Transplant is often the preferred treatment for patients with end-stage renal disease (ESRD). The need for transplants is great; however, the demand for organs far exceeds the supply. As of February 14, 2014, the number of candidates on the waiting list to receive a kidney was 99,366. However, the total number of kidney donors recovered, including both live and deceased donors for 2013 was 12,098, similar to previous years in the preceding decade. African Americans are overrepresented among those in need of an organ, particularly kidneys. Between January 1, 1988 and February 21, 2014, despite comprising 28% of those who have received a deceased donor kidney transplant (DDKT) and 14% of those who received a live donor kidney transplant (LDKT), African Americans represented 34% of patients on the waiting list for a kidney.

Compared with DDKT, LDKT has numerous benefits, including the opportunity to bypass the waiting list and often years of time waiting for an organ; superior graft survival outcomes with less likelihood of acute tubular necrosis immediately after transplant and decreased risk of rejection, and improved quality of life when compared with the rigors of dialysis and the complications of ESRD. Evidence also suggests that recipients of living donor versus deceased donor kidneys tend to live longer.

**Living donor transplant education for African American patients with end-stage renal disease**

**Context**—Despite numerous benefits of live donor kidney transplant (LDKT), patient-level barriers often prevent African Americans from considering LDKT. Educational interventions designed to address patient-level barriers may increase willingness among African American patients with end-stage renal disease to explore LDKT as a treatment option.

**Objective**—To assess the effectiveness of a culturally sensitive educational intervention called Living ACTS (About Choices in Transplantation and Sharing) that was designed to address patient-level barriers to LDKT among African American patients with end-stage renal disease.

**Design/Participants**—Patients were randomized to intervention (n = 136) or control (n = 132) groups. They completed baseline measures and then viewed either the Living ACTS or control video. Both groups then completed an immediate follow-up measure and a 6-month assessment administered via telephone.

**Main Outcome Measures**—Self-reported knowledge about LDKT, willingness to talk to the patient’s family about LDKT, and perceived benefits of LDKT were measured at 3 time points.

**Results**—At 6-month follow-up, intervention participants demonstrated a significantly greater increase in knowledge of LDKT than control participants (F\(_{1,229} = 3.08, P = .05\)). Intervention participants expressed greater willingness to talk to patients’ families about LDKT than did control participants from baseline through 6-month follow-up (F\(_{1,229} = 7.11, P = .008\)). Finally, at immediate follow-up, intervention participants reported greater endorsement of the benefits of LDKT than did control participants (F\(_{1,229} = 14.27, P < .001\)); however, this effect had disappeared by the 6-month follow-up.

**Conclusions**—Living ACTS is effective at increasing and maintaining knowledge about LDKT among African American patients with end-stage renal disease who are considering transplant. (Progress in Transplantation. 2014;24:362-370)
Unfortunately, a complex interplay of patient-, physician-, and system-level factors affect both the demand for and the availability of organs. The available supply of organs is a function of public knowledge, attitudes, and beliefs about both transplant and health care in general; family-related knowledge, communication, and health status; and the efficiency of the organ procurement system. Analogously, the demand for organs relies on patients’ knowledge, preferences, and attitudes; a host of physician-level factors; and system-level factors that relate to placement and movement on the waiting list and health insurance status. Increased demand for LDKT among African American patients with ESRD would require attention to patient-, physician-, and system-level factors. Because patients’ interest in LDKT is necessary (albeit not sufficient) for LDKT to occur, there could be value in designing interventions to improve interest in LDKT among African American patients with ESRD.

Despite the clear medical benefit of LDKT over DDKT, patient-level barriers often prevent African Americans from exploring LDKT as an option. Patient-level barriers pertain to knowledge, preferences, and communication with family and friends about the possibility of serving as a living donor. Often complicating this communication process is concern about a potential donor’s or the patient’s own lack of medical suitability. Although family members could be ideal donors, many patients are reluctant to discuss LDKT with their family because of concerns about the donor’s well-being, possible resentment after donation, and a feeling of indebtedness to the donor. Innovative interventions have been implemented to improve use of LDKT by engaging patients and their families. However, there is virtual consensus of the need to appeal to the cultural context of target population to maximize the effectiveness of an intervention. Thus, one way to optimize the effectiveness of an intervention that seeks to increase interest in LDKT among African American patients with ESRD is to ensure that the intervention is aligned with the patient’s cultural values and belief systems.

Living ACTS: About Choices in Transplant and Sharing

Living ACTS is a culturally sensitive intervention designed to address patient-level barriers to LDKT among African American patients. Adapted from a community intervention that sought to improve public commitment to deceased donation, Living ACTS is informed by the Two-Dimensional Model of Cultural Sensitivity in Public Health. According to this model, cultural sensitivity is conceptualized as comprising 2 primary dimensions: surface structure and deep structure. Surface structure involves matching intervention materials and messages to observable, “superficial” (though important) characteristics of a target population. Surface structure would be exemplified by the inclusion of people, places, and language familiar to, and preferred by, the target audience (eg, including African American physicians in a video targeting African Americans). Deep structure cultural sensitivity requires understanding the cultural, social, historical, and psychological forces that influence the target behavior in the proposed target population, as well as the unique environmental and psychological barriers, and addressing these forces. For example, deep structure sensitivity would acknowledge and address the influential roles that family discussion and family impact play in many African Americans’ decision making about health care. It is theorized that surface structure is a prerequisite for acceptance of an intervention, but deep structure is a necessary for an intervention to be effective.

For the current study, we conducted a randomized controlled trial to compare the effectiveness of the Living ACTS intervention (with its attention to deep structure cultural sensitivity) with the effectiveness of the standard transplant education currently used within a particular transplant program. We hypothesized that at immediate and 6-month follow-up, intervention participants would report (1) greater knowledge of the process, benefits, and risks of LDKT; (2) greater willingness to share information about LDKT with family; and (3) greater perceived benefit of LDKT than control participants.

**Materials and Methods**

**Participants and Sample Size**

This study protocol was approved by the institutional review board at Emory University. Participants were recruited through the Emory Transplant Center’s kidney transplant program during an 8-month enrollment period. Inclusion criteria required that participants self-identify as Black/African American, have a scheduled appointment to be evaluated for kidney transplant during the enrollment period, and be 18 years of age or older. Initially, potential participants were identified through the outpatient transplant center’s appointment system. Additionally, study recruitment flyers were included in information packets pertaining to the evaluation that are mailed to all patients before their appointment dates. Interested patients were instructed to contact the project coordinator to learn more about the study. The project coordinator was also embedded in the outpatient transplant clinic, and with assistance from clinic staff, eligible patients were identified and approached about the study. Recruitment continued until the desired study sample size of 296 was reached (Figure 1).

Our sample size estimate focuses on the evaluation of the impact of the intervention. In particular,
we focus on the number of participants required to detect a difference from baseline to 6-month follow-up across 2 groups in the primary dependent variable, knowledge. The sample size formula for a difference in means indicated that the number of study participants required would be 63 per group (or 126 people). This number is similar to the 64 participants to detect a medium effect size for a 2-group analysis of variance with \( \alpha = .05 \) and \( \beta = .20 \).\(^{22}\) We next inflated our estimate 2-fold to account for 3 outcome variables (knowledge, willingness to talk to family, and perceived benefit of LDKT) that are likely to be correlated. This produced a total number of 252. We next inflated our estimate to account for attrition. Assuming 15% attrition, we started with a sample size of 296 in order to retain at least 252 participants for 6 months.

**Intervention**

Project staff conducted 5 focus groups in order to ensure that the intervention is informed by issues that reflect deep structure cultural sensitivity. One group each was conducted with the following types of persons: recipients of DDKT, recipients of LDKT, kidney donors, patients who had undergone evaluation for transplant and had been placed on the waiting list, and patients who had been referred for evaluation but had yet to undergo transplant orientation (unpublished data). Our intent was to ensure that the intervention was informed by a range of perspectives on transplant in general and LDKT in particular. From this work, it was clearly important to include African American patients, families, and health care professionals in the DVD in order to achieve surface structure cultural sensitivity. However, we also emphasized the impact of LDKT on families, how family decision making around LDKT may occur, myths about organ recipients taking on characteristics of the donor, and the availability of resources to help finance a transplant. All of these factors, in addition to the desire for the DVD to build trust in transplant health care professionals, were expected to address relevant aspects of deep structure cultural sensitivity.

The Living ACTS DVD included information from health professionals, who address the concerns raised by the focus group participants by providing information about the process, risks, and benefits of LDKT. The DVD also features personal stories from donor/recipient pairs, including a pair of African American brothers, African American sisters, and an unrelated mixed race pair (ie, an African American recipient and an Asian-American donor). The sibling pairs describe how family dynamics and family discussion played a role in their decision to pursue LDKT; the unrelated pair discuss how family members responded to the donor’s decision. All 3 pairs describe their thought processes and concerns about the donation/transplant procedure. Additionally, the video features discussion of financial resources available to assist those in need of a transplant. The Living ACTS booklet complements the DVD by providing additional information, including web links to various resources and tips for patients starting conversations about LDKT with family members (Table 1).

**Measures**

**Knowledge of LDKT.** Knowledge of LDKT was assessed by using 18 true-false items, developed by the authors on the basis of their previous studies, and experiential knowledge of the field (eg, “After they donate, living donors lose half of their kidney function for the rest of their lives”). The number of items that participants got correct was summed, yielding a total knowledge score ranging from 0 to 18. As this measure is an index (not a scale), no attempt was made to compute Cronbach \( \alpha \).\(^{23}\)

**Willingness to Talk to Family Members About LDKT.** Willingness to talk to family members about LDKT was assessed by using a 9-item scale (eg, “Asking a family member to be my living kidney donor is appropriate for me”), with responses ranging from 1 = “strongly disagree” to 5 = “strongly agree,” and a total score ranging from 9 to 45 (Cronbach \( \alpha=.87, .90, \) and .86 at baseline, immediate follow-up, and 6-month follow-up, respectively). Three items from this scale were drawn from the Asking Appropriateness Scale,\(^ {24} \) and 6 items were from the Outcome Efficacy Scale.\(^ {25} \)
Perceived Benefits of LDKT. Perceived benefits of LDKT were measured by using a 5-item scale (eg, “I wouldn’t have to wait as long for an organ if I got a living donor transplant”), with response options ranging from 1 = “strongly disagree” to 5 = “strongly agree,” and a total score ranging from 5 to 25 (Cronbach α=.76, .77, and .80 at baseline, immediate follow-up, and 6-month follow-up, respectively). One of the 5 items came from the Opinions about Transplant (Decisional Balance-Pros) scale, and the remaining items were created by the authors. After examining all 3 total scores for normality (ie, 1 per outcome), only the 5-item total Perceived Benefit of LDKT violated assumptions of normality as it was left skewed (skewness=-1.21, SD=3.77). Thus, we transformed this variable by reflecting the variable, then taking the square root to achieve normality (skewness=0.26, SD=0.80). Because this variable was reflected, higher scores would normally indicate weaker endorsement of the benefits of LDKT. However, for ease of discussion, we present unreflected means based on the original scale, to better align with the findings from the knowledge and willingness to talk to family members about LDKT dependent variables.

Procedures
The study used a pre-post experimental research design with control, in which participants were randomized to 1 of 2 groups: (1) the control group, which received standard transplant education materials plus an exercise DVD (Exercise, Live Well, and Feel Better), and (2) the intervention group, which received standard transplant education materials plus the Living ACTS intervention (Table 1). The exercise DVD was used in order to standardize participant attention across both study conditions. Standard transplant education included general information about transplant procedures, risks and benefits of transplant, and information for potential donors. In addition, before or on the day of their transplant evaluation appointment, as part of standard care, patients were required to complete an online course with more detailed information about transplant. This online course was an interactive online series of short animated slide and audio presentations for patients. Topics included an overview of organ transplant; information about the process, risks, and benefits of undergoing kidney transplant (both for living and deceased donor kidneys); living with a new kidney transplant; and becoming a living kidney donor.

Baseline and Immediate Follow-up. The study was conducted during participants’ appointments for multidisciplinary evaluation for kidney transplant. Researchers adhered to a standard data collection protocol for all study participants. Each participant was individually recruited and had consent obtained by the project coordinator and then was given the baseline survey to complete. Upon its completion, participants were randomly assigned to either the intervention or control condition and watched the appropriate DVD in a small room in the transplant center. The intervention participants watched the Living ACTS DVD described earlier. Control participants viewed a DVD about healthy living and exercising while on dialysis (Table 1). After watching 1 of the 2 DVDs, all participants completed the immediate follow-up instrument, provided contact information for the 6-month follow-up, and received a $30 cash incentive. In addition, those in the intervention condition were given a lunch bag with the intervention logo, a copy of the Living ACTS DVD, and the Living ACTS informational booklet.

Table 1 Comparison of intervention and control videos

<table>
<thead>
<tr>
<th>Intervention: Living ACTS: About Choices in Transplantation and Sharing</th>
<th>Control: Exercise, Live Well, and Feel Better</th>
</tr>
</thead>
<tbody>
<tr>
<td>General premise: Live donor transplant is a practical treatment option to explore among patients with end-stage renal disease.</td>
<td>General premise: Dialysis patients/kidney transplant recipients may improve their circumstances through exercise.</td>
</tr>
<tr>
<td>Vehicle: Personal stories that emphasize the role of family, factual information from health care professionals</td>
<td>Vehicle: Personal stories</td>
</tr>
<tr>
<td><strong>Key points:</strong></td>
<td><strong>Key points:</strong></td>
</tr>
<tr>
<td>Live donors/recipients discuss the decision to pursue living donation.</td>
<td>People can exercise through everyday tasks.</td>
</tr>
<tr>
<td>Medical providers discuss the benefits of live donor transplant over deceased donor transplant.</td>
<td>It is important to stick to a regular workout routine.</td>
</tr>
<tr>
<td>Transplant social worker discusses the process for donors and recipients to explore living donation.</td>
<td>Exercise offers numerous benefits, including a more positive mood, more energy, lower blood sugar, weight loss, muscle gain, and increased mobility.</td>
</tr>
<tr>
<td>Medical provider discusses the importance of preventing organ rejection.</td>
<td>Multiple persons discuss resources for persons interested in exploring live donor transplant.</td>
</tr>
<tr>
<td>Multiple persons discuss resources for persons interested in exploring live donor transplant.</td>
<td></td>
</tr>
</tbody>
</table>
Six-Month Follow-up. Approximately 5 months after the baseline/immediate questionnaire was administered, participants received a reminder packet in the mail, which included the contact information of the project coordinator and a copy of the 6-month follow-up questionnaire. Six months after the participant’s baseline assessment, study staff initiated calling the participant if he or she had not already called to schedule time to conduct the follow-up survey. Once the follow-up survey was completed, the researcher thanked the participant and mailed the follow-up incentive (the participants’ choice of a $40 gift card or money order).

Statistical Methods

First, we examined frequency distributions for all relevant variables. Next, we used *t* test (for age) and *χ²* test (for ethnicity, sex, marital status, highest level of education, employment status, income, and health insurance status) to explore whether those who were retained in the study differed significantly from those who were lost to follow-up (ie, a drop-out analysis). We then used a *t* test to explore mean differences in age across study condition. A *χ²* test was used to determine whether there were differences in ethnicity, sex, marital status, highest level of education, employment status, income, and health insurance status by study condition.

The main outcome analysis used general linear models, specifically, repeated-measures analysis of variance, to allow analysis of data collected at 3 points in time. Three models were run, 1 each for the following dependent variables: knowledge of LDKT, willingness to talk to family about LDKT, and perceived benefit of LDKT. The model effects that were tested were condition (intervention vs control), time (baseline, immediate, and 6-month follow-up), and their interaction. Relevant confounding variables were included in the models. All analyses were conducted by using SPSS 19.0. An α level of .05 was used to determine statistical significance.

Results

Demographic Characteristics

At baseline, a total of 296 participants were recruited into the study. Two-hundred sixty-eight participants (91%) completed the 6-month follow-up telephone survey, and the proportion of those retained did not differ by study condition. A dropout analysis was done to determine whether those who were retained in the study (n = 268) were demographically different from those who were lost to follow-up (n = 28) and showed no significant differences. Participants (n = 268) ranged in age from 20 to 76 years. Just more than half of participants were male, and less than half were married (Table 2). The vast majority of participants

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### Table 2  Baseline sample characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total (N = 268)</th>
<th>Intervention (n = 136)</th>
<th>Control (n = 132)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean (range), y</td>
<td>51.7 (20-76)</td>
<td>50.9 (21-76)</td>
<td>52.5 (20-75)</td>
</tr>
<tr>
<td>Male</td>
<td>147 (54.9)</td>
<td>70 (51.5)</td>
<td>77 (58.3)</td>
</tr>
<tr>
<td>Black/African American&lt;sup&gt;b&lt;/sup&gt;</td>
<td>250 (93.3)</td>
<td>130 (95.6)</td>
<td>120 (90.9)</td>
</tr>
<tr>
<td>Married</td>
<td>108 (40.3)</td>
<td>51 (37.5)</td>
<td>57 (43.2)</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;High school</td>
<td>30 (11.2)</td>
<td>16 (11.8)</td>
<td>14 (10.6)</td>
</tr>
<tr>
<td>High school graduate/GED</td>
<td>159 (59.3)</td>
<td>81 (59.6)</td>
<td>78 (59.1)</td>
</tr>
<tr>
<td>Completed college</td>
<td>55 (20.5)</td>
<td>29 (21.3)</td>
<td>26 (19.7)</td>
</tr>
<tr>
<td>Professional degree</td>
<td>16 (6.0)</td>
<td>8 (5.9)</td>
<td>8 (6.1)</td>
</tr>
<tr>
<td>Not employed</td>
<td>208 (77.6)</td>
<td>106 (77.9)</td>
<td>102 (77.3)</td>
</tr>
<tr>
<td>Income categories</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to $10000</td>
<td>47 (17.5)</td>
<td>25 (18.4)</td>
<td>22 (16.7)</td>
</tr>
<tr>
<td>$10000-$19999</td>
<td>61 (22.8)</td>
<td>31 (22.8)</td>
<td>30 (22.7)</td>
</tr>
<tr>
<td>$20000-$29999</td>
<td>38 (14.2)</td>
<td>23 (16.9)</td>
<td>15 (11.4)</td>
</tr>
<tr>
<td>≥ $30000 or more</td>
<td>92 (34.3)</td>
<td>46 (33.8)</td>
<td>46 (34.8)</td>
</tr>
<tr>
<td>Has private health insurance</td>
<td>111 (41.4)</td>
<td>55 (40.4)</td>
<td>56 (42.4)</td>
</tr>
<tr>
<td>Length of time on dialysis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-6 months</td>
<td>84 (31.3)</td>
<td>43 (31.6)</td>
<td>41 (31.1)</td>
</tr>
<tr>
<td>7 months to &lt;2 years</td>
<td>70 (26.1)</td>
<td>36 (26.5)</td>
<td>34 (25.8)</td>
</tr>
<tr>
<td>≥2 years</td>
<td>96 (35.8)</td>
<td>49 (36.0)</td>
<td>47 (35.6)</td>
</tr>
</tbody>
</table>

<sup>a</sup> Values are expressed as number (percentage) unless otherwise indicated. Percentages may not total 100 because of missing data.

<sup>b</sup> Per inclusion criteria, all participants were “Black,” but could further indicate ethnicity (eg, Black/Cariibean).
identified as Black/African American; 4% identified as Black/Caribbean, Black/Hispanic, African, or other. Participants tended to be unemployed, have incomes of $20,000 per year or more, and be primarily covered by Medicare or Medicaid.

None of the demographic variables were significantly related to study condition. However, this analysis revealed that the highest level of education, income, and health insurance status were significantly associated with knowledge, sex was significantly associated with willingness to talk to family, and sex and marital status were significantly associated with the perceived benefit of LDKT. Therefore, these variables were entered as covariates into their respective models. Last, of the intervention group members, 63 (46%) reported watching the intervention DVD at least once after leaving the transplant center. An analysis of whether the means for the 3 study outcomes differed depending on whether intervention participants reported watching the Living ACTS DVD during the 6-month follow-up period showed no significant differences.

**Main Outcome Analysis**

The main outcome analyses examined the condition, time, and condition by time effect separately for each of the 3 analysis of variance models (Table 3). Results regarding knowledge of LDKT indicate a significant condition by time interaction, such that intervention participants demonstrated a significantly greater increase in knowledge of LDKT after the intervention than control participants did, and this was maintained thorough the 6-month follow-up ($F_{2,223} = 3.08, \ P = .05$) (Figure 2). Regarding willingness to talk to family about LDKT, there was a significant effect of condition ($F_{1,230} = 7.11, \ P = .008$), such that individuals in the intervention group expressed greater willingness to talk to family about LDKT scores from baseline through 6-month follow-up; however, there was no condition by time interaction. Finally, a condition by time interaction was noted for perceived benefits of LDKT such that at immediate follow-up, intervention participants reported greater endorsement of the benefits of LDKT than control participants reported ($F_{1,223} = 14.27, \ P < .001$); however, this effect had disappeared by the 6-month follow-up (Figure 3).

**Discussion**

A randomized controlled trial was conducted to compare the effectiveness of the Living ACTS intervention with the effectiveness of standard transplant education alone. As hypothesized, intervention participants showed greater knowledge of LDKT than control participants showed. Unfortunately, our intervention did not significantly increase willingness to talk to family members about LDKT, and although intervention participants did perceive greater benefit of LDKT than control participants at immediate follow-up, both groups reported near baseline levels of endorsement of the benefits of LDKT at 6-month follow-up, indicating that this effect was not sustained over time.

Evidence of the importance of increasing knowledge of LDKT among patients with ESRD is accumulating. This study demonstrates that Living ACTS contributes to increased and sustained knowledge about LDKT. Intervention participants heard from experts in the field about patients’ concerns about the process, as well as personal stories from individuals who had already experienced it. By presenting information in the DVD from individuals with similar racial/ethnic backgrounds (surface structure cultural sensitivity) and directly addressing concerns about LDKT stemming from cultural values, such as emphasizing the familial impact of LDKT (deep structure cultural sensitivity), we believe that the intervention may have greater salience for participants.

In terms of willingness to talk to family members about LDKT, although there was a significant effect of condition, this effect appeared to be due to failed
randomization, as the intervention group had significantly higher scores for willingness to talk to family at baseline, and this baseline difference was maintained over time. We believe that this also may be attributed to the general difficulty of initiating conversations about live kidney donation, particularly among African American patients. In a study with African American dialysis patients, findings indicated that although the majority of study participants showed a high knowledge about LDKT and a desire to undergo LDKT, rates of discussion among the physician, patient, and the patient’s family were low. As demonstrated in previous research, family discussion plays a vital role in one’s decision to consider LDKT as a treatment option.

Although we believe that the format of the Living ACTS DVD accomplished a great deal in increasing study participants’ knowledge, future directions might incorporate more of the actual mechanics of initiating conversations with family members. Although we did include information about how to do so in the intervention booklet, the DVD may need more explicit guidance on how to initiate conversations about LDKT in ways that are well received by patients’ family and friends.

For perception of the benefits of LDKT, although intervention participants’ scores increased immediately after the intervention, scores had declined to baseline levels by 6-month follow-up. Another study showed a similar decline in the intervention group’s scores after the intervention, but at immediate follow-up, rather than at 6-month follow-up as in the present study. The reasons for the lack of a sustained effect are unclear. It could be that participants simply experienced information overload on the day of their evaluation appointment given that the intervention was being implemented in the context of multiple medical appointments. This overload would affect participants’ ability to retain the information beyond the day of the evaluation appointment.

A second possibility is that some participants, while initially encouraged to explore LDKT after watching the video, became discouraged by not being able to find a suitable donor or by other barriers to transplant. Specifically, if the participants were either told and/or believed they needed to improve certain health factors (eg, lose weight) before they would be accepted for transplant listing, they may have “self-selected” themselves out of consideration for LDKT, either officially or unofficially.

Another possible source of discouragement might have been the result of their kidney evaluation appointments or subsequent conversations with family members. However, owing to funding constraints, we were prohibited from examining whether participants initiated actual conversations with family members about LDKT and/or ultimately pursued LDKT; but it is conceivable that if patients who were interested in pursuing LDKT faced barriers related to family communication and/or their ability to identify an eligible donor, these factors may also drive down perceptions of the benefit of LDKT among those who stayed in the study and those who were lost to follow-up.

A third possibility is that although participants became more knowledgeable about LDKT, they simply did not support its overall benefit to their lives. The worry about involving family members as potential donors and the issues surrounding living donation,
as well as fear of potential outcomes, such as kidney rejection (as seen in a study\textsuperscript{12} of patients who had already received a transplant) might have been too great of a deterrent to patients. Major treatment decisions such as this one include a range of financial, social, emotional, and cultural considerations that exist alongside medical considerations. It should be noted that the purpose of Living ACTS was not to encourage LDKT; LDKT may not be the best treatment option for everyone. However, the value of Living ACTS lies in providing information in order to support patients’ abilities to make informed choices.

Limitations

This study had some potential limitations. First, we used a convenience sample of African American patients with ESRD who were recruited from a single transplant center located in the southeastern United States. There might be inherent differences in how patient education and follow-up is conducted at this transplant center, as well as in the participants who sought services there, compared with other local transplant centers. In addition, because the participants had either been referred to the transplant center or had made an appointment and actually showed up for the appointment, a self-selection bias may be present, in that these patients might be more motivated to seek information about transplant and/or consider it as a treatment option than are patients who declined to schedule or to keep their appointment. However, the response rate for the study was high (96% of those approached agreed to participate), which suggests that the effects of this limitation may be minimal.

A third limitation is in the way in which data were collected. The data were collected during participants’ evaluation appointment; thus, it was not possible to control for how much information the patient had received from doctors and transplant coordinators before taking the immediate follow-up measures. However, we mitigated this potential issue by administering baseline and immediate follow-up measures relatively early in each participant’s evaluation schedule, so this issue was unlikely to have had much of an effect on study findings. In addition, this potential source of contamination would be distributed equally across study conditions, thereby having little effect on study outcomes.

Last, the investigators relied on self-reported data to determine whether intervention group participants viewed the DVD after leaving the center; there may be a tendency to overreport viewing of the DVD at home. Although a second viewing of the DVD might affect later retention of information, a strength of the study design is that participants received at least 1 full dose of the intervention by reviewing the DVD and the booklet immediately after the baseline assessment while in the transplant center.

Conclusions

Study findings suggest that supplementing standard education with Living ACTS effectively increased knowledge of LDKT as a treatment option. Further evidence indicates that the intervention had an immediate effect on the extent to which participants perceive the benefits of LDKT, although perceptions of these benefits were attenuated over time. Further research is needed to understand the nature of family discussions that occur relative to LDKT as a result of interventions such as Living ACTS. It is acknowledged that the decision to pursue LDKT is a personal one; this treatment option may not be optimal for all patients. Even among patients who are interested in LDKT, some patients may not be deemed suitable for transplant; others may not be able to find a suitable donor. Indeed the factors that shape whether an interested patient undergoes LDKT are complex. Nevertheless, evidence indicates that Living ACTS may be a vehicle that improves knowledge of LDKT as a practical treatment option among African American patients with ESRD, which is a necessary first step for any patient who ultimately undergoes LDKT.

Financial Disclosures

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References