# Feasibility and Acceptability of the TALK Social Worker Intervention to Improve Live Kidney Transplantation

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Live kidney transplantation (LKT) is underused by patients with end-stage renal disease. Easily implementable and effective interventions to improve patients' early consideration of LKT are needed. The Talking About Live Kidney Donation (TALK) social worker intervention (SWI) improved consideration and pursuit of LKT among patients with progressive chronic kidney disease in a recent randomized controlled trial: Patients and their families were invited to meet twice with a social worker to discuss their self-identified barriers to seeking LKT and to identify solutions to barriers. The authors audio recorded and transcribed all social worker visits to assess implementation of the TALK SWI and its acceptability to patients and families. The study social worker adhered to the TALK SWI protocol more than 90 percent of the time. Patients and families discussed medical (for example, long-term risks of transplant), psychological (for example, patients' denial of the severity of their disease), and economic (for example, impact of donation on family finances) concerns regarding LKT. Most patients and families felt that the intervention was helpful. Consistently high adherence to the TALK SWI protocol and acceptability of the intervention among patients and families suggest that the TALK SWI can be feasibly implemented in clinical practice.

KEY WORDS: *clinical interventions; clinical social work; health disparities; transplants*

Live kidney transplantation (LKT) is an optimal therapy for patients with end-stage renal disease; it offers substantially improved length and quality of life compared with dialysis (Abecassis et al., 2008; Terasaki, Cecka, Gjertson, & Takemoto, 1995). Preemptive LKT (pLKT), initiated before potential recipients need renal replacement therapy, typically yields superior clinical outcomes (Mange, Joffe, & Feldman, 2001; Terasaki et al., 1995). However, this type of transplant is largely underused, particularly among African Americans, who have up to 50 percent less odds of becoming preemptive transplant recipients when compared with their white counterparts (Gore, Danovitch, Litwin, Pham, & Singer, 2005; Grams, Massie, Coresh, & Segev, 2011; Kasiske et al., 2002). Reasons for inadequate use of pLKT are poorly understood. However, some studies have attributed underuse to several factors, including potential recipients' difficulties identifying willing, eligible, or compatible donors (Schweitzer et al., 1997; Tankersley et al., 1997; Young & Gatson, 2000); insufficient access to health care (Ayanian, Cleary, Weissman, & Epstein, 1999; Kasiske et al., 2002); and a lack of knowledge about transplantation (Waterman et al., 2006). Many of these factors (for example, poor access to health care) disproportionately affect ethnic and racial minorities and may contribute to disparities in their receipt of pLKT. Interventions that address common barriers to potential recipients' access to and receipt of pLKT are greatly needed to improve rates of pLKT overall and to narrow ethnic and racial pLKT disparities.

For potential recipients to have access to pLKT, they must first have discussions about pLKT with their health care providers (HCPs) as well as their families, who represent key sources of support for decision making and for kidney donation. Nonetheless, prior studies have demonstrated that patients with chronic kidney disease (CKD) often fail to engage in LKT discussions (Smith,

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Nazione, LaPlante, Clark-Hitt, & Park, 2011). In our qualitative study, minority and nonminority patients with CKD reported a variety of reasons for not engaging in LKT discussions, including their concerns that their family members would feel coerced to donate or feel guilty, concerns that discussions could be misconstrued as donation requests, and difficulties initiating conversations about LKT (Boulware, Hill-Briggs, Kraus, Melancon, Senga, et al., 2011).

The Talking About Live Kidney Donation (TALK) social worker intervention (SWI) was designed to directly address patients' with CKD and their family members' self-identified barriers to discussing pLKT (Boulware, Hill-Briggs, Kraus, Melancon, McGuire, et al., 2011; Boulware, Hill-Briggs, Kraus, Melancon, Senga, et al., 2011). In a previously described randomized controlled trial (Boulware et al., in press), the TALK SWI was effective in improving patients' consideration and pursuit of pLKT compared with patients not receiving the TALK SWI. Although the success of the TALK SWI during the clinical trial is encouraging, the effectiveness of the TALK SWI in clinical practice will be determined, in part, by the degree to which it can be easily delivered and is acceptable to patients and families. To better understand the ease with which the TALK SWI can be used in real-world settings, we examined the extent to which the TALK study social worker (SW) was able to adhere to the TALK SWI protocol, assessed the acceptability of the intervention to patients and their families, and described the content of discussions occurring during TALK SW visits.

## METHOD

### Description of the TALK SWI

***Overview***. The TALK SWI consisted of both educational and behavioral interventions to ameliorate consideration and pursuit of LKT among patients with advanced, progressive CKD. The educational video featured CKD patients and their family members discussing their experiences with considering LKT as a treatment option, as well as HCPs and SWs citing key factors that patients and families should consider when contemplating LKT. The educational booklet provided a synopsis of the LKT process from recipient and donor perspectives and included a listing of publicly available resources from which additional information about LKT could be obtained. To assist patients and family members with initiating discussions about LKT or addressing complex issues pertaining to the pursuit of LKT, the booklet also presented model conversations.

The behavioral SWI was designed as a protocol-driven, individual- and family-based social intervention that applied a social construction–based family problem-solving theoretical framework (Bray, 1995; Cox, 2002; Tallman, 1970). According to this framework, families are problem-solving units; their optimal structure for confronting problems that potentially affect all group members, such as CKD and pLKT, is achieved when a neutral authority figure is designated as the mediator for relaying messages between all members (Bavelas, 1950; Leavitt, 1951) and encouraging open channels of communication to enable each member to contribute to the problem's resolution (Guetzkow & Dill, 1957; Guetzkow & Simon, 1955), which ultimately enhances group satisfaction (Maier & Hoffman, 1960, 1962). Using this framework as a guide, we designated a trained SW, with more than 10 years of clinical experience working with patients experiencing organ transplantation and confronting challenges associated with chronic illness, to deliver the intervention using a predefined standard protocol.

The protocol specified that the TALK SW would meet with patient participants for up to one hour to assess their perceived barriers to completing five key pLKT consideration and pursuit behaviors. The TALK SW used motivational interviewing techniques to help participants self-identify potential barriers they faced toward completing pLKT consideration and pursuit behaviors and helped patients strategize about ways they might overcome these self-identified barriers. The TALK SW also invited patients to bring family members or friends for a second visit. Study staff distributed an educational video and booklet to the TALK SWI participants at the time of enrollment. Ideally, participants watched the video, read the booklet, and shared both with family members before their first or second visit with the SW; this enabled participants to discuss the content, as well as their reactions, with the TALK SW.

***Patient Visits with the SW***. Study staff contacted patients by telephone to assess their readiness to pursue LKT via questionnaire. Questionnaires consisted of 12 yes/no questions with skip

patterns to assess patients' performance of LKT consideration and pursuit behaviors (see Table 1) (Boulware, Higg-Briggs, Kraus, Melancon, McGuire, et al., 2011). Study staff provided the TALK SW with patients' answers to questions about their readiness to pursue LKT prior to their first visit with the SW. On the basis of each patient's answers, the protocol directed the TALK SW to pose specific questions to each patient to assess whether he or she had progressed in consideration and pursuit of LKT since the telephone interview (see the Appendix). The TALK SW was then directed to ask patients to self-identify barriers they perceived as inhibiting them from initiating or progressing through behaviors necessary to achieve LKT. At the conclusion of individual visits, the TALK SW offered patients the option of participating in a subsequent family visit to explore family barriers to patients' pursuit of LKT.

**Table 1: TALK Social Worker Intervention Assessment of Participant Readiness to Consider or Pursue Preemptive Live Kidney Donation**

| Questions Asked Prior to Social Worker Visits |
|---|
| Have you already completed the testing process to get a kidney transplant? |
| Did you receive a letter from the hospital or transplant center telling you that you have completed all the forms and testing needed to get a transplant? |
| Has a family member or friend told you that they would give you a kidney? |
| Have you talked with family or friends about the possibility of someone giving you a kidney? |
| Have you started the testing process to get a kidney transplant (this includes any paperwork you may have started, laboratory tests you may have taken, or meetings you may have had with HCPs or nurses from a kidney transplant center)? |
| Has a family member or friend told you that they would give you a kidney? |
| Have you talked with family members or friends about the possibility of someone giving you a kidney? |
| Have you talked with your HCP about getting a kidney transplant either by being placed on the waiting list for a kidney or by getting a kidney from someone you know? |
| Has a family member or friend told you that they would give you a kidney? |
| Have you talked with family or friends about the possibility of someone giving you a kidney? |
| Has a family member or friend told you that they would give you kidney? |

Note: Answers were in yes/no format and used a skip pattern. HCP = health care provider; TALK = Talking About Live Kidney Donation.

***Family Visits with the SW.*** During family visits, the TALK SW assessed the extent to which previous family discussions about the patients' CKD had occurred and the results of such conversations, determined whether family members had communicated about LKT with patients' HCPs, and identified any barriers family members perceived in discussing LKT with HCPs.

## Data Collection

We audio-recorded and transcribed all TALK SWI visits. Patient and family member participants also completed a written questionnaire after their visits, to assess their satisfaction with the TALK SW. Questions assessed whether the TALK SW was courteous and respectful, supportive, helpful, trustworthy, attentive, caring, and a good communicator. Questions also assessed whether the TALK SW was intrusive and whether patients encountered problems receiving help from her. Potential answers for all questions included "strongly agree," "agree," "disagree," and "strongly disagree."

## Analyses to Assess the Ease and Content of the TALK SWI

To assess the ease of delivering the TALK SWI, we assessed the TALK SW's ability to adhere to the intervention as planned and the content of the intervention. For both analyses, we reviewed transcripts of audio recordings obtained during each TALK SW visit. We adapted a previously developed structured assessment tool to rate the TALK SW's adherence to the intervention protocol (Borrelli et al., 2005; Gearing et al., 2011). Two trained investigators reviewed transcripts of each visit and used the structured assessment form to assess the TALK SW's adherence to 27 key elements of the protocol. After the investigators independently completed their evaluations, they met to determine the concordance of their assessments. They resolved discrepancies in assessments through a joint rereview of transcripts and developed a final consensus rating based on discussions.

To assess the content of the TALK SWI visits, the two investigators independently performed a qualitative content analysis of all visit discussions. Each investigator identified themes commonly discussed among patients, family members, and the TALK SW. Investigators also noted common challenges the TALK SW confronted in adhering to the intervention protocol, such as patients' or

their family members' engagement in conversational drift or dialogue deviating from the protocol script for extended time periods. After performing independent analyses, the investigators met to review their identified themes. The investigators compared themes and compiled a final listing of the themes that they agreed had emerged most frequently. The Johns Hopkins School of Medicine Institutional Review Board approved all study procedures.

## RESULTS

### Participant Characteristics

Forty-three patient participants were randomly assigned to the TALK SWI. Fourteen (33 percent) of the 43 patients refused participation in the TALK SWI. The 29 (67 percent) remaining patient participants attended both SW visits. Participants who refused to attend TALK SWI visits were similar to those who participated in visits with respect to their demographic characteristics (see Table 2). Most patient participants were female and under the age of 65. Nearly half of all participants were African American. Most patient participants had attained a high school degree. A majority of patient participants were either married or living with a partner, and many were disabled or retired. Annual household income varied among participants. All patient participants had health insurance.

Among the 27 participants who attended a second visit, a majority ($n = 22$, 81 percent) brought family members with them, whereas the remaining participants attended follow-up visits alone. Most patient participants brought one family member to visits. Most family members were female and had various relationships to patient participants. Nearly half of family members were African American. A majority of family members had at least a college-level education and were employed full-time. Annual household incomes varied. All family members had health insurance (see Table 3).

### TALK SW's Adherence to the Intervention Protocol

Initial one-on-one visits between patient participants and the TALK SW ranged from 11 to 42 minutes in duration. Follow-up visits ranged from 10 to 69 minutes in duration. The TALK SW adhered to individual components of the intervention at a consistently high rate by achieving most desired protocol behaviors more than 90 percent of the time (see Table 4).

Of the 27 behaviors, the TALK SW adhered least to asking patients to self-identify barriers they believed were inhibiting them from initiating or achieving LKT behaviors. Visits in which the TALK SW did not ask barrier questions often featured participants' conversational drift; the patient unintentionally addressed the barrier question when answering a specific protocol question; or the barrier question was not applicable to the patient based on his or her response to the protocol question (for example, the barrier question addressed challenges to the patient in completing the evaluation process but the patient refused to undergo surgery, start dialysis, or partake in transplantation). There were also occasions in which the specific protocol question was no longer applicable for a patient and another question had to be asked instead (for example, the TALK SW planned to discuss initiating conversations with HCPs but the patient was experiencing more difficulty in communicating with family members). When conversational drift occurred, the TALK SW was able to regain control of the conversation by using strategies such as empathizing with the patient, reiterating what the patient had said, notifying the patient of the need to move forward, asking the patient if he or she had questions; thanking the patient for his or her time; and explaining the need to conclude the visit. The TALK SW consistently assessed patient participants' comprehension of the intervention as well as their skills in implementing behaviors to achieve LKT. There were no differences in the TALK SW's adherence to the protocol according to patient participants' race, gender, or income levels.

### Content of Discussions During TALK SWI Visits

Review of audio-recorded TALK SWI visits suggested patient participants' self-identified barriers could be categorized into eight themes, including their (1) desires not to involve family members in LKT, (2) psychological fear or denial of the need for pLKT, (3) difficulty completing the evaluation process, (4) lack of information regarding CKD, (5) distress about the financial implications of

**Table 2: TALK Social Worker Intervention Participant Characteristics**

| Patient Characteristic | Participants ($n = 29$) $n$ (%) | Nonparticipants ($n = 14$) $n$ (%) | $\chi^2$ | $p$ |
|---|---|---|---|---|
| Age | | | 0.0199 | .888 |
| 37–64 | 18 (62) | 9 (64) | | |
| 65–72 | 11 (38) | 5 (36) | | |
| Gender | | | 0.1268 | .722 |
| Male | 12 (41) | 5 (36) | | |
| Race and ethnicity | | | 3.6673 | .453 |
| Non-Hispanic white | 13 (46) | 8 (57) | | |
| Non-Hispanic African American | 14 (48) | 5 (36) | | |
| Other | 1 (3) | 1 (7) | | |
| Biracial | 1 (3) | | | |
| Educational attainment | | | 2.3619 | .670 |
| Graduate or professional school | 5 (17) | 3 (21) | | |
| College | 7 (24) | 2 (14) | | |
| Two years of college | 5 (17) | 2 (14) | | |
| High school graduate or GED | 8 (28) | 6 (43) | | |
| Some high school (grades 9–12) | 4 (14) | 1 (7) | | |
| Employment status | | | 5.0736 | .407 |
| Unemployed/looking for work | 1 (3) | 1 (7) | | |
| Disabled | 10 (35) | 4 (29) | | |
| Homemaker | 2 (7) | 3 (21) | | |
| Retired | 8 (28) | 2 (14) | | |
| Part-time employee | 1 (3) | 2 (14) | | |
| Full-time employee | 7 (24) | 2 (14) | | |
| Marital status or living with a partner | | | 0.0085 | .927 |
| Yes | 18 (62) | 8 (57) | | |
| Income | | | 3.4426 | .752 |
| >$100,000 | 7 (24) | 4 (29) | | |
| $80,001–$100,000 | 3 (10) | 1 (7) | | |
| $60,001–$80,000 | 2 (7) | 3 (21) | | |
| $40,001–$60,000 | 7 (24) | 1 (7) | | |
| $20,001–$40,000 | 2 (7) | 1 (7) | | |
| $0–$20,000 | 7 (24) | 4 (29) | | |
| Missing | 1 (3) | | | |
| Insurance | | | 5.2940 | .258 |
| Medical assistance or Medicaid | 2 (7) | 2 (14) | | |
| Medicare | 7 (24) | 2 (14) | | |
| Private insurance | 9 (31) | 3 (21) | | |
| Other | | 2 (14) | | |
| More than one form of health insurance | 11 (38) | 5 (36) | | |

Note: TALK = Talking About Live Kidney Donation.

pLKT, (6) concerns about long-term effects of transplantation or dialysis on lifestyle, (7) prior surgeries or current comorbidities, and (8) concerns about LKT medications (see Table 5). Many patients reported feeling hesitant to involve family members in discussions about LKT because of their concerns about burdening family members, potential health risks associated with LKT, and unintentionally making family members feel pressured or coerced to donate. To address patient participants' perceived barriers, the TALK SW facilitated participants' self-identification of solutions to their self-identified problems. For instance, patient participants who reported their need for psychological support to cope with CKD worked with the social worker to identify people with whom they might openly talk about their disease (see Table 5).

**Table 3: Family Members' Characteristics (*n* = 23)**

| Characteristic | *n* (%) |
|---|---|
| Patients accompanied by family members to the intervention | |
| Patients with no family members in attendance | 7 (23) |
| Patients with one family member in attendance | 22 (73) |
| Patients with more than one family member in attendance | 1 (3) |
| Gender | |
| Male | 7 (30) |
| Relation to patient | |
| Spouse | 9 (39) |
| Mother | 1 (4) |
| Daughter | 4 (17) |
| Friend | 2 (9) |
| Sibling | 4 (17) |
| In-law | 2 (9) |
| Grandchild | 1 (4) |
| Race and ethnicity | |
| Non-Hispanic white | 12 (52) |
| Non-Hispanic African American | 10 (43) |
| Biracial | 1 (4) |
| Educational attainment | |
| Graduate or professional school | 6 (26) |
| College | 7 (30) |
| Two years of college | 2 (9) |
| High school (grades 9–12) | 7 (30) |
| Elementary (grades 1–6) | 1 (4) |
| Employment status | |
| Unemployed/looking for work | 1 (3) |
| Retired or disabled | 5 (22) |
| Homemaker | 2 (9) |
| Employed full or part-time | 15 (65) |
| Income | |
| $80,001–$100,000 | 5 (22) |
| $60,001–$80,000 | 4 (17) |
| $40,001–$60,000 | 2 (9) |
| $20,001–$40,000 | 2 (9) |
| $0–$20,000 | 7 (30) |
| Missing | 3 (13) |
| Insurance | |
| Medical assistance or Medicaid | 3 (13) |
| Medicare | 1 (4) |
| Private insurance | 13 (57) |
| Other | 1 (4) |
| More than one form of health insurance | 5 (22) |

**Table 4: Assessment of Social Worker Adherence to TALK Social Worker Intervention Protocol and Demonstration of Professional Skills in Executing Intervention**

| Adhered to protocol | *n* (%) |
|---|---|
| SW explained her role within the TALK study. | 26 (90) |
| SW incorporated information gathered from baseline and one month follow-up (for example, asked whether patient watched the video or read the booklet, prompted the patient to explain where he or she is in the process—level of kidney function or disease, asked patient how long he or she has been dealing with the disease, asked patient what he or she understands about kidney disease). | 28 (97) |
| SW asked patient the patient-specific question outlined in protocol. | 29 (100) |
| SW accompanied patient-specific question with its respective response options. | 28 (97) |
| SW asked relevant "barrier" question based on the patient's response to his or her specific question (applicable to 27 patients). | 23 (85) |
| SW asked additional questions outlined in protocol following the patient-specific question (applicable to 18 patients). | 17 (94) |
| SW discussed recommendations for action with patient (for example, a discussion based on the next steps the patient claims he or she is going to make, patient-perceived barriers, and how the patient believes he/she is going to accomplish actions). | 26 (90) |
| Demonstration of professional skills in executing intervention | |
| SW showed evidence of rapport building. | 29 (100) |
| SW appeared competent. | 29 (100) |
| SW asked relevant follow-up questions. | 29 (100) |
| Conversational drift was not evidenced in the first visit (applicable to 25 patients). | 21 (84) |
| Conversational drift was not evidenced in the second visit (applicable to 27 patients). | 25 (93) |
| SW assessed patient's comprehension of the intervention (for example, SW asked patient if he or she had any questions, needed clarification about a particular topic, and so forth). | 28 (97) |
| SW assessed patient's ability to perform intervention skills in a setting in which the intervention may be implemented. | 28 (97) |

Note: SW = social worker; TALK = Talking About Live Kidney Donation.

Family members identified three barriers to initiating discussions pertaining to the patient's CKD and pLKT: (1) concerns about the transplantation process or dialysis, (2) difficulties in communicating with family members, and (3) fears or denial of the patient's medical condition (see Table 6). Family members also expressed their desire for more specific information applicable to the patient's current stage of kidney disease and treatment options, as well as concern about who would care for the patient posttransplantation if

**Table 5: Patient-Perceived Barriers**

| Frequently Mentioned Patient-perceived Barriers | Representative Quote | Example of SW-Facilitated Solutions |
|---|---|---|
| Do not want to involve family members in LKT | "If I had to get a donor, I would like to get it from the, you know, a cadaver if possible. I wouldn't want to get one from my wife or from my daughter or any friends because … I would rather—I'm at a point now here, you know, I'm not real, real old, but I've had a pretty full life, so I wouldn't want to take a kidney, like, from my daughter or my wife, which might shorten their life." | Ask an HCP for information about long-term health effects of LKT. |
| Psychological barrier of fear/ denial/stress | "Maybe I'm trying to shield myself. I can take things, but maybe it's just my way of dealing with what I'm dealing with right now. Then I said, well I'll deal with it if it comes up more later, and I shouldn't be like that, … 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." | Identify supportive people with whom the patient could discuss CKD. |
| Difficulty completing the evaluation process | "I'm a little nervous.…I'm feeling challenged. I just feel nervous.…I want to get it done and in a way I don't want to get it done. But I know I have to get it done.…Like I said, I've never been through this before or nothing like that. The more and more I hear about it—just makes me nervous. I just want to get it done and get the process done and get it over with." | Think of what would be motivating in moving forward, and identify reasons to complete the process. |
| Lack of information regarding CKD | "I also think it's easier to talk to people about it and ask these things when there's a sense of urgency.…As things settled down and started to reach a level where they could be maintained for a longer period of time, the direction got very obtuse. Well, it could be five years … it could be 15 years. Then it becomes something you can't grasp onto. So we've gone from, you're going to need a transplant by the end of the year to you're going to need one, but we don't know when. So it's hard to really initiate additional conversations with people without that sense of urgency. It's hard to go back and start the process without any definition of the process." | Call the transplant team and ask for an approximate timeline. |
| Financial concerns | "I don't think it's so much the transplant that scares me as much as the financial burden, because we're already strapped penny to penny. And I know it's very expensive. I don't know how we'll do it. And I guess that that's what I just worry about." | Ask the insurance company about eligibility for disability or Medicare; also ask transplant team about options for financial coverage. |
| Concerns about long-term effects of transplantation and/or dialysis on lifestyle | "With the dialysis, that would totally, from my understanding, disrupt what I do.…I like to go out, do things whenever I choose.…I enjoy walking, I always have. So that will be, from the way I'm foreseeing it, a real interruption of my lifestyle. I mean, total interruption, not a minor one. This would be drastic, which at this time is hard to grasp." | Speak with a nurse, HCP, or SW about an accommodating dialysis schedule. |
| Prior surgeries or current comorbidities | "So that was my only concern, you know, would I be a good candidate for a transplant because of all the prior surgeries that I've had?" | Address this concern with a HCP. |
| Concerns about LKT medications | "They say it's overwhelming for some people, the amount you have to take. And I'm thinking, I take 18 to 20 pills a day now, what in the world would I do?" | Medication is individualized; amount may decrease over time. |

Note: CKD = chronic kidney disease; HCP = health care provider; LKT = live kidney transplantation; SW = social worker.

**Table 6: Family Members' Perceived Barriers to Live Kidney Transplantation**

| Frequently Mentioned Family Member–perceived Barriers | Representative Quote | Example of Social Worker–Facilitated Solutions |
|---|---|---|
| Concern or confusion about transplantation and/or dialysis | "There's fear because, you know, two of us have kids, and you know, you wonder what if one of my kids down the road needs a kidney? What if, you know, I get kidney disease or something happens? And so those are questions that I guess I would like answered…. I just … need to know more information about what that would do to me … having one kidney." | Write down and ask the patient's HCP and transplant team questions, as well as search for information on the Internet. |
| Difficulty communicating with family members, especially the patient | "For my sister, when she goes to the doctor, I'll call and see how she's doing and all. She just says, 'Well, you know, they didn't find anything new,' or something like that. You know, you don't really get an explanation as to what's wrong … 'cause she didn't say anything about needing it [transplant], just that she got a kidney problem.…I can only go by what she says … she says … she don't want to bother us and all, but we're there for her, and she's got to realize it … I'm always available to help her." | Write down questions for the HCP to address during the medical visit (provided patient with example questions), as well as concerns, so that this information can then be relayed to family members. |
| Fear of and denial about the patient's medical condition | "It's not that my head's in the sand by any means, but, you try not to think about it. I don't dwell on it. I certainly am aware, as I said, he probably is only going downhill.…He'll need more and more help to do things, so that there is probably going to come a time where we're going to have to look at what additional help we need to come in to accomplish that." | Refer to the TALK study materials to become familiar with treatment options and to see whether questions or concerns are addressed in the video. |

Note: HCP = health care provider; TALK = Talking About Live Kidney Donation.

family members were not available. The TALK SW also facilitated family members' self-identification of solutions to their perceived barriers, such as preparing questions for HCPs before medical visits (see Table 6).

Both patient participants and family members also discussed topics that were not specific barriers to their pursuit of pLKT, but were factors that were relevant to their pursuit of pLKT, including concerns about comorbidities or other health issues in addition to CKD, use of religion or faith as a coping mechanism, relationships with HCPs, and distrust of the health care system.

### Participant Satisfaction with TALK SWI Visits

Patient participants ($n = 29$, 100 percent) and their family members ($n = 18$, 100 percent) reported that they strongly agreed or agreed that the TALK SW was a good communicator and was supportive, helpful, attentive, courteous and respectful, and caring in questionnaires administered after their initial and follow-up visits.

## DISCUSSION

We found that the TALK SWI was successfully implemented by an experienced transplant SW in the vast majority of study visits. TALK SWI discussions focused on patients with CKD and their family members' self-identified barriers to pursuing pLKT as well as their self-identified solutions to barriers, suggesting a key role of therapeutic discussions as an important mediator of intervention effectiveness. A majority of patient and family member participants found the TALK SWI useful. The most common difficulty the TALK SW confronted during visits was conversational drift introduced by patients due to their desires to discuss factors related to their CKD (for example, other comorbidities, distrust of medical system, relationship with physician, etc.) but not directly related to their consideration and pursuit of pLKT.

To the best of our knowledge, this is the first study to assess the ease with which a SW could use an effective intervention to improve patients with CKD and their families' consideration and or pursuit of pLKT. This study provides SWs in clinical practice with valuable information regarding what to expect when implementing the TALK SWI. Our findings also identify factors that could hinder effective implementation of the TALK SWI.

Many of the concerns raised by patient participants and their family members during TALK SWI visits were similar to those previously identified among patients with CKD and their family members in our foundational focus groups (Boulware, Hills-Briggs, Kraus, Melancon, Senga, et al., 2011); these include patients' reluctance to involve family members in LKT for numerous reasons such as guilt, burdening loved ones, unintentionally inducing guilt or coercion, and the complexity surrounding donation requests, and family members' fear about the patient's illness and uncertainty regarding their own health or the health of others who might donate a kidney in the future. The TALK SW's direct focus on these concerns and the therapeutic process of having patients and family members identify their solutions to self-identified barriers may represent one mechanism through which the TALK SWI can be most effective in helping patients and their families consider or pursue pLKT. Patients and families' self-identified solutions to barriers may represent paths they are most likely to pursue to overcome barriers to pLKT (rather than solutions prescribed by others).

Conversational drift among patients and their families during TALK SWI visits likely reflects the broad range of challenges patients with CKD and their families face as patients' kidney function declines. Patients may need assistance coping with a variety of lifestyle (Jaber & Madias, 2005), emotional (Fabrazzo & De Santo, 2006), and physical changes (Padilla et al., 2008) as their kidney disease progresses. SWs who are prepared to help patients and families consider and address these challenges may be better able to facilitate useful discussions about renal replacement therapy and pLKT. Our analyses revealed that the SW was often successful in overcoming this barrier with a variety of commonly used professional communication skills, such as displaying empathy, thanking patients for sharing their thoughts, and notifying patients of the need to return to the topic at hand. These strategies may enhance the effectiveness of the TALK SWI.

Limitations of our study deserve mention. First, the experiences of a small sample of participants recruited in Baltimore, Maryland, may not generalize to the experiences of other CKD patients,

their family members, or individuals from different parts of the United States. Moreover, although we recruited patients with varying degrees of kidney severity, some patients may have a more advanced disease than others, which may have influenced their experiences with LKT discussions. TALK SWI visits were limited to a single patient and single family visit. It is possible that additional visits could have enhanced the effectiveness of the intervention and allowed patients and families to address additional barriers or concerns about pLKT. Finally, nearly one-third of participants randomly assigned to receive the TALK SWI did not participate. We did not assess the reasons for nonparticipation, which would have given us further insight into mechanisms by which the intervention could be enhanced to better engage patients and their families. Future research is needed to identify patients who could most benefit from interventions like ours, as well as strategies for enhancing patient participation. Additional research on the ideal intensity and frequency of SW visits in this setting is also needed.

The TALK SWI was feasibly and consistently implemented by an experienced transplant SW, and it was well received by patients with advanced CKD and their families. SWs who use the TALK SWI may be most effective when they focus on helping patients and their family members to self-identify barriers to considering or pursuing pLKT and to develop strategies for addressing or overcoming these barriers. HSW

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## APPENDIX: QUESTIONS DELIVERED BY SOCIAL WORKER TO PATIENTS WITH CHRONIC KIDNEY DISEASE AND THEIR FAMILIES DURING THE TALKING ABOUT LIVE KIDNEY DONATION (TALK) SOCIAL WORKER INTERVENTION VISITS

### LKT Behavior 1: Completed Evaluation Process

**Objective**: Explore with the patient perceived issues or challenges for care.

**A. Patient-specific question**: "On a scale from zero to five, how prepared do you feel you are to deal with the potential challenges posttransplant?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared
5 = no preparation needed

What are the challenges you think you will experience?
How will you approach dealing with these challenges?

### LKT Behavior 2: Identify a Donor

**Objective**: Explore with the patient potential challenges in requesting a family member or friend to donate one of their kidneys?

**A. Patient-specific question:** "On a scale from zero to five, how prepared to do you feel you are to make this request?"

0 = have not thought about a donor
1 = have given this only a little thought
2 = unable to think of who I would or could ask
3 = have thought about who I would approach
4 = have opened the discussion about donation with someone
5 = have actually identified and approached a potential donor

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to identifying a potential donor.

Follow-up questions:

If question response = 0
What are the barriers for thinking about making request?

If question response = 1
What are the barriers for thinking about making request?

If question response = 2

What are the barriers for thinking about making request?

If question response = 3
What are your plans for approaching family/friends about donation?

If question response = 4
What are your plans for approaching family/friends about donation?

If question response = 5
How did you approach family/friends about donation? How successful do you feel your approach was?

### LKT Behavior 3: Preparing for Family Discussion

**Objective**: Identify perceived barriers to initiating conversations with family members and friends about living kidney donation (LKD).

**A. Patient-specific question:** "On a scale from zero to five, how prepared do you feel you are to talk with your family/friends about living kidney donation?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared
5 = no preparation needed

What are the challenges you think you will experience?
How will you deal with these challenges?

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to talking with family/friends.

Follow-up questions:

If question response = 0
What are the barriers for talking with family/friends?

If question response = 1
What are the barriers for talking with family/friends?

If question response = 2
What are the barriers for talking with family/friends?

If question response = 3
What are your plans for approaching family/friends about donation?

If question response = 4
What are your plans for approaching family/friends about donation?

If question response = 5
How did you approach family/friends about donation? How successful do you feel your approach was?

### LKT Behavior 4: Scheduled for Evaluation

**Objective**: Identify barriers for completing the kidney transplantation evaluation process.

**A. Patient-specific question**: "On a scale from zero to five, how challenged do you feel about your ability to complete the evaluation?"

0 = unable to complete the evaluation
1 = feeling very challenged
2 = feeling challenged
3 = feeling minimally challenged
4 = feeling comfortable with challenges
5 = experiencing no challenges

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to completing the evaluation process.

Follow-up questions:

If question response = 0
What do you perceive the challenges to be? Are they external or internal?

If question response = 1
What do you perceive the challenges to be? Are they external or internal?

If question response = 2
What do you perceive the challenges to be? Are they external or internal?

If question response = 3

What do you perceive the challenges to be? Are they external or internal?

If question response = 4
How do you propose to address the challenges?

If question response = 5
What helped you to arrive at this point?

### LKT Behavior 5: Complete Evaluation

**Objective**: Identify barriers for completing the kidney transplantation evaluation process.

**A. Patient-specific question:** "On a scale from zero to five, how challenged do you feel about your ability to complete the evaluation?"

0 = unable to complete the evaluation
1 = feeling very challenged
2 = feeling challenged
3 = feeling minimally challenged
4 = feeling comfortable with challenges
5 = experiencing no challenges

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to completing the evaluation.

Follow-up questions:

If question response = 0
What do you perceive the challenges to be? Are they external or internal?

If question response = 1
What do you perceive the challenges to be? Are they external or internal?

If question response = 2
What do you perceive the challenges to be? Are they external or internal?

If question response = 3
What do you perceive the challenges to be? Are they external or internal?

If question response = 4
How do you propose to address the challenges?

If question response = 5
What helped you to arrive at this point?

### LKT Behavior 6: Preparing for Discussion with Family and Friends

**Objective**: Identify perceived barriers to initiating conversations with family members and friends about LKD.

**A. Patient-specific question:** "On a scale from zero to five, how prepared do you feel you are to deal talk with your family/friends about living kidney donation?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared
5 = no preparation needed

What are the challenges you think you will experience?
How will you deal with these challenges?

**B. Barriers**

Based on the responses, challenge the client to discuss the barriers to initiating conversations with family/friends.

Follow-up questions:

If question response = 0
What are the barriers for talking with family/friends?

If question response = 1
What are the barriers for talking with family/friends?

If question response = 2
What are the barriers for talking with family/friends?

If question response = 3
What are your plans for approaching family/friends about donation?

If question response = 4
What are your plans for approaching family/friends about donation?

If question response = 5

How did you approach family/friends about donation? How successful do you feel your approach was?

#### LKT Behavior 7: Initiate Evaluation Process

**Objective**: Identify perceived barriers to initiating evaluation process for kidney transplant.

**A. Patient-specific question**: "On a scale from zero to five, how challenged do you feel you are to start the evaluation process?"

0 = unable to initiate
1 = feeling very challenged in initiating
2 = feeling challenged in initiating
3 = feeling minimally challenged
4 = feeling comfortable in initiating
5 = experiencing no challenges in initiating

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to initiating the evaluation process.

If question response = 0
What are the challenges you face in initiating evaluation?

If question response = 1
What are the challenges you face in initiating evaluation?

If question response = 2
What are the challenges you face in initiating evaluation?

If question response = 3
What are the challenges you face in initiating evaluation?

If question response = 4
How do you propose to meet the challenges?

If question response = 5
What has helped you to arrive at this point?

#### LKT Behavior 8: Identify Donor

**Objective**: Explore with the patient the potential challenges in requesting a family member or friend to donate one of their kidneys?

**A. Patient-specific question:** "On a scale from zero to five, how prepared do you feel you are to make this request?"

0 = have not thought about a donor
1 = have given this only a little thought
2 = unable to think of who I would or could ask
3 = have thought about who I would approach
4 = have opened the discussion about donation with someone
5 = have actually identified and approached a potential donor

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to identifying a potential donor.

Follow-up questions:

If question response = 0
What are the barriers for thinking about making request?

If question response = 1
What are the barriers for thinking about making request?

If question response = 2
What are the barriers for thinking about making request?

If question response = 3
What are your plans for approaching family/friends about donation?

If question response = 4
What are your plans for approaching family/friends about donation?

If question response = 5
How did you approach family/friends about donation? How successful do you feel your approach was?

#### LKT Behavior 9: Preparing for Discussion with Family and Friends

**Objective**: Identify perceived barriers to initiating conversations with family members and friends about LKD.

**A. Patient-specific question:** "On a scale from zero to five, how prepared do you feel you are to talk with your family/friends about living kidney donation?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared
5 = no preparation needed

What are the challenges you think you will experience?
How will you deal with these challenges?

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to initiating conversations with family/friends.

Follow-up questions:

If question response = 0
What are the barriers for talking with family/friends?

If question response = 1
What are the barriers for talking with family/friends?

If question response = 2
What are the barriers for talking with family/friends?

If question response = 3
What are your plans for approaching family/friends about donation?

If question response = 4
What are your plans for approaching family/friends about donation?

If question response = 5
How did you approach family/friends about donation? How successful do you feel your approach was?

### LKT Behavior 10: Starting Evaluation

**Objective**: Identify perceived barriers to initiating evaluation process for kidney transplant.

**A. Patient-specific question:** "On a scale from zero to five, how challenged do you feel you are to start the evaluation process?"

0 = unable to initiate
1 = feeling very challenged in initiating
2 = feeling challenged in initiating
3 = feeling minimally challenged
4 = feeling comfortable in initiating
5 = experiencing no challenges in initiating

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to initiating the evaluation process.

If question response = 0
What are the challenges you face in initiating evaluation?

If question response = 1
What are the challenges you face in initiating evaluation?

If question response = 2
What are the challenges you face in initiating evaluation?

If question response = 3
What are the challenges you face in initiating evaluation?

If question response = 4
How do you propose to meet the challenges?

If question response = 5
What has helped you to arrive at this point?

### LKT Behavior 11: Preparing for Discussion with Doctor

**Objective**: Identify perceived barriers to initiating conversations with doctor about LKD.

**A. Patient-specific question:** "On a scale from zero to five, how prepared do you feel you are to talk with your doctor about living kidney donation?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared

5 = no preparation needed

What are the challenges you think you will experience?
How will you deal with these challenges?

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to identifying talking with the doctor.

Follow-up questions:

If question response = 0
What are the barriers for talking with your doctor?

If question response = 1
What are the barriers for talking with your doctor?

If question response = 2
What are the barriers for talking with your doctor?

If question response = 3
What are your plans for approaching your doctor about donation?

If question response = 4
What are your plans for approaching your doctor about donation?

If question response = 5
How did you approach your doctor about donation? How successful do you feel your approach was?

### LKT Behavior 12: Preparing for Discussion with Doctor

**Objective**: Identify perceived barriers to initiating conversations with the doctor about LKD.

**A. Patient-Specific Question:** "On a scale from zero to five, how prepared do you feel you are to talk with your doctor about living kidney donation?"

0 = totally unprepared
1 = not prepared
2 = almost prepared
3 = prepared
4 = fully prepared
5 = no preparation needed

What are the challenges you think you will experience?
How will you approach dealing with these challenges?

**B. Barriers**

Based on the responses, challenge the patient to discuss the barriers to identifying talking with doctor.

Follow-up questions:

If question response = 0
What are the barriers for talking with your doctor?

If question response = 1
What are the barriers for talking with your doctor?

If question response = 2
What are the barriers for talking with your doctor?

If question response = 3
What are your plans for approaching your doctor about donation?

If question response = 4
What are your plans for approaching your doctor about donation?

If question response = 5
How did you approach your doctor about donation? How successful do you feel your approach was?

### Recommendations for Action

What are your next steps?
Are there any barriers?
How are you going to accomplish this?
Note: LKT = live kidney transplantation