

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

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

PATIENT AND FAMILY MEMBER DISCUSSIONS ABOUT LIVE KIDNEY TRANSPLANTATION

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

Social workers, because of their expertise in helping families confront challenging social and medical issues, could be particularly effective in helping patients and families overcome barriers to pursuing LKT. To our knowledge, however, interventions designed to help social workers facilitate patients' consideration and/or pursuit of LKT have not previously been developed. In the Talking About Live Kidney Donation (TALK) Social Worker Intervention study, we developed a social worker intervention to help patients with CKD and their families identify and overcome barriers to considering and/or pursuing LKT as a treatment option (Boulware et al., 2013; Boulware, Hill-Briggs, Kraus, Melancon, McGuire, Bonhage, et al., 2011). A detailed description of the TALK Social Worker Intervention research protocol has been published elsewhere (DePasquale, Hill-

Briggs, Darrell, Boyer, Ephraim, & Boulware, 2012). When tested in a randomized controlled trial, the TALK Social Worker Intervention improved patients' consideration and pursuit of LKT in comparison to patients who received the usual care from their nephrologists (Boulware et al., 2013). In this paper, we provide practical guidelines for the successful implementation of the TALK Social Worker Intervention in routine clinical practice.

DELIVERING THE TALK SOCIAL WORKER INTERVENTION

The TALK Social Worker Intervention was delivered in three stages:

- Stage 1: Pre-visit use of TALK educational materials;
- Stage 2: Patient visits; and
- Stage 3: Family member visits (see **Table 1**.)

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

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

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

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

Stage 2: Patient Visits

Step 1: Introductions and Background Information

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

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

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

Step 2: Referencing the TALK Educational Video and Booklet

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

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

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

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

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

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

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

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

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

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

Social worker: “So *what are the challenges that you’re facing in completing the evaluation process?*”

Patient: “Well, so I have to go meet a whole bunch of new medical employees and medical doctors, a whole bunch of people I don’t know, tell them all my medical history, and I have to trust that they are going to be able to make decisions that feel okay with me.”

Social worker: “Okay.”

Patient: “And everybody’s different. Do you know what I mean? Some of them are great and human, and some of them are like robots...next, next, next, kind of deal. And it’s really kind of a very vulnerable position to be in....Plus they’re going to be touching you and everything....I don’t even go for a full body massage....I’m not having somebody touch my naked body that I don’t know. Get out; that’s my parts, you know?”

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

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

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

Step 6: Recommendations for Future Action

The social worker also made recommendations for future actions patients could implement to advance their consideration and/or pursuit of LKT (e.g., finding reliable sources of information about CKD, writing down questions prior to medical visits, becoming knowledgeable about the evaluation process, calling an insurance company to determine cost of LKT, etc.). For example, a patient told the social worker that he was struggling to complete the evaluation

process due to his wife’s recent cancer diagnosis. When the social worker learned that the patient had only one remaining step to complete in his evaluation process, she recommended the following:

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

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

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

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

Stage 3: Family Member Meetings

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

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

In Step 1, with patients’ consent, the social worker began by summarizing the key points of the initial visit to remind patients and update family members about what had been

discussed. The social worker either made a simple summary statement, such as, “Well, the last time we met, one of the things we talked about was sharing the video with your family and friends. Have you had an opportunity to do that?” Or, the social worker directly addressed the family member(s) in attendance. For instance, during one such visit the social worker said,

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

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

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

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

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

Step 4: Recommendations for Future Action

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

Social worker: *“And so, what about communication like (sic) with your family in terms of what’s going on with your health?”*

Patient: *“Well, I told my husband what the doctor had said, you know. He...he thinks I’m over-concerned and I want to be perfect or something.”*

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

Stage 1: Pre-visit Use of TALK Educational Materials

Provide an educational video and booklet to patients during an in-person meeting

Stage 2: Patient Meetings

Step 1: Give initial introductions

Step 2: Discuss TALK educational materials

Step 3: Identify patient’s readiness to consider or pursue LKT by assessing how prepared they*

are to: 1) discuss LKT with family, 2) discuss LKT with the physician, 3) start the LKT evaluation process, 4) complete the LKT evaluation process, or 5) identify a donor

Step 4: Help patient identify barriers to considering and/or pursuing LKT

Step 5: Help patient identify their own solutions to barriers they identify in Step 4

Step 6: Provide recommendations for future action

Step 7: Invite family member(s) to a follow-up visit

Stage 3: Family Member Meetings

Step 1: Review what happened at the patient visit (with patient’s permission)

Step 2: Reassess patient’s progress in considering and/or pursuing LKT

Step 3: Facilitate a discussion between patient and family about their perspectives on ongoing barriers to considering and/or pursuing LKT

Step 4: Provide recommendations for future action

*LKT = live kidney transplantation/donation

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

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

CHALLENGES TO IMPLEMENTATION

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

Conversational Drift

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

Family Visits Without Family Members Present

While every patient attended both the initial and follow-up visits with the social worker, not all patients brought a family member with them to the follow-up visit. When

patients arrived without family members for their second visit, the social worker delivered the intervention as she had done in the initial patient visit, by resuming discussions with patients about barriers they were facing in the consideration and/or pursuit of LKT.

COMMON EXPERIENCES WITH THE TALK SOCIAL WORKER INTERVENTION

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

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

IMPLICATIONS FOR CLINICAL PRACTICE

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

AUTHOR NOTE

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

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