

**Transplant Social Worker Support for Live Kidney Donation in African Americans**  
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**Abstract**

Live donor kidney transplantation (LDKT) represents an optimal therapy for many patients. However, African Americans have been persistently and significantly less likely to receive LDKT when compared to Whites. The process of seeking and establishing a live donor for LDKT requires potential donors overcome several potential obstacles to LDKT. As a critical first step to seeking LDKT, patients must engage their physicians and their family members or friends (who provide support for patients' health decisions and could also be potential donors) in discussions about LDKT to determine whether LDKT is a viable and/or desirable treatment option. LDKT discussions with physicians help patients and family members understand the risks and benefits of LDKT to both the potential recipient and any potential donors. Families' LDKT discussions help them establish whether it is possible to identify willing and medically eligible live donors, and they help families discuss the potential psychological, physical, and financial strains of LDKT on patients and families. Once discussions have occurred, potential donors must confront logistical (e.g., childcare or travel to transplant centers) and financial (e.g., unpaid time away from work) challenges associated with LDKT. Studies have shown that even when African American patients desire LDKT, rates of LDKT discussions are suboptimal. Further, African American potential live kidney donors are less likely than their White counterparts to complete the donor evaluation process, and they may be more sensitive than Whites to logistical and financial barriers to LDKT. Innovative strategies to overcome interpersonal, logistical and financial barriers to LDKT are sorely needed for African Americans, particularly those who may be highly motivated to seek this therapy. Transplant social workers routinely perform psychosocial evaluations on potential LDKT recipients and donors and are well suited to support families' navigation of LDKT discussions. Transplant social workers are also well versed in the financial aspects of LDKT (e.g., insurance coverage rules) and frequently provide financial guidance to potential LDKT recipients and donors. We propose to study innovative transplant social worker led interventions that will help African American potential LDKT recipients and their families overcome interpersonal, logistical and financial barriers to LDKT. We will randomly assign African Americans on the deceased kidney donor waiting list to receive their usual care on the transplant list or to one of two social worker led interventions—one which helps patients and families discuss LDKT with each other and with patients' physicians, and one which provides families with financial support to overcome logistical and financial barriers to LDKT. As a primary outcome, we will measure whether the interventions activate live kidney donation on African American potential recipients' behalves. The proposed study leverages our multidisciplinary team's substantial prior experience studying culturally sensitive interventions to overcome barriers to LDKT among African Americans.

**Primary Objectives**

We will study the effectiveness of highly innovative transplant social worker led interventions that intervene on key knowledge, interpersonal, logistical and financial barriers to live kidney donation for African Americans patients on the deceased donor kidney waiting list.

**Objectives and Hypothesis**

- A. Transplant Social Worker Educational and Behavioral Intervention.** In our previous work, we developed the Talking About Live Kidney Donation Social Worker Intervention (TALK SWI), a culturally sensitive educational and behavioral intervention to improve consideration and pursuit of live donor kidney transplants among patients with chronic kidney disease (CKD) and their families. TALK SWI is tailored to accommodate patients with low reading (i.e., 4<sup>th</sup> grade) and health literacy levels and helps patients and their

families overcome self-identified interpersonal barriers to discussing and pursuing live donor kidney transplants. TALK SWI educational materials were determined to be culturally sensitive based on our conduct of 8 focus groups of African American and non-African American patients with chronic kidney disease (with and without live donor kidney transplant experience) and their family members identifying their concerns about live donor kidney transplantation<sup>19</sup>. In a recently completed randomized controlled trial, we found TALK SWI was effective in improving rates of consideration and pursuit of pre-emptive live donor kidney transplantation among patients with stage 4 CKD not yet on dialysis.<sup>22</sup> We propose to study the effectiveness of the TALK SWI intervention to activate live kidney donation among African Americans who have recently registered on the transplant waiting list. We hypothesize the TALK SWI will be a powerful catalyst to increase live kidney donation for these patients who have already overcome some barriers to live donor kidney transplantation (i.e., completed the transplant evaluation).

- B. Transplant Social Worker Financial Assistance Intervention.** We hypothesize a financial assistance intervention delivered by transplant social workers to help patients and their potential donors overcome logistical and financial obstacles to live donor kidney transplantation will be well-received by social workers, patients, and their families.

If effective, our financial intervention will provide a rationale for potentially expanding current National Live Donor Assistance Center (NLDAC) policies. In a separately funded study, we are currently testing the effectiveness of a financial assistance intervention to improve access to live donor kidney transplantation among patients with end stage renal disease (ESRD) who are not yet on the transplant waiting list. We hypothesize that patients who are on the waiting list and highly motivated to receive a kidney (who we propose to study in this application) will view this intervention favorably. **The current study leverages our substantial previous work to develop and test these interventions. Our proposed study is a distinct and novel extension of our previous work in three ways:** (1) Placing the TALK SWI and the Financial Assistance Intervention in the transplant social work environment: Neither intervention has previously been studied in the transplant center, although this is a place where social workers are already routinely employed in clinical care. Social workers have all the skills necessary to execute both interventions, making this proposal a natural extension of our prior work. (2) Studying patients on the deceased donor transplant waiting list: We have not previously employed either intervention among patients waiting for a deceased donor kidney. Because these patients are highly motivated to receive kidneys, employing the interventions among this population could prove highly effective. (3) Combining TALK SWI with the Financial Assistance Intervention: We have not previously employed these interventions simultaneously. Because the interventions address distinct key barriers to African Americans' receipt of live donor kidney transplantation, we hypothesize combining them could have an additive effect in overcoming barriers to live donor kidney transplantation. To enhance the perceived long-term relevance of our interventions to African Americans, we will measure the cultural competence of the transplant social worker interventions using established measures developed by the Agency for Health Care Research and Quality<sup>35</sup> and tailor the interventions to enhance their cultural competence based on our findings.

## **Background and Significance**

### **Promise of Live Donor Kidney Transplantation to Address Disparities in Access to**

## **Kidney Transplants for African Americans**

Ethnic/race disparities in the incidence and prevalence of end-stage renal disease (ESRD) are striking. Over the past 20 years, African Americans have consistently had ESRD incidence and prevalence rates four times greater than Whites after adjustment for age and gender.<sup>1</sup> Kidney transplantation offers patients with ESRD several benefits, including improved survival and quality of life at less cost than that of dialysis care.<sup>2-6</sup> However African Americans have been persistently less likely than Whites to receive kidney transplants.<sup>7</sup> Donation rates of African Americans have remained disproportionately low relative to the need for transplants among African Americans when compared to donation rates of Whites for the past 10 years.<sup>1,7</sup> Suboptimal availability of deceased donor kidneys contributes to African Americans' longer waiting times on transplant waiting lists when compared to Whites.<sup>8</sup> Live donor kidney transplantation (LDKT) represents a promising strategy to improve access to kidney transplants for African Americans. LDKT not only offers improved outcomes over deceased donor transplantation but may also have the benefits of bypassing certain barriers to deceased donor kidney transplantation, including immunological incompatibility and longer waiting times.<sup>9-12</sup>

## **Barriers Faced by African Americans to the Pursuit of LDKT and Live Kidney Donation**

Despite technological improvements in LDKT (such as laparoscopic donor nephrectomy) and widely publicized successes of LDKT, African Americans with ESRD continue to trail behind Whites with respect to the receipt of LDKT.<sup>1,13,14</sup> A variety of barriers may contribute to persistently lower rates of LDKT among African Americans compared to Whites including (1) inadequate knowledge or awareness of LDKT as a treatment option; (2) interpersonal difficulties initiating and sustaining discussions with families and the health care team about LDKT; (3) difficulties identifying willing and medically eligible live kidney donors; and (4) logistical and financial barriers to live kidney donation.

### Inadequate knowledge or awareness of LDKT.

Studies show that African Americans with progressing chronic kidney disease (CKD) often have poor knowledge of transplantation as a treatment option when compared to their White counterparts.<sup>15</sup> Further, African Americans with ESRD often initiate dialysis therapy with little to no prior discussion of transplantation with their health care providers, limiting their knowledge of LDKT.<sup>16</sup> Inadequate health literacy (defined as the ability to understand health information) has also been linked to lower rates of transplantation<sup>17</sup> and may represent a barrier to receipt of LDKT for African Americans.

### Interpersonal difficulties initiating and sustaining discussions about LDKT.

African American patients often report they have difficulties initiating and sustaining discussions about LDKT with their families and health care providers<sup>8,11-14</sup>, which presents a major roadblock to their active pursuit and ultimate receipt of LDKT. Even when African American patients on dialysis state that they desire LDKT, they have been shown to discuss LDKT only variably with their closest family members and their physicians.<sup>18</sup> Discussions about LDKT help patients and families become informed about the risks and benefits of LDKT, explore the feasibility of identifying potential related donors, and take the steps necessary to complete donor and recipient medical evaluations in a timely manner. In studies, African American patients and their families have reported that their difficulties discussing LDKT stem from a variety of reasons, including their insufficient skill or discomfort with initiating discussions, their awkward feelings about discussing LDKT (e.g., concerns about coercing potential donors (for

patients) or about openly expressing hesitance to be evaluated (for family members), and their desires for professional support to help them navigate complex family issues related to LKT (e.g., needs of children or financial considerations).<sup>19,20</sup> Initiating and sustaining discussions may be particularly challenging to accomplish when many patients experience denial regarding their need to consider or discuss LDKT.<sup>19,21</sup> In our own recently completed study among patients with progressing CKD but who had not yet started dialysis, an intervention designed to enhance patients' and families' pre-emptive discussion of LDKT was associated with patients' greater pursuit of pre-emptive LDKT as a treatment option.<sup>22</sup>

#### Difficulties identifying willing and medically eligible donors.

Compared to Whites, African Americans may have pronounced difficulties identifying medically eligible and willing potential live kidney donors. African Americans in the general population are at greater risk than non-African Americans to experience diabetes and hypertension, the major risk factors for ESRD, which decrease their likelihood of being eligible to donate live kidneys.<sup>23-25</sup> African American family members of patients with ESRD may have even greater future risk of developing kidney disease when compared to those without a family history, adding further difficulty to identifying healthy related potential live kidney donors.<sup>26</sup> Because their likelihood for identifying potential donors with risk factors for ESRD is so high, African American potential LDKT recipients may need to identify many willing potential live donors, to improve their chances of identifying one medically eligible potential donor. Nonetheless, studies show that even when African Americans have no obvious contraindications to donation, they are less likely to complete their medical donation evaluations when compared to Whites with the same potential health risks.<sup>27</sup>

#### Logistical and financial barriers to LDKT.

Live kidney donation poses several potential logistical and financial hurdles, such as travel/lodging expenses, lost wages from time off work, and expenses for domestic help among donors which may pose substantial barriers to live kidney donation among African Americans.<sup>28</sup> A recent study of the general public identified potential living donors who were concerned about out of pocket expenses related to donation had 50% less odds of being willing to donate when compared to persons not concerned about expenses.<sup>29</sup> In a separate study, an overwhelming majority of the U.S. general public reported having favorable attitudes toward financial assistance programs which could help cover indirect costs for living donors, including costs associated with leave from work, with African Americans reporting significantly more favorable attitudes towards some forms of financial assistance when compared to Whites.<sup>30</sup> The recently established National Live Donor Assistance Center, which provides financial subsistence to low income families represents the first national effort to address financial needs of the very poor (i.e., 300 percent of the Department of Health and Human Services (HHS) Poverty Guidelines) for whom these financial and logistical challenges pose barriers to their being evaluated for live kidney donation.<sup>31</sup> To date, however, the studies demonstrating the effectiveness of this program or similar programs to enhance consideration or pursuit of live kidney donation among African Americans have not been published.

### **Value of Transplant Social Worker Led Education and Support Interventions to Improve LDKT and Live Kidney Donation among African Americans on the Deceased Donor Kidney Waiting List**

Interventions providing African American patients and families with the support they need to

overcome commonly encountered barriers to LDKT are critically needed. African American patients with ESRD who are waiting on the deceased donor kidney waiting list represent an excellent target population for such interventions, as they are highly motivated to receive transplants, have already overcome some barriers to receiving transplants (i.e., completed the transplant evaluation process), but may face barriers to identifying medically eligible and willing live kidney donors. Many transplant centers employ social workers to assess psychosocial needs of potential recipients and donors in the pursuit of LDKT.<sup>32</sup> Social workers are trained to help potential recipients and donors address a broad variety of challenging health-related problems<sup>33,34</sup> and may be particularly well suited to help patients navigate commonly encountered barriers to LDKT, including interpersonal barriers to initiating and sustaining LDKT discussions as well as identifying strategies (e.g., public or privately available programs providing financial assistance) to help them overcome logistical and financial challenges to LDKT. In our own previous work, patients with CKD and their families felt social workers could be particularly useful in helping them navigate often complex discussions about LDKT (including addressing issues such as potential donor coercion and discussing LDKT with children) as well as for helping them identify ways to overcome financial barriers to LDKT.<sup>19</sup> To date, however, effective interventions designed specifically to help social workers adequately address barriers to LDKT for African American potential recipients on the deceased donor kidney waiting list have not yet been established. Rigorously studied and effective transplant social worker led interventions could be employed widely across the US with confidence and could help to narrow ethnic/race disparities in access to kidney transplants.

## **Design and Procedures**

### **Conceptual Framework**

We will refine and test the effectiveness of transplant social worker led educational, behavioral support, and financial assistance interventions to overcome barriers to receipt of LDKT among African American patients awaiting deceased donor kidneys and their families. Our conceptual framework draws from the PRECEDE-PROCEED behavioral model. In the model, *Predisposing Factors* (including knowledge, beliefs, attitudes, values, and motivations) are antecedents to behavior and provide the rationale for motivation for health behaviors of interest. Interventions designed to activate patients and families toward LDKT must address predisposing factors that pose barriers to pursuit of LDKT.

*Reinforcing Factors* (such as social support, peer influence, significant others, and vicarious reinforcement) are factors that follow a behavior (e.g., potential recipient discussion and pursuit of LDKT) and provide continuing reward or incentive for the persistence or repetition of the behavior. For instance, interventions providing patients and their families with education and support for considering and pursuing LDKT may provide them with greater confidence to engage in behaviors leading to LDKT. *Enabling Factors* (such as programs, services, and resources necessary for persons to develop skills that enable health behavior changes) are antecedents to behavior that allow a motivation to be realized directly or indirectly through an environmental factor.<sup>59</sup> For instance, financial assistance interventions addressing their logistical and financial concerns could propel family members to donate. Our study interventions will intervene on *Predisposing Factors* which pose barriers to African American's pursuit of LDKT, including patients' and their families' inadequate knowledge of LDKT, interpersonal difficulties initiating and sustaining family discussions about LDKT and LDKT discussions with health care providers, and logistical or financial barriers to LDKT. We will perform a randomized

controlled trial to test the effectiveness of these transplant social worker led interventions as *Reinforcing* (through the effect of educational video and booklet providing basic education about LDKT and emphasizing the importance of engaging in discussion and pursuit of LDKT) and *Enabling* (by providing social worker support for family discussions about LDKT and by providing financial support to overcome logistical and financial barriers to live kidney donation). We hypothesize that the behavioral intervention will lead to patients' and families' greater pursuit of LDKT compared to usual care and the financial assistance intervention paired with the behavioral intervention will be most effective in increasing LDKT among African Americans on the kidney waiting list. Our primary outcomes will measure potential live kidney donors' activation toward donating.

## Overview of General Approach

We will study the incremental effectiveness of (1) an educational and behavioral social worker intervention and (2) a live donor financial assistance intervention to improve live donor activation and live kidney donation for African American patients on the deceased donor kidney transplant waiting list. The proposed mechanisms through which the interventions intervene on knowledge, interpersonal, financial, and logistical barriers to LDKT are listed in **Table 1**. In a two-phase study, we will first adapt the previously developed Talking About Live Kidney Donation (TALK) Social Worker protocol for use with transplant social workers (Phase 1), and we will then conduct a randomized controlled trial (Phase 2) to study the effectiveness of interventions to improve pursuit of LDKT (in recipients) and live kidney donation (among potential donors).

## Study Interventions

**1. TALK Educational and Behavioral Social Worker Intervention ("TALK SWI").** The Talking about Live Kidney Donation Social Worker Intervention (TALK SWI) is a culturally sensitive theory-based intervention, which we previously rigorously developed in collaboration with a behavioral psychologist, transplant nephrologists, transplant surgeons, transplant social workers, patient advocacy experts from the National Kidney Foundation of Maryland, and the input from patients and families with CKD and LDKT experience.<sup>39</sup> It consists of an educational module (booklet and video) as well as a social worker led brief behavioral support intervention to help patients and their families overcome barriers to considering and pursuing LDKT. In a recently completed randomized controlled trial, the TALK SWI was effective in activating patients to consider and pursue LDKT, including their increased engagement in LDKT discussions, their completion of LDKT medical evaluations, and their identification of potential live donors.<sup>22</sup> TALK SWI consists of (1) an educational module and (2) a protocol-driven social worker behavioral support intervention. TALK SWI directly addresses many concerns we previously identified among African American patients and families considering LDKT.<sup>19</sup>

- a. **TALK SWI Educational Module.** The TALK SWI education module consists of an educational 20-minute video and an educational booklet that are designed for patients or their families to review alone or together. The video features minority and non-minority patients who have undergone LDKT and their family members discussing their experiences with considering LDKT as a treatment option from the recipient and donor perspectives, as well as health care providers (transplant surgeon, transplant nephrologist, transplant social worker) citing key factors patients and families should consider when contemplating LKT. It also directly addresses concerns that may pose specific barriers to LDKT for African Americans, including mistrust or fear of the LDKT process, difficulties discussing LDKT, and financial considerations related to pursuing LDKT. (The video can be viewed at: <http://www.youtube.com/watch?v=Wmo->

[aTjZR64&feature=youtu.be](https://www.youtube.com/watch?v=aTjZR64&feature=youtu.be)) The educational booklet provides a synopsis of the LDKT process from recipient and donor perspectives. It also includes a listing of publicly available resources from which further information about the LDKT evaluation, transplant, and donation process, clinical risks with LDKT, and financial issues related to LDKT can be obtained. To assist patients and family members with initiating LDKT discussions or addressing complex issues during LDKT discussions (e.g., donor coercion), the booklet also presents several 'model conversations' presenting examples on how to initiate and sustain LDKT discussions. **(Booklet can be best viewed at: <http://diseasemanagementboulware.org/wpcontent/themes/jhm/flipbook/talk-study/>).**

- b. TALK SWI Behavioral Support. TALK SWI Behavioral Support is a protocol-driven individual and family- based social intervention applying a Social Construction-based Family Problem Solving theoretical framework.<sup>44-</sup>  
<sup>46</sup>According to this framework, families are problem solving units whose optimal structure for confronting problems potentially affecting all group members, such as ESRD and LDKT, is achieved when a neutral authority figure is designated as the mediator for relaying messages between all members and encouraging open channels of communication to enable each member to contribute to the problem's resolution, ultimately enhancing group satisfaction. The protocol specifies that the TALK Social Worker will meet with patients considering LDKT for up to one hour to assess their perceived barriers to completing key behaviors reflecting their consideration and pursuit of LDKT (discussing LDKT with their families, discussing LDKT with their physicians, identifying a potential live donor). The TALK Social Worker employs motivational interviewing techniques to help participants self-identify potential barriers they face toward completing LDKT helps and patients strategize about ways they might overcome barriers. The TALK Social Worker also invites patients to bring family members and/or friends for a second visit. During family visits, the TALK Social Worker assesses the extent to which previous family discussions about patients' kidney disease had occurred, the results of such conversations, whether family members have communicated about LDKT with patients' physicians, and any barriers family members perceive toward achieving LDKT.<sup>39,47</sup> However, our focus groups identified additional support roles that transplant social workers would be well qualified to fill, including a role as a point of contact for patients and families seeking financial assistance with LDKT.<sup>19</sup> During our Study Phase 1, we will refine the TALK SWI behavioral support protocol to include these additional roles that are routinely filled by social workers in transplant centers.
2. ***Live Donor Financial Assistance Intervention.*** We have designed a financial assistance intervention to provide support for potential living kidney donors' medical and non-medical expenses associated with pursuing live kidney donation. The intervention is modeled after existing federal live donor financial assistance programs (including the National Live Donor Assistance Center (NLDAC) program), and it is intended to provide financial support for potential live kidney donors in circumstances where existing federal programs do not provide support. The intervention strictly adheres to US law governing the reimbursement of expenses for potential live kidney donors. We will offer study participants the option of enrolling their willing potential live kidney donors (i.e. persons wishing to pursue medical evaluations to potential live kidney donors on their behalf)

reimbursement for medical and non-medical expenses related to the evaluation, surgery, and recovery periods associated with live kidney donation. Each study participant (potential kidney recipient) will be offered a “bank” of \$2100.00 from which potential donors can receive reimbursement for live kidney donation related expenses. While multiple people may step forward to be evaluated for donation and incur expenses, the total amount available per patient study participant is \$2100.00. Our intervention will provide reimbursement to a broad group of participants, of which many may not meet NLDAC income requirements. Participants not qualifying for NLDAC may not require the same level of financial reimbursement, or those choosing to forgo NLDAC may desire more broadly applicable financial assistance (e.g., for lost wages from work) than assistance provided by NLDAC. Based on national data, \$2100.00 corresponds to 3 weeks of paid leave from work for production or non-supervisory workers<sup>48</sup>, approximately 4 weeks of child care<sup>49</sup> and travel and lodging needs for donors coming from other geographic areas. If effective, our intervention will provide rationale for expanding current NLDAC qualification requirements.

Features of our Live Donor Financial Assistance Intervention Compared to the National Living Donor Assistance Program (NLDAC) <sup>31</sup>		
Feature	Proposed Intervention	NLDAC
Financial Assistance Amount	\$2100	\$6000
Potential Donor and Recipient Income Limits	No	300% poverty level or less
Proof of Donor Financial Hardship Required	No	Yes
Covers Travel, Hotel, Parking and Meal Costs Related to Donor Evaluation, Surgery, and Follow-up	Yes	Yes
Covers Lost Wages from Work Related to Donor Evaluation, Surgery, and Follow-up	Yes	No
Covers Child Care Related Costs Related to Donor Evaluation, Surgery, and Follow-up	Yes	No
Adheres to NOTA	Yes	Yes

Specific Intervention Details. We will reimburse potential donors for approved financial assistance through the study by submitting formal original invoices, receipts, and other documentation of their need for reimbursement of qualified medical and non-medical expenses related to live kidney donation evaluation, donation, or convalescence (up to 10 weeks post LDKT procedures). Qualifying expenses include travel, doctor’s and hospital visits, lodging, meals, incidental expenses (e.g., parking, long distance calls), lost wages, and childcare costs incurred by the potential donor as part of (1) donor evaluation, clinic visit or hospitalization, (2) hospitalization for the living donor surgical procedure, and/or (3) medical or surgical follow-up clinic visit or hospitalization. All receipts must be submitted within 1 year (365 days) of the date the kidney patient (recipient) joined the study. Participants will be permitted to utilize the \$2100.00 for multiple approved purposes, as long as the total value is not greater than \$2100.00. Furthermore, more than one potential donor may draw from these funds, as the total



value of reimbursed expenses does not exceed the value of \$2100.00 per patient study participant. We developed the live donor financial assistance intervention following guidelines of the “Organ Donation and Recovery Improvement Act (ODRIA),” (Section 3, 42 U.S.C. 274f) signed into law on April 5, 2004, establishing the authority and legislative parameters to provide reimbursement for travel and subsistence expenses incurred towards living organ donation. The intervention is also modeled after the National Living Donor Assistance Center (NLDAC), a federally funded program administered by the Division of Transplantation (DoT), Healthcare Systems Bureau (HSB), Health Resources and Services Administration (HRSA), United States Health and Human Services (HHS) through a cooperative agreement with the University of Michigan and the American Society of Transplant Surgeons (<http://www.livingdonorassistance.org/default.aspx>). We will advise all participants that it is possible that they may be disqualified from participating in other living donor assistance programs by participating in the TALKS Study program and they take personal responsibility to confirm their eligibility for other programs.

### **Study Phase 1 (Planning Phase). Adaptation of TALK SWI for use in Transplant Centers**

Rationale. The TALK SWI was designed with input from African American and non-African American patients and families with CKD to address common concerns about LDKT.<sup>19</sup> The TALK booklet and video were screened to ensure their appropriateness for all persons considering LDKT, including minority and non-minority persons with low (i.e. 4<sup>th</sup> grade) reading level and low health literacy.<sup>39</sup> The TALK Social Worker Behavioral Support Intervention was originally conducted by an independently practicing social worker affiliated with nephrology practices. The TALK SWI protocol was therefore tailored to be used by transplant social workers working in transplant centers.

TALK SWI Adaptation Procedures. We reviewed the original TALK SWI protocol with transplant social workers and adapt the TALK SWI into their existing workflows. Adaptation focused on (1) ensuring the intervention provides adequately addresses patients’ communication and financial needs in social workers’ views, and (2) ensuring the intervention can be feasibly implemented and sustained by transplant centers long-term. For instance, we asked social workers to identify the resources they typically provide to patients and families concerned about the financial aspects of LDKT and we incorporated provision of these materials into the protocol. We also identified potential challenges transplant social workers typically encounter with TALK SWI implementation.

### **Study Phase 2 (Randomized Controlled Trial Phase)**

We will perform a randomized controlled trial to assess the effectiveness of TALK SWI and the TALK SWI plus financial support intervention to improve rates of LDKT among African American potential transplant recipients on the deceased donor kidney waiting list at the Duke Kidney and Pancreas Transplant Program compared to usual care. We will follow potential recipients for 1 year via questionnaire and 2 years via medical records (post baseline questionnaire completion) to assess live kidney donor activation on their behalves (live donor inquiries, completed new live donor evaluations, or live kidney donation) (primary outcome). We will assess all primary outcomes at 1 year after baseline enrollment. We will also assess potential recipients’ self-reported behaviors reflecting their pursuit of LDKT, including their conduct of LDKT discussions with physicians and with their families and their identification of potential live donors.

- A. Study population: We will recruit a total of **300 (100 per each study arm) adult African American patients with ESRD who are currently on the deceased donor kidney waiting list with no prior kidney transplant** from the Duke Kidney and Pancreas Transplant Program (DKPTP). The DKPTP cares for a highly diverse set of patients with ESRD, with nearly 55% of the deceased donor kidney transplant waiting list comprised of African Americans annually. As of January 2014, the DKPTP had 297 (55%) African American patients registered on the deceased donor kidney waiting list. DKPTP added approximately 100 new African American waiting list registrants per year in 2012 and 2013. African Americans on the deceased donor kidney waiting list at DKPTP are sociodemographically diverse, and reflect the local Durham, NC population in which 19% have incomes below the Federal Poverty Level.<sup>50</sup>
- B. Study Setting: The kidney/pancreas transplant program at DKPTP is a highly innovative center, providing national leadership in the development and implementation of numerous clinical strategies to improve rates of live kidney donation and donor safety (performed first kidney transplant in NC and had performed their 3000<sup>th</sup> kidney transplant in 2010). The center also features a complete team of transplant surgeons, nurse transplant coordinators, administrative transplant coordinators, psychologists, and social workers to support both potential recipients' and donors' medical and psychosocial needs. The program currently does not have a social worker program tailored specifically to address knowledge, interpersonal, logistical or financial barriers to LDKT in African American potential recipients.
- C. Study Design: We will recruit, enroll and then randomly assign participants to one of three study conditions ("arms"). We will follow participants actively for 1 year to assess the effectiveness of interventions to improve live kidney donation and receipt of LDKT among study participants.

**Arm 1. Usual Care (N=100):** Participants randomly assigned to this arm will receive their usual care with the transplant team while awaiting a deceased donor kidney transplant. Participants are periodically contacted (approximately once per year) to establish their continued desire to be listed on the waiting list and to address any administrative issues related to transplant (i.e., updated contact and insurance information) by the DKPTP. They will be mailed the booklet and video at the end of the study.

**Arm 2. TALK SWI (N=100):** Participants randomly assigned to this arm will receive the TALK SWI delivered by a transplant social worker.

**Arm 3. TALK SWI Plus Financial Assistance (N=100):** Participants randomly assigned to receive the TALK SWI Plus the Financial Assistance for Living Donor Expenses will receive the TALK SWI as described for Arm 2. Study staff will also provide participants with information about the study Live Donor Financial Assistance Intervention, and provide instructions on how to use the Intervention (details on Financial Assistance Intervention described above)

- D. Study Outcomes and Assessments: We perform assessments at baseline, 4 months and 12 months for all participants in Arms 1, 2 and 3. Transplant coordinators at DKPTP routinely capture names and contact information of potential donors contacting the center to inquire about donation procedures on potential recipients' behalves and enter it in the Phoenix (PHX) transplant application, which is part of the EpicCare Ambulatory

module. For our **primary outcome**, we will assess “live kidney donor activation”, defined as the composite rate of live kidney donor inquiries on behalf of participants (clinic records of individuals inquiring about the process of being considered for LDKT on participants’ behalfs), completed live kidney donor transplant evaluations (recorded and tracked by transplant coordinators), and live kidney donor transplants (LDKT) in each arm after 12 months study enrollment. To determine which behaviors were most strongly activated by our interventions, we will also assess rates of these individual events in each arm in post-hoc analyses. **Secondary outcomes** will include measurement of behaviors reflecting patients’ and their families’ interest and pursuit of LDKT, including: self-reported LDKT discussions with physicians, self-reported LDKT discussions with family, and identification of a potential live donor. We will also assess several other **correlates** of participants’ willingness or ability to pursue LDKT, including their demographic characteristics, family function, self-efficacy with regard to decision-making about LDKT, perceptions of trust in their health care team. We will ask all participants about their use of any financial assistance programs, including the types and amounts of expenditures reimbursed. We also will track expenditures reimbursed specifically by participants in Arm 3. We will also passively follow participants for one additional year through their medical records to determine if participants achieve outcomes of interest after 1 year.

Assessment of Environment and Intervention Cultural Competency: We will measure the cultural competency of the DKPTP and transplant social workers using the Agency for Health Care Research and Quality CAHPS Cultural Competence Item Set<sup>35</sup>, designed to capture patients’ perspectives on the cultural competence of health care providers. Items include information on (a) research subject-health care provider communication including shared decision-making; (b) experiences of discrimination due to race, ethnicity, insurance, or language; (c) experiences leading to trust or distrust; and linguistic competency. We will also add questions to ask specifically about the communication and shared decision-making skills of transplant social workers employing TALK SWI.

Intervention Fidelity and Uptake: We will ask participants whether they have used the TALK Education Module and/or shared it with family members through telephone questionnaires administered at 4 and 12 months follow up. To assess social workers’ fidelity to the SWI protocol, we will audiotape and transcribe all TALK SWI meetings and assess the TALK social worker’s adherence to key behaviors specified in the protocol. We have previously assessed social workers’ adherence to the TALK social worker intervention in this manner and found the TALK SWI could be consistently executed.<sup>47</sup> For participants randomly assigned to the Financial Assistance Intervention, we will assess via questionnaire whether participants made others (i.e., family members) aware of their participation in the Financial Assistance Intervention. We will also assess family members’ inquiries to use the Intervention and types and amounts of expenditures they reimburse.

## **Selection of Subjects**

Patient Participants: Patients with end stage renal disease, who have completed the evaluation for kidney transplantation, are aged 18 and older, African American, and are on the deceased donor waiting list will be recruited from the DKPTP. We will work with DKPTP/Maestro Care

(Duke's electronic medical record) to identify eligible patients over a period of potentially two years, or until we reach our sample size.

**NOTE:** We later expanded our inclusion criteria to include persons who have previously received a deceased donor kidney transplant but who have not previously received a live donor kidney transplant.

Family/Friend Participants: Family/friend participants will only be enrolled for patient participants enrolled in Arms 2 and 3 if patient participants identify them. Once a patient participant is enrolled in the study and has completed their first TALK SWI meeting, they will be asked if they would like to identify at least one family member or friend to bring to the second TALK SWI meeting and be approached for participation in the study.

Potential Live Kidney Donor Participants: Potential live kidney donors will only become aware of the Donor Financial Support Intervention through referrals by patient participants randomized to ARM 3 who voluntarily choose to make potential donors aware on their own accord, without prompting from study staff or the study Social Worker. Study staff and the study Social Worker will not contact or attempt to contact any family, friends, or acquaintances of enrolled patient participants. Patient participants in ARM 3 will be given a brochure (by study staff after the first TALK SWI meeting) for the donor financial support program and encouraged to share the information with people.

We will advise patient participants to ask potential donors to contact us directly only for questions related to the financial program. The financial assistance program being offered as part of this study is intended to provide reimbursement only in those circumstances when payment cannot reasonably be covered by other sources of reimbursement. Under Federal law, reimbursement to any living organ donor for travel and other qualifying expenses may only be provided if the donor cannot receive reimbursement for these expenses from any of the following sources:

1. any State compensation program, an insurance policy, or any Federal or State health benefits program;
2. an entity that provides health services on a prepaid basis; or
3. the recipient of the organ.

All persons who wish to become living organ donors are eligible to receive reimbursement from this study for their travel and qualified expenses if they cannot receive reimbursement from the sources outlined above and if they meet all the requirements for donor reimbursement as outlined below:

1. prove that they are either U.S. citizens or lawfully admitted residents of the U.S.;
2. have primary residence in the U.S. or its territories;
3. travel is originating from the donor's primary residence;
4. donor and recipient attest to full compliance with section 301 of the National Organ Transplant Act (NOTA), as amended (42 U.S.C. 274e) which stipulated in part " \* \* \* (i) *t shall be unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation if the transfer affects interstate commerce. The preceding sentence does not apply with respect to human organ paired donation*";
5. the transplant center where the donation procedure occurs attests to its status of good standing with the Organ Procurement and Transplantation Network (i.e., it is not a

Member Not in Good Standing); and any individual who in good faith incurs qualifying expenses toward the intended donation of an organ but with respect to whom no donation of the organ occurs.

### **Subject Recruitment and Compensation**

We will recruit three types of participants: (1) patients (“patient participants”) with ESRD, (2) their family members and friends (“family/friend participants”), and (3) their potential live donors (“live kidney donor participants”) for this study. Participants will be informed their participation will have no effect on patients’ or their own subsequent insurance or health care, including their access to a kidney transplant, and that none of their data will be given to their physicians so they could be personally identified. Participants will also be advised and they can refuse to participate in any aspect of the study at any time.

### **A. Patient Participants**

#### **1. Screening, Recruitment, and Random Assignment**

- a) Potential patients will be identified through Maestro Care and the DKPTP PHX reporting system for screening purposes and updates throughout the two year recruitment period or until we reach our sample size.
- b) Study staff will review the list to ensure potential patient participants meet preliminary study criteria (i.e., African American, age 18 or older, are on deceased kidney transplant waiting list, no prior kidney transplant).

A letter from DKPTP, signed by all physicians and surgeons in the DKPTP will be mailed to potential participants and will be accompanied by a letter from Dr. Boulware describing the study and offering potential participants an opportunity to contact the research team with interest in participating or to opt-out from participation by either returning the provided form with a self-addressed mailed envelope, or by emailing or calling the telephone number provided prior to the first telephone call. A consent form will be included for them to sign and return, and additional one to keep for their records. (Note: A label with the unique TALKS Study ID will be placed on the back of the signature page to verify we have documented the return for the correct participant.) Risk and REALM questions will be included for them to refer to during the baseline questionnaire.

- c) Following the 14-day opt-out period, study staff will contact potential patient participants, who have not opted out, via telephone to confirm eligibility, answer any questions, review the consent form and obtain verbal consent. (If patients contact us prior to that, they are allowed to take part then.) Study staff will administer the baseline questionnaire. Potential patient participants will be asked to also sign and return the written consent form within the week. We will attempt to remind them to return their signed consent form at future contacts.
- d) Random assignment to intervention arms will take place immediately following completion of the baseline questionnaire while patient participants are on the telephone so they can be informed of their upcoming contacts.
- e) Study staff will mail the DVD and booklet to patient participants randomly assigned to Arms 2 and 3, as well as the TALKS Financial Assistance Program pamphlet and forms to Arm 3 only.
- f) Study staff will mail patient participants a thank you note and \$30 check for completing the baseline questionnaire.

### Usual Care (Arm 1)

- h) Patient participants assigned to receive Usual Care (Arm 1) will receive their care at DKPTP as they usually would.

### TALK Social Worker Intervention (Arms 2 and 3 only) and Financial Intervention (Arm3 only)

- i) Patient participants randomly assigned to Arms 2 and 3 will be asked to review the 20-minute TALK video and booklet related to living kidney donation, as well as attend two meetings with the study Social Worker to talk about LDKT. If the patient participant says they are unable to attend an in-person meeting due to distance, lack of transportation, or their health issues does not allow them to travel, we will offer the Social Worker meeting (SWI) via telephone. This will not be offered to any patient participant unless they mention the barriers noted above. We will offer this prospectively to newly consented patient participants as well as for those who were consented previously and were unable to take part in the SWI meeting due to these same barriers, (recorded in our database), we will contact them via phone to offer this option.
- j) Study staff will schedule patient participants first meeting with the study Social Worker following the baseline questionnaire and contact them a few days prior to remind them of the meeting and to encourage them to review the DVD and booklet.  
**In-Person SWI:** Study staff will also mail patient participants a reminder letter with the appointment date, time and directions.  
**Telephone SWI:** Study staff will ask if they want to provide a number to receive a text and/or an email address, or prefer a mailed letter with the appointment date, time and toll-free WebEx phone number and access code to call in to a social worker session with the study Social Worker. Study staff will also remind them of their appointment via phone/text/email a day or so prior.
- k) **In-person SWI:** On the day of their first meeting with the study Social Worker, study staff will meet the patient participant 30 minutes prior to the meeting to review the DVD and booklet.  
**Telephone SWI:** On the day of their first meeting, the Social Worker will call in to the toll-free WebEx number. If the patient participant does not join the call, study staff will contact the patient participant via phone/text to remind them of the call and reschedule if needed. If the patient participant joins the call, the Social Worker will verify they have reviewed the DVD and booklet. If they have not viewed the DVD, the Social Worker will encourage them to do so after the call and will proceed with the social worker session.
- l) The patient participant will then meet/talk with the study Social Worker for up to one hour. We will audiotape the social worker sessions (**In-person SWI:** encrypted audio voice recorder; **Telephone SWI:** encrypted audio voice recorder using speakerphone in a GIM private office) as described in the initial consent. If they refuse, the sessions will continue and only handwritten notes will be taken by the study Social Worker.
- m) **In-person SWI:** Patient participants will be asked to attend a second visit with the study Social Worker to further discuss their possible pursuit of LDKT. They will be instructed they may bring adult family members and friends to the second session, if they desire. We will schedule the second Social Worker session at a time that is convenient for patient participants and any family members or friends they wish to bring to the second session. **Telephone SWI:** Patient participants will be asked to take part in a second telephone SWI session with the study Social Worker to further discuss their possible pursuit of LDKT. They will be asked to invite adult family

members and friends they want to take part in the second session. Study staff will attempt to schedule the call at that time. They will ask the patient participant if they want to provide a number to receive a text and/or an email address, or prefer a mailed letter with the appointment date, time and toll-free WebEx phone number and access code to call in to a social worker session with the study Social Worker. They will be asked to share the call-in information with family/friends who may want to join the second SWI session.

- n) **In-person SWI:** Study staff will administer a brief 10-minute hardcopy questionnaire to the patient participant immediately following the Social Worker session to obtain feedback about the acceptability of the TALK SWI. We will provide assistance with reading the questions and checking the responses if needed. **Telephone SWI:** Once the SWI session is complete, the Social Worker will ask the patient participant to remain on the line to schedule their next session, complete their post assessment and paperwork for payment. The Social Worker will leave the call and immediately notify one of the other study staff to join the call and
- 1) administer the brief 10-minute questionnaire
  - 2) complete the paperwork required for payment; and,
  - 3) if in Arm 3, see item (o) below.

#### **Financial Intervention (Arm 3 only)**

- o) **In-person SWI:** Patient participants in ARM 3 will briefly meet with study staff immediately following their first session with the study Social Worker. Study staff will provide and review a brochure and materials for the donor financial support with patient participants. Patient participants will be encouraged to share the information with family members, friends and acquaintances if they desire, and to have potential donors contact study staff if interested.
- Telephone SWI:** Patient participants in ARM 3 will briefly review and discuss the brochure and materials they received in the mail for the donor financial support with study staff during the first SWI call. Patient participants will be encouraged to share the information with family members, friends and acquaintances if they desire, and to have potential donors contact study staff if interested. Study staff will mail additional copies of the materials if needed.

#### **TALK Social Worker Intervention (Arms 2 and 3 only)**

- p) Study staff will mail patient participants a thank you note and \$50 check for completing the first session with the study Social Worker.
- q) **In-person SWI:** Study staff will mail patient participants a reminder letter with the appointment date, time and directions. Study staff will contact patient participants by telephone a few days prior to their second Social Worker session to remind them of their meeting and to invite any family members or friends they wish to bring to the second session.
- Telephone SWI:** If the patient participant did not schedule the second social worker session, study staff will contact them to schedule a date and time. Study staff will ask the patient participant if they want to provide a number to receive a text and/or an email address, or prefer a mailed letter with the appointment date, time and toll-free WebEx phone number and access code to call in to a social worker session with the study Social Worker. Study staff will email, text and/or mail patient participants a reminder letter with the appointment date, time and toll-free WebEx phone number and access code. Study staff will also remind them of their appointment via phone/text/email a day or so prior to the session. Study staff will remind them to share the call-in information with family/friends.
- r) **In-person SWI:** On the day of their second session with the study Social Worker,

study staff will meet with the patient participant and their consenting family member(s)/friend(s). **Telephone SWI:** On the day of their second session, Study Staff will call in to the WebEx toll-free line. If family/friends call in, the Study Staff will verify they are 18 or older, review the study and obtain verbal consent from each family/friend as well as request a contact number to call them back individually after the session to complete a brief 10-minute questionnaire via phone immediately following the social worker session; and, 2) complete the paperwork required for payment. If the patient participant does not join the call, study staff will contact the patient participant via phone/text to remind them of the call and reschedule if needed. The session cannot occur without the patient participant present even if family/friends have joined the call. No family/friends will be consented without the patient participant present on the call. Study staff will contact the patient participant to reschedule if they do not join the call. Once family/friends are consented, the study staff will leave the call and the Social Worker will join to begin the session.

- s) The patient participants and family/friend participant(s) will then meet/talk with the study Social Worker for up to one hour. The session will be audio recorded (**In-person SWI:** encrypted audio voice recorder; **Telephone SWI:** encrypted audio voice recorder using speakerphone in a GIM private office) as described in their consents, but if they refuse to be audio recorded, the session will continue and only handwritten notes will be taken by the study Social Worker.
- t) **In-person SWI:** Study staff will administer a brief 10-minute hardcopy questionnaire to the patient participant immediately following the Social Worker session to obtain feedback about the acceptability of the TALK SWI. We will provide assistance with reading the questions and checking the responses if needed. **Telephone SWI:** Once the SWI session is complete, the Social Worker will ask the patient participant to remain on the line to complete their post assessment and paperwork for payment. They will remind the family/friends that Study Staff will contact them shortly to complete their post assessment and paperwork for payment. The Social Worker will leave the call and immediately notify one of the other study staff to join the call. The Study Staff will 1) administer the brief 10-minute questionnaire, and 2) complete the paperwork required for payment. If consented family/friends attended, the Study Staff will call the family/friends to 1) administer the brief 10-minute questionnaire, and 2) complete the paperwork required for payment.
- u) Study staff will mail patient participants a thank you note and \$50 check for completing the session with the family/friend participant(s) and study Social Worker.

## **2. Assessments**

- v) All patient participants (regardless of their random assignment) will be contacted at 4 and 12 months to complete follow up questionnaires via telephone. Study staff will mail a thank you note and \$30 check for completion of each of the questionnaires. All questionnaires are approximately 60 minutes in length.
- w) All patient participants will be followed for 2 years (post baseline questionnaire completion) via electronic medical records (i.e., MaestroCare and DKPTP PHX reporting system) to passively assess live kidney donor activation on their behalves (live donor inquiries, completed new live donor evaluations, or live kidney donation) as well as their status on their wait list (active/inactive).

## **B. Family/Friend Participants**

Adult family members and friends are only eligible to participate in the TALK SWI session



if they agree to participate after being invited by a patient participant.

**In-Person SWI:** At patient participants' request, they will attend the SWI session with the study Social Worker and patient participant and will be approached to assess their willingness to participate in the study by study staff when they arrive with the patient participant for the social worker session.

**Telephone SWI:** Patient participants will share the call-in information with family/friends whom they want to join the session. They will be asked their willingness to participate in the study by study staff when they call in for the social worker session.

### 1. Recruitment and Consent

- a) **In-Person SWI:** When family/friends (up to 5 family members per patient participant) attend the second social worker session with patient participants, study staff will ask to meet with potential family/friend participants separately from patient participants, to verify they are 18 or older, review the consent form and obtain their signature. Study staff will tell family/friend participants they will be asked to join the patient participant and study Social Worker to talk about LDKT one time only and that their session will be audio recorded as described in their consent, which they can refuse at any time. Study staff will also tell family/friend participants they will complete a brief 5-10 minute in-person questionnaire after their meeting with the social worker to collect gender, race and ethnicity, date of birth, mailing address, if they are a current Duke employee, and social security number (required by Duke for payment of incentives) and ask what they thought of the meeting.

**Telephone SWI:** Patient participants will be provided the call-in information for the the social worker session and asked to share with any family/friends they wish to join the call. Once family/friends join the call, Study staff will ask each family/friend to verify they are 18 or older, review the study and obtain verbal consent. Study staff will tell family/friends they will be asked to join the patient participant and study Social Worker in a telephone conference call to talk about LDKT one time only and that their session will be audio recorded as described in their consent, which they can refuse at any time. Study staff will also tell family/friends they will be asked to complete a brief 5-10 minute questionnaire immediately following the session (study staff will ask them to provide a contact number to call them as soon as the social worker session is over) to collect gender, race and ethnicity, date of birth, mailing address, if they are a current Duke employee, and social security number (required by Duke for payment of incentives) and ask what they thought of the session. Once the family/friend consents, study staff will document the date and time of the consent.

### 2. TALK Social Worker Intervention

- b) The patient participant and family/friend participant(s) will then meet with/talk to the study Social Worker for up to one hour.

### 3. Assessments

- c) **In-Person SWI:** Study staff will administer a brief 10-minute hardcopy questionnaire immediately following the social worker session to obtain feedback about the acceptability of the TALK SWI. We will provide assistance with reading the questions and checking the responses if needed. **Telephone SWI:** Study staff will 1) contact each consenting family/friend participant and administer the brief 10-minute questionnaire via phone immediately following the social worker session; and, 2) complete the paperwork required for payment.
- d) Study staff will mail family/friend participants a thank you note and \$20 check for completing the questionnaire and session with the patient participant and study social worker.

### **C. Potential Live Donor Participants**

Potential live donor participants will only become aware of the financial assistance program through direct referral by patient participants in Arm 3. **Research study staff will not contact or attempt to contact any family, friends, or acquaintances of enrolled patient participants for any reason related to live kidney donation unless they contact us and express interest in the program.**

- a. Patient participants in Arm 3 will be provided with information about the donor financial assistance program by study staff following the completion of their first social worker session (discussed in-person for In-person SWI and via phone for Telephone SWI). Study staff will advise potential participants that they may provide this information to potentially interested donors if they wish to, and that potentially interested donors should contact the study team if they are interested in participating in the program. They will be given pamphlets and forms with study contact information.
- b. When potential donors contact study staff via telephone, study staff will discuss the program. Study staff will also mail a brochure describing the financial assistance program to potential donor(s) and forms required for possible reimbursements from our program if they choose to take part.
- c. Study staff will schedule a call back time to review the mailed materials and seek participation if interested. Study staff will inform them that their participation in the financial assistance program offered by this study may preclude them from receiving financial assistance from any other federal, state or private program (e.g. National Living Donor Assistance Center (NLDAC)). Each potential donor participant will be offered a “bank” of \$2,100 from which potential donors can receive reimbursement for live kidney donation related expenses. While multiple people may step forward to be evaluated for donation and incur expenses, the total amount available per patient study participant is \$2,100.
- d. Study staff will contact those potential donors via telephone who requested a return call to answer any questions and seek participation. Interested potential donors will then undergo approved consent procedures and enroll in the study via telephone. We anticipate that 70% of the 100 patient participants randomized to Arm 3 will have at least one potential donor who will utilize the donor financial support program and will therefore also be included as human subjects in this study (N=70). Study staff will obtain potential donor participants’ gender, race and ethnicity, date of birth, mailing address, telephone number, and if they are a current Duke employee (required by Duke for payment of incentives).
- e. Potential donors incurring eligible expenses will be asked to complete a Living Donor Assistance Program Donor Worksheet summarizing expenses as well as sign an attestation form to confirm that they understand the legal restrictions of the intervention. This is required with each submission of receipts. Study staff will mail potential donors checks reimbursing approved eligible expenses.

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