code, "Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary." Authors who submit manuscripts to *JNSW* must disclose potential conflicts of interest which may include, but are not limited to, grants, remuneration in payment or in kind, and relationships with employers or outside vendors. When in doubt, authors are expected to err on the side of full disclosure. Additional information about conflicts of interest may be obtained via the International Committee of Medical Journal Editors' Uniform Requirement for Manuscripts Submitted to Biomedical Journals (URMSBJ): Ethical Considerations in the Conduct and Reporting of Research [**http://www.icmje.org/ethical_4conflicts.html**].

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Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

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Note: A sixth edition of the APA style guide has been published. However, there were errors in the first printing which were corrected in subsequent printings. For now, *JNSW* will adhere to the fifth edition.

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4) References
5) Appendices
6) Author note
7) Footnotes
8) Tables
9) Figures
10) Figure captions

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the APA style guide for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

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Reference Examples

Journal Article, Two Authors

Wassner, S. J., & Holliday, M. A. (1989). Protein metabolism in chronic renal failure. *Seminar in Nephrology, 9*, 19–23.

Journal Article, Three to Six Authors

Gartner, J., Larson, D. B., & Allen, G. D. (1991). Religion commitment and mental health: A review of the empirical literature. *Journal of Psychology and Theology, 19*, 6–25.

Journal Article, More Than Six Authors

Larson, D. B., Sherrill, K. A., Lyons, J. S., Craigie, F. C., Thielman, S. B., Greenwold, M. A., et al. (1992). Associations between dimensions of religious commitment and mental health reported in the *American Journal of Psychiatry* and *Archives of General Psychiatry*: 1978–1989. *American Journal of Psychiatry, 149*, 557–559.

Journal Article in Press

Odaka, M. (in press). Mortality in chronic dialysis patients in Japan. *American Journal of Kidney Diseases*.

Complete Book, Edited

Levine, D. Z. (Ed.). (1983). *Care of the renal patient*. Philadelphia: Saunders.

Chapter of an Edited Book

Nixon, H. H. (1966). Intestinal obstruction in the newborn. In C. Rob & R. Smith (Eds.), *Clinical surgery* (pp. 168–172). London: Butterworth.

Article from a Journal Supplement

Paganini, E. P., Latham, D., & Abdulhadi, M. (1989). Practical considerations of recombinant human erythropoietin therapy. *American Journal of Kidney Diseases*, *14*(Suppl. 1), 19–25.

Abstract

Bello, V. A. O., & Gitelman, H. J. (1990). High fluoride exposure in hemodialysis patients [Abstract]. *American Journal of Kidney Diseases, 15*, 320.

Editorial

Piantadosi, S. (1990). Hazards of small clinical trials [Editorial]. *Journal of Clinical Oncology, 8*, 1–3.

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If a manuscript is accepted for publication, the author will be required to send the following to the editorial office:

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The Chronic Disease Self-Management Program:
A Resource for Use with Older CKD Patients

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This commentary will briefly highlight the importance of promoting chronic disease self-management among older adults who are disproportionately affected by chronic kidney disease (CKD) stage 5. Older adults represent the fastest-growing segment of the CKD stage 5 population. Undoubtedly, the rapidly aging population will present new challenges and demands for the CKD health care community. The Chronic Disease Self-Management Program (CDSMP) is one existing intervention that has been recognized as potentially having utility for use with the CKD population. In this paper, we highlight opportunities for expanding the CDSMP to the population of older adults undergoing hemodialysis. The CDSMP is a six-week, lay-led, evidence-based program that includes interactive activities, such as behavior-specific action plans to improve chronic disease self-management behaviors. The CDSMP covers a wide range of health-related topics, including dealing with emotional struggles, effective communication, exercise, and nutrition. Special considerations for effective implementation of the CDSMP in hemodialysis settings are emphasized.

INTRODUCTION

Living with a chronic disease can be burdensome, often resulting in high levels of depression and low levels of quality of life (Centers for Disease Control and Prevention, 2007; Kimmel & Peterson, 2006). Patient-centered health promotion strategies, such as chronic disease self-management, can lessen the burden of chronic disease (Beattie, Whitelaw, Mettler, & Turner, 2003). Chronic disease self-management refers to an individual's ability to manage the symptoms associated with a disease, and perform daily tasks to reduce the impact of a disease on one's physical status (Lorig & Holman, 2003). The concept of self-management is important for many chronic conditions, and chronic kidney disease (CKD) is no exception. Self-management of CKD, like other chronic conditions, requires long-term behavior change and attention to dietary and medication management (Browne & Merighi, 2010; Kammerer, Garry, Hartigan, Carter, & Erlich, 2007). Other aspects of CKD self-management include regulation of fluid intake, blood pressure and electrolytes, and vascular access care (Mason, Khunti, Stone, Farooqui, & Carr, 2008; Richard, 2006). Currently, comprehensive self-management programs to reduce the health-related burdens and improve quality of life experienced by older CKD stage 5 patients in particular, are limited (Curtin, Mapes, Schatell, & Burrows-Hudson, 2005). While some interventions show promise, others lack rigor and are not always guided by theory (Chodosh et al., 2005; Mason et al., 2008). Furthermore, self-management programs targeting socially disadvantaged CKD stage 5 subgroups who may experience difficulties accessing low-cost, community-based resources are scarce (Becker, Gates, & Newsom, 2004). This commentary will briefly highlight the importance of promoting chronic disease self-management among older adults who are disproportionately affected by CKD stage 5, and discuss the potential applicability of one existing, accessible program that is designed to help people living with chronic disease manage their conditions successfully.

CKD IN THE AGING POPULATION

CKD is a serious chronic condition with significant health and health care cost implications for aging populations who have poorer clinical outcomes when compared to other subgroups (Nzerue, Demissachew, & Tucker, 2002). Older adults with CKD are at increased risk for cardiovascular disease morbidity and mortality (Stevens et al., 2010). Forty years ago, people with CKD stage 5 were younger and healthier than individuals in stages 1-4 (Stevens, Viswanathan, & Weiner, 2010). Today, older adults are the fastest growing segment of the CKD stage 5 population. The 2010 United States Renal Data System Annual Data Report identified an important and emerging issue with regard to the aging population; that is, aging baby boomers will greatly contribute to the growth of the CKD stage 5 population (USRDS, 2010). In recent years, the adjusted incident rate has increased by nearly 10% for adults age 75 and older, and between 1978 and 1999, the incident rate of patients age 65 and older has risen from 27% to 48%, respectively (Silva, 2005). This is a cause for concern, particularly given that older adults are already at risk for chronic diseases, such as diabetes and arthritis (Centers for Disease Control and Prevention, 2007).

It is no surprise, then, that the Centers for Disease Control and Prevention's State of Aging and Health in America report (2007) identified seven top priority calls to action, six of which are related to self-management behaviors among older

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adults. Nephrology professionals may consider introducing new programs that emphasize greater patient involvement to reduce the overwhelming impact of CKD stage 5 on the lives of older adults. Introducing new programs that teach chronic disease self-management is timely and relevant, especially given the recent changes to the Conditions for Coverage for End-Stage Renal Disease facilities, in which the Centers for Medicare and Medicaid Services (CMS) places great emphasis on increased patient participation in their health care through better engagement of patients, or their designees, as active members of the interdisciplinary treatment team (Alt & Schatell, 2009; Federal Register, 2008 [§ 494.80]). This declaration promotes self-management by requiring facilities to educate patients about treatment options (V458), vascular access care (V550), dietary and fluid management (V562, V545, and V546), the dialysis experience, dialysis management, infection prevention, quality of life, rehabilitation, and coping (V562) (Alt & Schatell, 2009; Federal Register, 2008). Self-management programs are useful tools for educating patients about the various aspects of care, and empowering them to be more involved in their health care. This recognition by CMS is noteworthy, and provides an opportunity for nephrology professionals to encourage older patients to be active self-managers.

THE CHRONIC DISEASE SELF-MANAGEMENT PROGRAM

In light of the benefits of successful chronic disease self-management, one such program that shows promise when used with chronically ill older adults is the Chronic Disease Self-Management Program (CDSMP). Developed by Lorig and colleagues at Stanford University, the CDSMP was designed to promote successful self-management behaviors by empowering participants to take an active role in their health and health care, and is based on the assumptions that people with different chronic conditions will have similar self-management tasks, and will experience improved health by learning these tasks (Lorig et al., 1999; Lorig et al., 2001; Stanford Patient Education Center, 2012). This evidence-based intervention was evaluated in a randomized study of 952 patients with a mean age of 65 representing a variety of disease categories, and has been adapted for use with minority groups (Gitlin, Chernett, Harris, Palmer, Hopkins, & Dennis, 2008).

The program is offered in six lay-led two-and-a-half hour sessions consisting of interactive activities and homework assignments that address symptom management, exercise, nutrition, medications, and other important self-management topics (**Table 1.**). Participants receive a patient-friendly text that provides an overview of chronic disease and self-management, and offers useful tips and strategies for improving one's health status. For example, participants are guided through activities that promote positive and healthy self-talk as a way to use the mind to manage unpleasant symptoms (Lorig, Holman, Sobel, Laurent, Gonzalez, & Minor 2006). A diabetes version of the program also exists, which covers additional topics, including preventing hypoglycemia and reading nutrition labels. Guided by Social Cognitive Theory (Bandura, 1986), the program aims to increase self-efficacy through modeling (i.e., skill-building through observation) and

Table 1. *CDSMP Session Topics*

Session	Topics
Session 1	Overview of self-management Action plans (ongoing) Symptom management
Session 2	Problem solving (ongoing) Dealing with difficult emotions Exercise
Session 3	Pain management Nutrition
Session 4	Future plans for health care Effective communication
Session 5	Medications Making treatment decisions Managing depression
Session 6	Working with health care professionals Working with the health care system

Table 2: *Basics of a Successful Action Plan*

Action Plan Basics	Rationale
Something you want to do	The "self" in self-management implies that the patient (or designee) is the primary manager of his or her chronic condition.
Reasonable	The plan must be something you can expect to accomplish in a specified time period.
Behavior-specific	Being behavior-specific is the difference between "I want to avoid fluid overload" and "I will not drink more than 64 ounces of fluids daily."
Answers the question: What?	Exactly what is the behavior the patient desires to achieve?
Answers the question: How much?	How much of the behavior will the patient perform? For example, walk for 10 minutes.
Answers the question: When?	When will the behavior take place? For example, walk for 10 minutes after dinner.
Answers the question: How often?	How often will the behavior occur? For example, walk for 10 minutes after dinner for one week.
Confidence level	On a scale from 1 to 10, a confidence level of at least 7 indicates the behavior is likely to occur.

Adapted from Lorig et al., 2006, p. 23.

mastery (i.e., skill-building through repeat performance of a task). Also, the program emphasizes short-term planning through the development of an action plan, an essential self-management tool (Lorig, et al., 2006). Action plans are behavior-specific, allowing participants to identify tasks that must be performed. The basics of a successful action plan are listed in **Table 2**.

Funding from the Administration on Aging to 45 states, the District of Columbia, and Puerto Rico has increased CDSMP offerings in a variety of community settings, including senior centers, churches, and libraries in the United States (Administration on Aging, 2011). In North Carolina, for example, the Division of Aging and Adult Services and the Division of Public Health have enacted a campaign to offer the CDSMP throughout the state to reduce the impact of chronic disease on older adults. Health care professionals and people living with a chronic disease who have completed the program can receive training to offer the program in their respective clinics and facilities, complete with program materials. Social workers, physicians, and other health care professionals may refer their patients to participate in the CDSMP at no cost, or work with their local Area Agency on Aging (AAA) that is licensed to offer the program in their facilities and clinics. Some businesses are working with their AAA to offer the CDSMP to their employees. Other states are implementing the program using this or a similar model of dissemination. Dialysis facility social workers can find out about statewide CDSMP offerings, licensing, and training to offer the program in their facilities by contacting their local AAA or by visiting the Administration on Aging website at **www.aoa.gov**.

The CDSMP is recognized as having utility with the CKD stage 5 population (Curtain et al., 2005) because the workshops have been successful at increasing patients' confidence in their ability to successfully manage their disease. The CDSMP is an established program that offers an array of educational materials easily adaptable for the CKD stage 5 population. Most hemodialysis patients visit a dialysis facility three times per week for three to five or more hours each visit (NKUDIC, 2011); this substantial and consistent amount of contact with nephrology professionals lends itself to increased opportunities for engaging patients in disease self-management. Further, the camaraderie that often builds among CKD stage 5 patients due to their frequent and consistent interactions in the dialysis facility is yet another factor that may contribute to the success of disease self-management programs in CKD stage 5 settings.

OPPORTUNITIES FOR ADVANCING SELF-MANAGEMENT INTERVENTIONS

Among Older Adults with CKD Stage 5

Why is it important to advocate for improved self-management behaviors for older CKD stage 5 patients? The answer is simple—because they, too, can benefit from greater involvement in their health and health care. Older adults are at an increased risk for experiencing age-related physiological changes, such as visual and hearing impairment, declined physical functioning, malnutrition, and cognitive impairment (Falvo, 2009). These and related conditions increase the likelihood of poor psychosocial outcomes, such as economic hardships, depression, and isolation (Falvo, 2009). These same negative outcomes are exacerbated among older adults with CKD stage 5

(Silva, 2005). Thus, promoting disease self-management among older patients should become a priority due to its potential to improve quality of life, decrease health care utilization, and mitigate functional impairments. Disease self-management programs have proven useful for older adults with other serious illnesses (Lorig et al., 1999). Older CKD stage 5 patients may benefit from interactive self-management programs that are needs-focused and underscored by enhanced self-efficacy (Richard, 2006). The increasing demands that a rapidly aging population present on the health care system are inevitable. Therefore, it is in the field's best interest to promote self-management behaviors for older patients to lessen the impact of this growth on nephrology care.

Implementation Considerations

Special considerations are needed when implementing the CDSMP with any chronic disease population. First, issues such as high staff turnover, patient attrition, changes in corporate ownership, and regulatory changes act as barriers to successful implementation of interventions in health care settings (Buckwalter et al., 2009). When implementing the CDSMP, social workers should take into account these barriers, and develop strategies for overcoming them while maintaining fidelity to the program (Washington et al., in press). Second, given that there are marked disparities in both the incidence and prevalence of this disease among minority groups (e.g., the incidence rate among African Americans is 3.6 times greater than whites, (USRDS, 2010)), cultural considerations must be taken into account when implementing the CDSMP in this patient population. Social workers must consider adaptations that align with cultural values and practices such as the use of culturally appropriate language and marketing tools (Gitlin et al., 2008; Mingo, McIlvane, Jefferson, Edwards, & Haley, 2012). Third, although the CDSMP was designed for people living with many types of chronic disease, social workers might consider additional topics, such as vascular access care and fluid management when implementing this program with older adults in hemodialysis settings. Nonetheless, the CDSMP is one example of an effective self-management program that has proven useful for older persons living with chronic diseases.

CONCLUSION

With a core commitment to assisting patients in improving their self-management behaviors, health care professionals can help to ensure that all CKD stage 5 patients receive the high quality of care they deserve by implementing programs, such as the CDSMP. To achieve this, Browne & Merighi (2010) recommend a patient-centered approach in which the dialysis facility health care team works in collaboration with the patient to overcome barriers to successful self-management. Nephrology social workers are tasked with helping patients reduce psychosocial stressors and maximize their rehabilitation potential, and the CDSMP offers patients the opportunity to learn better self-management strategies to accomplish these goals. By increasing patient control over their own health, patients become more cognizant of any changes that occur, and more knowledgeable about the steps needed to return to their baseline level of health faster than they would without this type of self-awareness. Also, patients who can accurately assess their condition can better aid their health care providers by succinctly and efficiently relaying changes in their health. While more research is needed about the potential benefits of improved self-management behaviors among older CKD stage 5 patients, it is evident from the existing literature that programs like the CDSMP have positive potential with this population.

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The Talking About Live Kidney Donation (TALK) Social Worker Intervention: Putting it into Practice

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Live kidney transplantation (LKT) is underutilized among patients with kidney disease. Social workers may be particularly effective in helping patients and their families overcome barriers to considering and/or pursuing LKT because of their expertise in helping families confront challenging social and medical issues. Nonetheless, social workers' facilitation of patients' consideration of LKT has not previously been reported. The team at Johns Hopkins University developed and tested the Talking about Live Kidney Donation (TALK) Social Worker Intervention to improve patients' informed consideration of LKT. We provide practical guidelines for the implementation of the TALK Social Worker Intervention in clinical practice.

PATIENT AND FAMILY MEMBER DISCUSSIONS ABOUT LIVE KIDNEY TRANSPLANTATION

Many patients with chronic kidney disease (CKD) are unwilling to discuss the possible treatment option of live kidney transplantation (LKT), particularly with family members and friends, who may be eligible donors (Boulware, Hill-Briggs, Kraus, Melancon, Senga, Evans, et al., 2011; Kranenburg et al., 2009; Pradel, Jain, Mullins, Vassalotti, & Bartlett, 2008; Rodrigue, Cornell, Kaplan, & Howard, 2008). Patients cite a variety of reasons for their reluctance to talk about LKT, including fear that discussions may be misinterpreted as donation requests, concern about unintentionally inducing guilt or coercing family members, and doubt pertaining to their own ability to initiate such conversations (Boulware, Hill-Briggs, Kraus, Melancon, Senga, Evans, et al., 2011). If patients' perceived barriers to initiating conversations about LKT are not addressed, they risk waiting years for a deceased donor kidney and requiring dialysis during the interim (Gordon, 2001; Smith, Nazione, LaPlante, Clark-Hitt, & Park, 2011). Interventions that address barriers to early discussions about LKT and identify mechanisms to overcome these barriers, are needed to encourage LKT.

Social workers, because of their expertise in helping families confront challenging social and medical issues, could be particularly effective in helping patients and families overcome barriers to pursuing LKT. To our knowledge, however, interventions designed to help social workers facilitate patients' consideration and/or pursuit of LKT have not previously been developed. In the Talking About Live Kidney Donation (TALK) Social Worker Intervention study, we developed a social worker intervention to help patients with CKD and their families identify and overcome barriers to considering and/or pursuing LKT as a treatment option (Boulware et al., 2013; Boulware, Hill-Briggs, Kraus, Melancon, McGuire, Bonhage, et al., 2011). A detailed description of the TALK Social Worker Intervention research protocol has been published elsewhere (DePasquale, Hill-Briggs, Darrell, Boyer, Ephraim, & Boulware, 2012). When tested in a randomized controlled trial, the TALK Social Worker Intervention improved patients' consideration and pursuit of LKT in comparison to patients who received the usual care from their nephrologists (Boulware et al., 2013). In this paper, we provide practical guidelines for the successful implementation of the TALK Social Worker Intervention in routine clinical practice.

DELIVERING THE TALK SOCIAL WORKER INTERVENTION

The TALK Social Worker Intervention was delivered in three stages:

Stage 1: Pre-visit use of TALK educational materials;

Stage 2: Patient visits; and

Stage 3: Family member visits (see **Table 1.**)

Research study staff distributed intervention materials in Stage 1, and a trained social worker devoted specifically to the intervention delivered Stages 2 and 3. It took between 2 and 6 months for patients and their families to complete all three stages. We briefly describe each intervention stage below, and include transcript excerpts from intervention sessions to help implement the TALK Social Worker Intervention into clinical practice.

Stage 1: Pre-visit Use of the TALK Educational Video and Booklet

Prior to their first social worker visit, all patients received the TALK educational video and booklet during an in-person visit with research study staff. The TALK educational booklet and video were developed through a partnership between our investigative team at Johns Hopkins University and the National Kidney Foundation of Maryland (Boulware, Hill-Briggs, Kraus, Melancon, McGuire, et al., 2011). In brief, the educational video featured testimonials from patients, family members, health care providers, and social workers regarding key factors to consider when contemplating LKT as a treatment option. Similarly, the booklet contained "model

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conversations" to assist patients and family members with initiating discussions about LKT. Patients were encouraged to familiarize themselves with these materials prior to their social worker visits and to discuss their reactions regarding the content (e.g., comprehension of the content, positive or negative feedback, questions that may have arisen, etc.) with their social workers. Patients were also encouraged to share the TALK educational materials with their family members and/or friends.

Stage 2: Patient Visits

Step 1: Introductions and Background Information

Of the 43 patients enrolled in the TALK Social Worker Intervention, 14 refused participation. The remaining 29 patients attended both the initial and follow-up visits. The social worker met with each patient for approximately one hour (actual visit times ranged from 11 to 42 minutes in duration). At the beginning of each social worker visit, the TALK social worker introduced herself to patients and described her role in the meeting. The social worker often began each meeting by saying:

> *"As a clinical social worker… my role is [to] help folks to deal with or address issues around communication as it relates to your kidney disease and any treatments that apply to that. Part of my role is* [to] *help facilitate those conversations or help identify the barriers* [to] *having those conversations."*

The social worker then asked patients about their current stage of kidney disease ("How long have you been dealing with kidney problems?") and what steps, if any, they had taken to pursue treatment ("Tell me a little bit about where you are in your own process with treatment.").

Step 2: Referencing the TALK Educational Video and Booklet

The social worker next asked patients if they had watched the TALK video, read the TALK booklet, and/or shared these materials with family members or friends. If patients reported viewing, reading, or sharing the TALK educational video and booklet, the social worker asked patients for their reactions as well as any questions that may have arisen. If the patient had not viewed, read, or shared any of the TALK educational materials prior to their social worker visit, the social worker reminded patients of their significance:

> *"The intent of the DVD is* [to] *educate people about live kidney donation. It…may help to generate some conversation around it. So, using the video might be one way or another way of putting it out there and getting people to at least talk about it, to come to a clear understanding about the whole process, and certainly to even ask questions that they may have."*

Step 3: Identify Patients' Readiness to Consider and/or Pursue Live Kidney Transplantation

Based on the background information patients provided, the social worker proceeded to ask patients how prepared they felt to consider or pursue LKT by asking whether they had completed one of five behaviors;:

1) started the transplant the evaluation process;
2) completed the transplant evaluation process;
3) prepared for or held a discussion about LKT with their family members;
4) prepared for or held a discussion about LKT with their physician; and
5) identified a potential living kidney donor.

Immediately after assessing whether patients had completed these behaviors, the social worker asked patients to rate, on a scale ranging from 0 (totally unprepared) to 5 (no preparation needed), how prepared they felt to carry out these behaviors. The social worker provided each patient with a piece of paper outlining their specific question and response options, and often asked this question in the following way:

> *"… there is a specific question that I'm going to ask you…it's a scale of responses, okay?...This question hopefully will help us to identify any…barriers* [you may have] *with initiating conversations with family members and friends about living kidney donation…On a scale from 0 to 5, how prepared do you feel you are to talk with your family, your friends, about living kidney donation? Zero being totally unprepared; 1, not prepared; 2, almost prepared; 3, prepared; 4, fully prepared; and 5, no preparation needed."*

Step 4: Patients' Self-Identification of Barriers to Consideration and/or Pursuit of Live Kidney Transplantation

Depending on patients' reported degree of preparedness for each behavior, the social worker asked patients to self-identify barriers they perceived as inhibiting them from accomplishing behaviors that could lead to LKT (e.g., "What are the barriers to talking with your doctor?"); asked them to explain their plans for overcoming perceived barriers (e.g., "What are your plans for approaching your doctor about donation?"); and held discussions with patients about prior successes they had with achieving behaviors (e.g., "How did you approach your doctor about donation? How successful do you feel your approach was?").

The following is an example of such an interaction between the social worker and a patient:

> Social worker: *"So what are the challenges that you're facing in completing the evaluation process?"*
>
> Patient: *"Well, so I have to go meet a whole bunch of new medical employees and medical doctors, a whole bunch of people I don't know, tell them all my medical history, and I have to trust that they are going to be able to make decisions that feel okay with me."*
>
> Social worker: *"Okay."*
>
> Patient: *"And everybody's different. Do you know what I mean? Some of them are great and human, and some of them are like robots…next, next, next, kind of deal. And it's really kind of a very vulnerable position to be in….Plus they're going to be touching you and everything….I don't even go for a full body massage….I'm not having somebody touch my naked body that I don't know. Get out; that's my parts, you know?"*

Step 5: Facilitating Patients' Self-Identification of Solutions to Self-Identified Barriers

After discussing challenges to their consideration and/or pursuit of LKT, the social worker facilitated patients' self-identification of solutions to their self-identified barriers. For instance, a patient told the social worker that although she was interested in learning more about LKT, she struggled with initiating such a discussion with her doctor and needed help to overcome this barrier. To facilitate the patient's self-identification of a solution to her barrier, the social worker asked, "Well, what do you think would help you to feel a little more comfortable with asking her the questions?" The patient replied,

> *"Maybe being honest with myself. It's not that I'm not being realistic, because I know what my health issues are. Maybe it's dealing with it, dealing with the truth….I can take things, but maybe it's just my way of dealing with what I'm dealing with right now….I say 'well I'll deal with it if it comes up more later' and I shouldn't be like that."*

Step 6: Recommendations for Future Action

The social worker also made recommendations for future actions patients could implement to advance their consideration and/or pursuit of LKT (e.g., finding reliable sources of information about CKD, writing down questions prior to medical visits, becoming knowledgeable about the evaluation process, calling an insurance company to determine cost of LKT, etc.). For example, a patient told the social worker that he was struggling to complete the evaluation process due to his wife's recent cancer diagnosis. When the social worker learned that the patient had only one remaining step to complete in his evaluation process, she recommended the following:

> *"Well…it certainly is important that she gets taken care of, but it's also important, I'm sure, to your family that you get taken care of as well….It's difficult enough with one person being challenged as she is being challenged with her health, but if you were to get sick or had some kind of infection, and then the two of you ended up being medically challenged, I'm sure that it would be a tremendous stress for you, for her, for your family. So, it's not so much putting yourself before her, as much as it is taking care of you so you don't have to be concerned about you and can focus your energies on helping her."*

The patient agreed with the social worker and said, "You know, you're right. Okay, that sounds good. You're very right. If I get sick, we're both losing out."

Step 7: Inviting Family Members to a Follow-up Visit

The social worker concluded each visit by inviting patients to an optional follow-up visit in which family members or friends could attend. The social worker usually asked patients who would accompany them to the follow-up visit in order to get a sense of their role in the patient's disease management and/or treatment considerations. The social worker then used this information to determine how to approach the family members or friends and involve them in discussions at the follow-up visit.

Stage 3: Family Member Meetings

Optional follow-up visits with patients' family members and/or friends closely resembled the initial patient-social worker visits. The social worker met with patients and their family members for up to one hour (actual visits ranged from 10 to 69 minutes in duration). The intervention protocol did not provide the social worker with a specific script since family members/friends play a variety of roles in helping patients with their disease and selection of treatment. Instead, the social worker used the information patients provided at the end of their initial visit to determine which topics would be the most important to address in the follow-up visits. During the majority of follow-ups, the social worker either asked family members for their opinions or they voluntarily provided comments and questions without prompting. The goal was to help establish open lines of communication about LKT between patients and their family members and to identify barriers preventing this from occurring.

Step 1: Summarizing Key Points from the Patient's Initial Visit

In Step 1, with patients' consent, the social worker began by summarizing the key points of the initial visit to remind patients and update family members about what had been discussed. The social worker either made a simple summary statement, such as, "Well, the last time we met, one of the things we talked about was sharing the video with your family and friends. Have you had an opportunity to do that?" Or, the social worker directly addressed the family member(s) in attendance. For instance, during one such visit the social worker said,

> *"So, the first time that your grandfather was here, we really just talked about where he was in the process of* [dealing with] *his kidney disease, what the doctors were telling him,* [and] *what his understanding was about what was going on. And you were pretty much the person he talked* [the] *most about, in terms of you're the person that he talks to, and you know, that you seem to have a really good relationship."*

Step 2: Reassessing Progress in Consideration and/or Pursuit of Live Kidney Transplantation

After providing a recap of the initial visit for patients and their family members/friends, patients typically informed the social worker if they progressed in their consideration and/or pursuit of LKT since their initial visit. Based on this new information, the social worker either asked patients about their readiness to pursue other behaviors or discussed ongoing perceived barriers to pursuing LKT.

Step 3: Facilitating Patients' and Family Members' Self-Identification of Solutions to Self-Identified Barriers

After patients acknowledged any ongoing barriers to pursuing LKT, the social worker usually directed similar questions to family members to assess their own perceived barriers to pursuing LKT. For instance, if the social worker asked a patient about difficulties discussing LKT with others, she then directed questions toward family members to determine if they were experiencing similar difficulties.

Step 4: Recommendations for Future Action

As with patient visits, the social worker often provided recommendations for future actions to further consideration and/or pursuit of LKT. In family visits, the social worker's recommendations typically pertained to discussions between patients and their family members. In one such visit, a patient mentioned the difficulty she experienced in communicating with her husband about her disease:

> Social worker: *"And so, what about communication like* (sic) *with your family in terms of what's going on with your health?"*
>
> Patient: "*Well, I told my husband what the doctor had said, you know. He…he thinks I'm over-concerned and I want to be perfect or something."*

Table 1. *Steps for Implementation of the TALK Social Worker Intervention*

Stage 1: Pre-visit Use of TALK Educational Materials
Provide an educational video and booklet to patients during an in-person meeting
Stage 2: Patient Meetings
Step 1: Give initial introductions
Step 2: Discuss TALK educational materials
Step 3: Identify patient's readiness to consider or pursue LKT by assessing how prepared they are to: 1) discuss LKT with family, 2) discuss LKT with the physician, 3) start the LKT evaluation process, 4) complete the LKT evaluation process, or 5) identify a donor*
Step 4: Help patient identify barriers to considering and/or pursuing LKT
Step 5: Help patient identify their own solutions to barriers they identify in Step 4
Step 6: Provide recommendations for future action
Step 7: Invite family member(s) to a follow-up visit
Stage 3: Family Member Meetings
Step 1: Review what happened at the patient visit (with patient's permission)
Step 2: Reassess patient's progress in considering and/or pursuing LKT
Step 3: Facilitate a discussion between patient and family about their perspectives on ongoing barriers to considering and/or pursing LKT
Step 4: Provide recommendations for future action

**LKT = live kidney transplantation/donation*

> Family member (husband): *"I don't know. Seems like you worry…she worries too much about a lot of different things, you know? And I told her that I think a lot of things that she thinks is wrong with her is in her head, you know? 'Cause she appears to be healthy to me. But I don't know. I'm not a doctor…I mean, physically, to me, she's healthy. But she's always doing research about different diseases and stuff like that on the computer all the time, and like she's worried about things and don't appear to be sick to me."*

After the patient's husband made this statement, the social worker asked if he had attended any of his wife's doctor appointments or had spoken to any of her physicians. When he admitted that he had not, the social worker explained that when someone has a chronic illness, they may not always appear to be ill. The social worker then suggested that the patient and her husband try to reach a compromise. To help the patient's husband understand his wife's disease, the social worker suggested that he consider attending her medical visits so that "everybody's kind of on the same page." To address the husband's concerns that his wife was unnecessarily causing herself stress by searching for health-related information on the Internet, the social worker suggested that the patient consider reducing her Internet activity. This family visit exemplifies how the social worker enacted the role of a mediator between a patient and family members to establish lines of communication that did not previously exist.

CHALLENGES TO IMPLEMENTATION

As with any clinical intervention, the social worker encountered situations in which she had to individualize her approach. This most often occurred when the focus of patient and family member conversations drifted to topics that did not pertain to LKT. In addition, the social worker had to make appropriate adjustments when family members did not accompany patients to their second visit.

Conversational Drift

Conversational drift occurred during social worker visits whenever dialogue deviated from the topic of LKT for an extended period of time. For example, patients often described their relationship with family members when telling the social worker about any prior family discussions regarding LKT. This occasionally led to conversations not focused on CKD or LKT. In these situations, the social worker attempted to employ professional communication skills such as displaying empathy, echoing patients' sentiments, asking for questions, drawing patients' attention to another topic, thanking patients and their family members for their participation in the study, and notifying patients of the need to conclude the visit to regain focus on topics central to the TALK Social Worker Intervention.

Family Visits Without Family Members Present

While every patient attended both the initial and follow-up visits with the social worker, not all patients brought a family member with them to the follow-up visit. When patients arrived without family members for their second visit, the social worker delivered the intervention as she had done in the initial patient visit, by resuming discussions with patients about barriers they were facing in the consideration and/or pursuit of LKT.

COMMON EXPERIENCES WITH THE TALK SOCIAL WORKER INTERVENTION

The TALK Social Worker Intervention enabled patients, as well as their family members or friends, to work directly with an experienced clinical social worker to help them identify barriers they perceived as inhibiting their achievement of LKT. Patients and their families identified numerous barriers to their consideration and/or pursuit of LKT during social worker visits, including: patients' fear of including family members in LKT; fear, denial, or stress associated with considering LKT; difficulty completing the evaluation process; lacking of information about CKD; financial concerns; concerns regarding the long-term effects of transplantation or live kidney donation on their current lifestyles; prior surgeries or comorbidities; and patients' and families' concerns about medication (DePasquale et al., 2012).

The TALK social worker also facilitated patients' self-identification of solutions to self-identified barriers. After identifying solutions and receiving recommendations on how to feasibly achieve them, patients had time prior to their follow-up visit to enact proposed solutions and then report their progress. Patients and their families were also able to obtain additional information resources about CKD or LKT. Overall, the TALK Social Worker Intervention led to greater patient activity in the 6 months following the intervention regarding discussions about LKT, evaluations, or donor identification, compared to patients who did not participate (28% more activity with TALK Social Worker Intervention) (Boulware et al., 2013).

IMPLICATIONS FOR CLINICAL PRACTICE

Social workers possess numerous characteristics that could facilitate the effective implementation of interventions to improve patients' utilization of LKT, including their commitment to their clients' welfare, value- and goal-directed practice, and professional accountability (Rosen, 2003). Moreover, in a recent study that assessed patients' and family members' perspectives on the potential usefulness of social workers to facilitate LKT discussions, participants reported that social workers could support such discussions by communicating in lay terms, helping families discuss financial concerns, offering family members strategies for coping with patients' CKD, and assisting patients and family members in addressing sensitive topics (Boulware et al., 2013). The TALK Social Worker Intervention is a useful tool to help patients and their family members consider and/or pursue LKT as a treatment option. For future replication, this intervention should be adapted to different patient populations and clinical settings to help other patients and family members with the complexity of treatment decision making.

AUTHOR NOTE

The TALK Social Worker Intervention was developed jointly by researchers at Johns Hopkins University and the National Kidney Foundation of Maryland. Persons interested in obtaining the TALK educational video and booklet, as well as the TALK Social Worker Intervention program itself, can contact Dr. L. Ebony Boulware (email: **lboulwa@jhmi.edu**) or the National Kidney Foundation of Maryland (**www.kidneymd.org**).

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African-American Attitudes Toward Kidney Transplant: A Comparative Analysis

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

AFRICAN-AMERICAN ATTITUDES TOWARD KIDNEY TRANSPLANT: A QUALITATIVE STUDY

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

Many factors have been identified as to why racial disparities in transplantation continue to persist. Researchers have identified "patient-related barriers," including cultural and religious beliefs, lower socio-economic status, and lower health literacy and education levels (Gillespie et al., 2011; Holley, McCauley, Doherty, Stackiewicz, & Johnson, 1996; Navaneethan & Singh, 2006). Systematic barriers have also been identified and include physician bias based on perceptions of transplant suitability and quality of post-transplant outcomes for African-American patients (Ayanian, 2004). Klassen, Hall, Saksvig, Curbow, and Klassen (2002) reported a history of perceived discrimination led to distrust in the transplant process by African Americans, and decreased their likelihood of completing the transplant work-up. Studies have also shown that African Americans may receive less information about transplantation due to physician bias (Ayanian, 2004).

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

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

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

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METHOD

Participants and Data Collection

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

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

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

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

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

Table 1.

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

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

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

Table 2.

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

AA = African Americans

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

ANALYSIS

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

RESULTS

Influence of Pre-dialysis Care

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

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

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

Transplant Education

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

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

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

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

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

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

LIVING KIDNEY DONATION

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

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

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

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

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

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

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

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

> *"Most of my family members* [are] *diabetic so I know they couldn't* [donate]. *My daughter offered but she's diabetic so she couldn't* [donate]."

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

PREFERENTIAL TREATMENT

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

> *"Lifestyle factors, whether you smoke or drink. Probably your age."*

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

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

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

Or:

> *"People who have money. You know. More money than I do, I think."*

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

Motivations

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

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

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

> *"I know it would* [be better]. *'Cause then I wouldn't have to, you know, go through the filtering and just the process of it* [dialysis] … *I can function, like I am supposed to."*

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

Barriers

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

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

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

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

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

> *"…I see people come back down here that have already had a transplant and that kind of scares me."*

> *"…if I have a transplant and everything went well, I'm scared about getting sick again and having to come back. I wouldn't want that."*

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

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

DISCUSSION

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

Subjects who received ENC were much more likely to be either listed for a transplant or in the process of a work-up. Among the 9 listed subjects in this study, 78% received ENC. They were more likely to have no reluctance or ambivalence about seeking a transplant with a common theme of viewing dialysis as a "bridge" to transplant. This is consistent with earlier studies showing that those receiving ENC were more likely to be referred for transplant pre-dialysis or within the first few months of starting dialysis and more likely to be listed for transplant in general (Vamos et al., 2009). And the longer it takes to be referred for transplant, the less likely one is to ever be listed and receive a transplant (Klassen et al., 2002).

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

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

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

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

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

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

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

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

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

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

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

Approximately three-quarters of subjects, regardless of race and listing status, thought the process of getting listed was not biased, or said they did not know if there was any bias. The researchers did not know if this was because the interviewers were both Caucasian and African-American and the subjects did not feel comfortable admitting to perceived racial bias. However, African Americans were more likely than Caucasian subjects to suggest that wealthy individuals have an advantage in the transplant process. This may indicate that African Americans think there is an economic bias in the work-up process, which is partially true. Most transplant centers take into account the ability of a person to pay for immunosuppressive medications long-term in their work-up for transplant eligibility. There was no direct correlation between the perception of economic bias and a person's motivation toward seeking a transplant, but financial concerns were often mentioned as a general barrier to getting listed.

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

Limitations

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

CONCLUSION

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

Our findings lead to many implications for practice. Social workers are an integral part of the treatment team; they lead in providing education about transplant. For those who practice in dialysis units, renal social workers can use this study to recognize differences between how African American and Caucasian patients view transplant, and how these backgrounds can lead to different treatment options. Social workers have the expertise to recognize these differences, the role one's background plays in their decision-making process, and how to individualize patient education to optimize their treatment. For transplant social workers, this highlights the need to be more cognizant of the education that is being provided to patients prior to transplant work-up and how this affects their reactions to work-ups. It also is a call to recognize that ambivalence or hesitation may be manifestations of fears based on cultural perceptions or history and this should be recognized in the assessment process.

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

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Appendix A.

Interview Guide: Unlisted

1. a. When did you find out you needed to be on dialysis?

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

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

Interview Guide: Listed

1. a. When did you learn you needed to be on dialysis?

   b. Can you tell me how you found out you needed dialysis? Did you know prior to starting

   dialysis that you had kidney disease?
2. Prior to starting dialysis (or when you started on dialysis), what was your understanding of the kind of treatment you would need?
3. Were you given information about kidney transplant when you started dialysis?
   a) What information was given to you?
   b) What this information useful?
   c) Who has given you the most information about transplant?

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

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

Interview Guide: Listing Work-Up in Progress

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

    If NO, have you been given information about it since your initial diagnosis?
4. What is your understanding of how getting a transplant works?
    - a) How do you get on the transplant waitlist?
    - b) Do you know why a person may be taken off the waitlist?
5. What have you been told about using a living kidney donor instead of being waitlisted for a deceased donor?
6. Have you ever talked to your family members about being an organ donor? Why or why not?
7. You are currently going through the waitlist process. What kind of information would help you make a decision? In what format?
8. Can you tell me what the process has been like? What's been the hardest thing about? What has been the easiest thing about it?
9. Are there barriers to completing the process for you? Any specific financial barriers?
10. Do you think it's easier for some people to get listed and get access to the transplant waitlist, or is it about equal for everyone?
    - a) For whom is it easier to get listed?
    - b) Why?