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# Kidney Transplant Evaluation and Listing: Development and Preliminary Evaluation of Multimedia Education for Patients

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**Background:**

Patient knowledge gaps about the evaluation and waitlisting process for kidney transplantation lead to delayed and incomplete testing, which compromise transplant access. We aimed to develop and evaluate a novel video education approach to empower patients to proceed with the transplant evaluation and listing process and to increase their knowledge and motivation.

**Material/Methods:**


We developed 2 theory-informed educational animations about the kidney transplantation evaluation and listing process with input from experts in transplantation and communication, 20 candidates/recipients, 5 caregivers, 1 anthropologist, 3 community advocates, and 36 dialysis or transplant providers. We then conducted an online pre-post study with 28 kidney transplantation candidates to measure the acceptability and feasibility of the 2 videos to improve patients' evaluation and listing knowledge, understanding, and concerns.

**Results:**

Compared with before intervention, the mean knowledge score increased after intervention by 38% (5.7 to 7.9;  $P < 0.001$ ). Increases in knowledge effect size were large across age group, health literacy, education, technology access, and duration of pretransplant dialysis. The proportion of positive responses increased from before to after animation viewing for understanding the evaluation process (25% to 61%;  $P = 0.002$ ) and waitlist placement (32% to 86%;  $P < 0.001$ ). Concerns about list placement decreased (32% to 7%;  $P = 0.039$ ). After viewing the animations, >90% of responses indicated positive ratings on trusting the information, comfort level with learning, and engagement.

**Conclusions:**

In partnership with stakeholders, we developed 2 educational animations about kidney transplant evaluation and listing that were positively received by patients and have the potential to improve patient knowledge and understanding and reduce patient concerns.

**Keywords:****Kidney Transplantation • Patient Education as Topic • Waiting List****Full-text PDF:**<https://www.annalsoftransplantation.com/abstract/index/idArt/929839> 3826 8 1 45

## Background

Kidney transplantation improves patient quality and length of life better than does dialysis treatment [1]. Yet, less than 20% of the 501 466 patients in the United States receiving long-term dialysis [2] are on the waiting list for a kidney transplant, and, of those on the list, 40% are ineligible to receive kidney offers owing to an inactive waitlisting status [3]. The low rates of progression to listing placement and maintenance of eligibility while waiting are due, in large part, to patient attrition caused by testing delays and the failure to complete testing. Potential recipients may take as long as a year to complete the transplant evaluation [4], and 50% fail to complete the evaluation stage, despite not having clear contraindications [5,6].

Many research studies have shown that patients are confused about the transplant evaluation and listing process and that these knowledge deficits contribute to testing delays and aborted medical evaluations [7-10]. Knowledge gaps reported by patients include a lack of clarity about where they are in the listing process [9], belief they are already on the list [11,12], lack of awareness that tests need to be repeated [13], and misunderstanding of an inactive status on the list [14]. In addition to difficulties navigating the healthcare system, knowledge gaps may lead to negative perceptions of the transplant process and reduce patient motivation to complete testing [14,15].

Patient education about the kidney transplantation evaluation and listing process typically occurs at transplant centers through educational classes, followed by consultations with multidisciplinary providers, which give patients the opportunity to ask questions. In-person education is supplemented with take-home materials and telephone conversations with transplant coordinators [16]. Patients characterize routine transplant education classes as being lengthy and presenting too much information at once [14,17]. Also, they forget to ask questions while meeting with providers [14], find the take-home print materials overwhelming [14], and do not recognize telephone conversations with coordinators as opportunities for education [14]. Some patients turn to websites to learn about kidney transplantation; however, patients have described publicly available websites as being confusing [18].

To impact the evaluation and listing process through patient education, interventions over the past decade have employed various combinations of trained educators, navigators, videos, and pamphlets [6, 19-23], with some interventions demonstrating effectiveness at increasing transplant evaluations or listings over those that are attained with standard care [6,19-21]. However, the adoption of interventions that require human educators is limited by health system resources and already burdened healthcare staff. One of these interventions resulted in a higher rate of evaluation completion with the use of a

video DVD and pamphlet alone than with the use of a video and pamphlet plus an educator [19], highlighting the potential value of stand-alone educational materials. However, the video and pamphlet education had been originally designed to encourage living-donor kidney transplantation and may lack meaningful content about the evaluation and listing process.

There remains a need for effective educational tools that can be efficiently used by healthcare providers to present information to patients or that patients can access independently to learn about the evaluation and listing process. To address this need, we developed 2 animated videos about the kidney transplant evaluation and waiting list process, which were targeted to kidney transplant candidates and their caregivers. The animation format offers efficient learning owing to the enhanced cognitive processing of the medium [24], and it has been found to be accessible across age, culture, and literacy level [25,26].

In this study, we (1) cover the development process of the 2 educational animations about evaluation and listing for kidney transplantation and (2) report preliminary acceptability and feasibility evidence from a pilot test of the animations in an online study that was conducted with potential kidney recipients. The results of the report will contribute to a comprehensive animation-based educational intervention to enhance access to kidney transplantation. This educational intervention will undergo formal program evaluation in the future.

## Material and Methods

### Study design

Qualitative methods were employed to develop 2 animations about the process of (1) evaluation and (2) listing for kidney transplantation. These methods were informed by health communication best practices and behavior theories [24,27,28]. We also developed surveys aligned with the animations to test patients' evaluation and listing knowledge, understanding, and concerns. Next, we performed a preliminary evaluation of both animations with an uncontrolled, single-group, quasi-experimental, pre-post study conducted online. This study was approved by the Institutional Review Board of the University at Buffalo, and the protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki.

### Development of the animations

The animations were developed between October 2018 and August 2019 through an 11-step process to gather input to iteratively develop the videos (**Figure 1**).

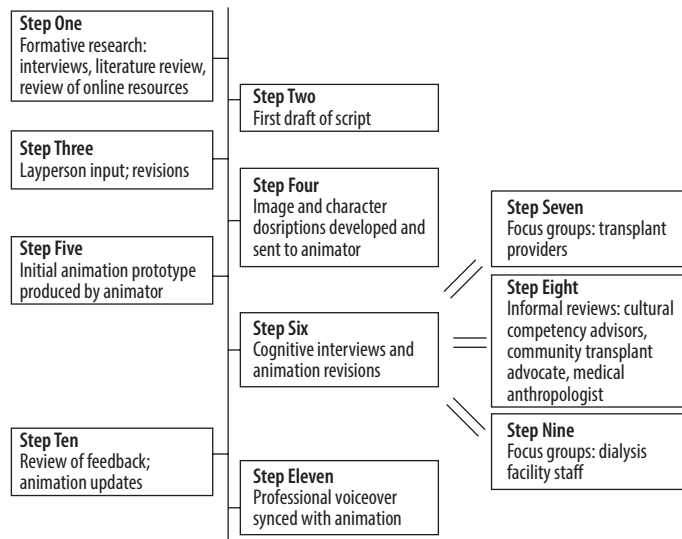


Figure 1. Animation development process.

Table 1. Baseline characteristics of study participants.

- **Evaluation video: How do I get a kidney transplant?** Explains the transplant evaluation. Uses simple representation to depict a recipient visiting a transplant center and bringing supports, a list of questions, and necessary documentation. Describes role of coordinator, physician, social worker, dietician, and financial counselor, multidisciplinary decision of eligibility, importance of keeping the coordinator's contact information, performance of some transplant testing at time of evaluation and need for further testing, time frame to complete testing, importance of updating the transplant coordinator upon completion of testing or changes in health.
- **Listing video: Am I on the kidney waiting list?** Explains waiting list placement and maintenance information: transplant center decision by multidisciplinary team, meaning of active and inactive status, written notification of listing status, possibility that completed tests may expire, conversion to inactive when testing not updated, transplant center notifications regarding repeat testing, importance of communication with the coordinator.

In Step 1, we conducted formative research through interviews [14,29] and a review of the published literature [8,11-13,30] and existing online resources to inform our outline for animation content. Key content (Table 1) was considered to be practical (applicable to real-life situations), facilitative (examples of behaviors and solutions), and inclusive of support network roles (friends, family members, and healthcare providers).

In Step 2, a first draft script was created using plain language, conversational style, and active voice. Information was organized following the elaboration theory [27]. Messages were also gain-framed and guided by the self-efficacy theory [28] to incorporate cognitive and emotional processing of health-relevant information [31].

In Step 3, a layperson gave input, and subsequent script revisions were made by the researchers. In Step 4, the researchers developed descriptions for images and characters for each scene or main point. Characters, which were chosen from those produced for videos on different transplant topics [32], were

diverse in age, race, and ethnicity. During Step 5, an initial prototype of the animation was produced using line drawings, which were synchronized to a temporary voice over.

Step 6 consisted of cognitive interviews [33] and animation revisions done iteratively following feedback [34], with specific emphasis on providing the information in an emotionally reassuring way. Through convenience sampling, 10 potential kidney transplant recipients, 10 recipients of deceased donor kidneys, and 5 caregivers were approached in the Erie County Medical Center transplant clinic and outpatient dialysis facility to participate in the cognitive interviews, resulting in 7 focus groups and 14 individual interviews. Feedback was solicited immediately after watching the animations (Table 2). We obtained information about the animations' suitability, acceptability, and anticipated usability and feasibility using an interview guide. Black patients (purposively approached to achieve a minimum of 40% of the sample) were interviewed separately from non-Black patients to promote a range in perspective. These sessions were audio recorded and transcribed verbatim.

**Table 2.** Animation revisions based on patient input from patients, experts, and stakeholders\*.

Stakeholder feedback	Animation revision
<p><b>Evaluation video</b></p> <ul style="list-style-type: none"> <li>• Content confusing and too long.</li> <li>• Lack of information about specific tests that need to be obtained, who schedules the appointments, what happens if the result of a test is problematic, and how the committee decision is conveyed to the patient.</li> <li>• Recommended providing information about the transplant coordinator specialty [ie, nurse] and that the candidate should bring a snack to the evaluation.</li> <li>• Listing status content not relevant within the evaluation stage. (transplant providers)</li> <li>• There should be an explanation that some test results lead to requirement for other tests. (<i>dialysis staff</i>).</li> </ul>	<ul style="list-style-type: none"> <li>• Separated single long animation into 2 shorter animations.</li> <li>• Added requirement for completion of routine surveillance studies as well as examples of common transplant-specific tests.</li> <li>• Added that the transplant coordinator is a nurse.</li> <li>• Added recommendation of bringing a snack to the evaluation.</li> <li>• Separate video regarding listing.</li> <li>• Added language about the potential need for further testing based on the results of prior tests.</li> </ul>
<p><b>Listing video</b></p> <ul style="list-style-type: none"> <li>• Lacks clarity regarding when to call the coordinator and need for blood work while active status.</li> <li>• Explanations of active and inactive status were confusing. (<i>dialysis staff</i>).</li> </ul>	<ul style="list-style-type: none"> <li>• Multiple changes to script and scenes to clarify and improve comprehension.</li> </ul>

\* Comments are from patients unless specifically (*indicated*).

Steps 7, 8, and 9 occurred in parallel with Step 6 and consisted of focus groups (Steps 7 and 9) and informal reviews with stakeholders and experts (Step 8, email or in-person reviews). The participants included 12 transplant practitioners, 2 focus groups, 2 hospital-based experts on cultural competency, a local kidney advocate from the Kidney Foundation of Western New York, a medical anthropologist, and 24 dialysis unit staff. The informal reviews were documented with field notes. The focus groups were audio recorded.

In Step 10, two researchers listened to and read the transcripts for each audio recording, consulted researcher notes, and selected messages reflective of each interview's context to capture meaningful feedback. Findings were promptly reported to the research team for consideration in the refinement of the animations. Updates to the narration, scripts, graphics, pacing, and animation were made based on ongoing feedback until the animations were finalized. Animation design was based on animation multimedia learning theory [24], which describes the method of synchronizing audio and visual information to enhance message comprehension. In Step 11, a professional voice over was set to the animations.

### Development of surveys

An interdisciplinary team of transplant practitioners and researchers designed questions that were aligned with animation content and written using simple language to measure kidney evaluation and listing knowledge, understanding, and

concerns. Research staff conducted cognitive interviews with 7 deceased donor kidney transplantation (DDKT) recipients regarding question clarity. Participants identified questions that were confusing and words that needed clarification.

### Final animation testing for feasibility and acceptability

The animations were evaluated with patients who were referred for kidney transplantation to Erie County Medical Center in New York between May 2020 and July 2020. Inclusion criteria were age  $\geq 18$  years, English-speaking, non-incarcerated, email available in the administrative record, and no previous attendance at a kidney transplant evaluation at the medical center. Some patients had already attended standard transplant education consisting of a 2-h oral and PowerPoint lecture presented in a group setting by a transplant nurse, which covered the kidney transplantation process, benefits, and risks. Others had not attended because the group education session had been replaced by one-on-one education administered on the same day as the transplant evaluation because of the cessation of group-based activities in response to the coronavirus disease 2019 (COVID-19) pandemic.

To recruit participants, consecutive kidney transplant candidates that had been referred to the transplant center and completed the clinical intake telephone call were emailed letters of invitation to the study. Those that did not opt out received a maximum of 2 telephone calls (and additional concurrent text and email invitations if nonresponsive to calls) 1 week apart. After

patients gave their consent verbally or by email or text, the patient received an email containing a link to the study. The study link was valid until their transplant medical evaluation visit at the hospital or until the end of the study, whichever came first. The link opened to the study and included an electronic consent, all survey instruments, and both videos back-to-back on a SurveyGizmo platform (Boulder, CO, USA). We developed the features of the study platform based on usability feedback that we received from transplant candidates at our center, which had led to a simple context-sensitive interface [35].

Participants opened the study link on the device of their choice and completed the following: electronic consent, 31 questions including sociodemographic characteristics (age, sex, race, education, employment, total annual household income, and marital status), pretransplant dialysis duration, health literacy [36], technology access [37], and measures of evaluation and listing knowledge (9 items, true/false/I don't know), understanding (3 items, 5-point Likert scale), and concerns (2 items, 5-point Likert scale). After survey completion, the participants were routed to a page with the first animation (about evaluation), which started automatically after a 3 s lag. After the video reached the end, a "next" button would appear. When the "next" button was pushed, a page with the second animation (about listing) would appear and play automatically. Both videos could be paused and replayed an unlimited number of times. After video viewing was complete, participants answered 1 question about whether they watched the videos and the device used, followed by survey questions identical to the pre-tests, with the sociodemographic questions replaced by animation acceptability questions (11 items, 5-point Likert scale), which was developed by the researchers ( $\alpha=0.92$ ) [38]. All survey questions were required and posed sequentially without the option of going backward. Participants were compensated with a \$25.00 check.

### Sample size determination

We determined that patient-level changes in evaluation and listing knowledge, understanding, and concerns before and after study with 24 participants would provide 80% power to detect at least a 0.60 standardized effect size using a 1-group *t* test (level of significance  $\alpha=0.05$ , 2-tailed). We expected a 30% dropout rate from the study; therefore, 35 participants were used as the target enrollment.

### Data analysis

Parallel to the collection of the qualitative data, the data were analyzed. Transcripts were reviewed and manually coded by a single investigator. All utterances were assigned to as many different concepts as they fit and then were grouped into similar themes related to the study aims. The findings were

discussed with a second investigator with expertise in qualitative analyses.

SPSS version 24.0 (IBM Corp, Armonk, NY, USA) was used to perform quantitative statistical analyses. Frequencies were computed for all categorical variables and compared using the McNemar's test. As a measure of effect sizes, point biserial correlation [39] was calculated with 0.1, 0.2, and 0.32 representing small, medium, and large effects, respectively. Knowledge scores (with unsure and unanswered questions considered as false) were calculated by adding the number of correct answers. All Likert scales, which were previously bounded by strongly agree and strongly disagree, were dichotomized for ease of interpretation. Higher scores reflected greater understanding and concerns. Animation acceptability data were categorized and presented in a histogram. A 2-tailed alpha of 0.05 was used to determine statistical significance.

## Results

### Video development

A total of 25 participants completed the cognitive interviews to help direct the development of the videos. Their ages ranged between 27 to 69 years; 8 were men; 11 were Black, 12 White, and 2 Asian; 11 had completed some college; most had annual household incomes between \$30 000 and \$50 000 or less; 10 were potential kidney transplant recipients, 5 were caregivers; and 10 had received DDKTs (Table 3). The roles of the experts and stakeholders, who also provided input, are shown in Table 3.

The process of video development (Table 2) began with an early prototype of a single video that covered topics about both the medical evaluation and kidney transplant waiting list. Some participants were confused by the extensive content and stated the video was too long and had too much information. Therefore, the video was split into 2 separate videos. Subsequent interviews included viewing of both animations.

Feedback regarding the evaluation animation noted the following: the video did not show the specific tests that needed to be obtained; the person who schedules the appointments was not shown; the procedure when there are "problematic" test results was not addressed; and how the committee decision is conveyed to the patient was not addressed. Patients also recommended that the candidate should be told to bring a snack to the evaluation and that the video should describe the medical background of the transplant coordinator. The dialysis staff members said there should be an explanation that some test results lead to the requirement of other tests. These aspects were added.



**Table 3.** Animation title and corresponding content.

Characteristic % or median (range or numerator/denominator)	Video development participants* N=25	Video evaluation participants N=28
Kidney transplant candidates	10	
Kidney transplant recipients	10	n/a
Caregivers	5	
Age, years	53 (27-69)	57 (35-76)
Sex, Male	32% (8/25)	43% (12/28)
Race		
Black	44% (11/25)	32% (9/28)
Non-Hispanic white	48% (12/25)	54% (15/28)
Asian	8% (2/25)	3.6% (1/28)
Other	0% (0/25)	11% (3/28)
Dialysis duration		
Not on dialysis	25% (5/20)	25% (7/28)
<1 year	15% (3/20)	29% (8/28)
1 to 3 years	30% (6/20)	29% (8/28)
>3 years	30% (6/20)	18% (5/28)
Education		
Below High School	4% (1/25)	0% (0/28)
High School or trade school graduate	52% (13/25)	36% (10/28)
Some college or higher	44% (11/25)	64% (18/28)
Lives with another adult in the household	44% (11/25)	68% (19/28)
Full- or part-time employment	36% (9/25)	29% (8/28)
Total household yearly income		
≤US\$ 30,000	36% (9/25)	39% (11/28)
US\$ 30,000-50,000	24% (6/25)	14% (4/28)
>US\$ 50,000	8% (2/25)	39% (11/28)
No response	32% (8/25)	7% (2/28)
Access to Technology		
Participant has a working internet capable cellular phone	84% (21/25)	93% (26/28)
Household has a working internet capable cellular phone	96% (24/25)	86% (24/28)
Participant has a working computer or tablet like an iPad	36% (9/25)	68% (19/28)
Household has a working computer or tablet like an iPad	52% (13/25)	75% (21/28)
Participant sends or receives text messages	96% (24/25)	100% (28/28)
Participant sends or receives email	64% (16/25)	100% (28/28)
Frequency that someone helps you read hospital materials		
Never	68% (17/25)	71% (20/28)
Sometimes	20.0% (5/25)	21% (6/28)
Often	0% (0/25)	4% (1/28)
A lot	12% (3/25)	4% (1/28)
Comfort level filling out forms alone		
Very comfortable	84% (21/25)	90% (25/28)
Somewhat comfortable	8% (2/25)	7% (2/28)
Somewhat uncomfortable	4% (1/25)	4% (1/28)
Very uncomfortable	4% (1/25)	0% (0/28)

\* Data describes patient-participants. Additional participants include 1 medical anthropologist, 3 community advisors, 24 dialysis providers, and 12 transplant providers.

**Table 4.** Video title, running time, number of narrated words, number of words embedded as text, and reading level.

Animation title	Total running time	Total # of words spoken	Total # of embedded words	Narrative Flesch-Kincaid grade
How do I get a kidney transplant?	2 m 28 s	395	27	6.0
Am I on the kidney waiting list?	1 m 50 s	295	5	6.5

m – minutes; s – seconds.

**Table 5.** Themes and representative quotes of messages received from the animations about kidney transplant evaluation and listing.

<b>Resources and support:</b> “It showed you everybody who will help you, that you’re not by yourself.” “Use your resources that they give you.” “Reach out to your social worker if she probably could plug you into whoever you need to talk to or what have you.”
<b>Caregiving:</b> “When it said bring a family member or friend, definitely because it’s a lot to process by yourself.” “They will help you build up your support team.”
<b>Communication:</b> “There’s, you know, if you got any kinds of questions or any doubt on anything, you know, make sure you reach out, you know, because they will make it a lot smoother.” “Saving the coordinator number. I think that is most important.” “They’ll tell you what you need to do to become active.” “Any questions go to the coordinator and they will help you get ready.”
<b>Follow-through:</b> “Make sure you do everything because it’s a lot of steps, lot a tests you got to take, but um conquer before you, uh, you know, stress test, uh, you know, blood work, all that.” “You got to make sure you got to do what you’re supposed to do so you could be placed on that list because there’s a lot of steps.” “They’ll call you and tell you and you try to fix it.”

Feedback from the dialysis staff members and patients regarding the video about the waiting list included that the explanations of active and inactive status were confusing. Extensive revisions were made in response to their comments until the content was understood as intended. We also received feedback suggesting the inclusion of a summary statement. An epilogue of the major educational topics in each video was created and retained for the waitlisting video, but was not retained in the evaluation video because it caused confusion. Two animations about kidney transplant evaluation and listing were produced, each approximately 2 min in duration. The content of the videos is described in **Table 1**, and their titles and data are depicted in **Table 4**.

The following 4 themes were identified from patient feedback about the videos: resources and support, caregiving, communication, and follow-through (**Table 5**). (1) Patients identified messages about the availability of resources and providers being there “to help you”. (2) Caregivers were described as helping patients remember information and provide support. (3) Feedback within the communication theme included knowing the coordinator’s contact information, reaching out, asking questions, and learning what to do. (4) Follow-through was described as “conquering” test completion and addressing results that required further testing to “get on the list”.

### Video evaluation pilot study

Of the 164 patients referred to the transplant center during the study time period, email addresses were available for 107

patients, who were invited to participate, and 32 patients provided consent (30% recruitment). Reasons given for nonparticipation were lack of availability, feeling sick, visual or motor impairment, poor Internet, and reason not given. Of the 32 consenting participants, 28 completed the study. **Table 3** depicts the demographic data of the 28 participants included in the final analytic sample. The patients’ median age was 57 years; 43% were men; 32% were Black, 54% White, and 11% Asian; 36% completed secondary education or less. The total household income was <\$30 000 annually among 39%, and the proportion that was unemployed was 29%. The majority (93%) owned a cell phone with Internet capability, and 100% used text messages. The device used to complete the study was computer/tablet for 25%, cell phone for 71%, and unknown for 4%.

### Knowledge

Patient knowledge gains on content about test scheduling, evaluation duration, caregiver attendance at evaluation, and inactive list status were significant (**Table 6**). Compared with before intervention, the mean knowledge score increased after intervention by 38% (5.7 to 7.9,  $P<0.001$ ) (**Table 7**). For knowledge, large effect sizes were seen for the whole cohort ( $r=0.57$ ) and those with age  $\geq 60$  years ( $r=0.54$ ), lower educational attainment ( $r=0.57$ ), lower health literacy ( $r=0.48$ ), dialysis duration  $\geq 1$  year ( $r=0.61$ ), less technology access ( $r=0.60$ ), and absence of transplant center formal education ( $r=0.60$ ).

**Table 6.** Knowledge survey, completed by participants before and after animation viewing.

	Pre video % correct*	Post video % correct*	p-Value**
You have to schedule all your own tests to get on the list for a kidney transplant.	53.6 (15/28)	85.7 (24/28)	<b>0.004</b>
A social worker at the transplant center will talk to you about getting support from family and friends.	89.3 (25/28)	100.0 (28/28)	0.250
A financial coordinator at the transplant center will talk to you about your insurance and how to reduce your costs.	82.1 (23/28)	96.4 (27/28)	0.125
If you're on the list and your status is active, you'll never need to get another test.	71.4 (20/28)	78.6 (22/28)	0.727
Your evaluation at the transplant center will take about 90 minutes.	28.6 (8/28)	75.0 (21/28)	<b>0.001</b>
Everyone on dialysis is also on the waiting list for a kidney transplant.	71.4 (20/28)	78.6 (22/28)	0.625
If you're on the list and your status is active, you could get a kidney offer any time.	89.3 (25/28)	100.0 (28/28)	0.250
During your evaluation at the transplant center, you are going to be very busy so you shouldn't bring anyone with you.	67.9 (19/28)	89.3 (25/28)	<b>0.031</b>
If you get a letter from us that says you are inactive, that means you have been removed from the list.	14.3 (4/28)	82.1 (23/28)	<b>&lt;0.001</b>

\* Participants who answered "Correctly" to the listed questions; \*\* McNemar's test p-value.

**Table 7.** Comparison of participant knowledge scores before and after video viewing.

Knowledge (range 1-7)	Pre-test Mean±SD	Post-test Mean±SD	% change	Z score	Effect size (r)*	P value**
Total cohort (n=28)	5.68±1.91	7.86±1.69	38%	4.2	0.57	<0.001
Education, less than college (n=10)	6.10 ±2.13	8.30 ±1.34	36%	2.6	0.57	0.120
Education, college level (n=18)	5.44±1.79	7.61±1.85	40%	3.4	0.57	0.012
High literacy/numeracy (n=19)	6.00±1.53	8.26±1.33	38%	3.8	0.61	0.012
Low literacy (n=9)	5.00±2.50	7.00±2.12	40%	2.0	0.48	0.504
Age ≥60 years (n=11)	5.91±1.87	7.82±1.72	32%	2.5	0.54	0.132
Age <60 years (n=17)	5.53±1.97	7.88±1.73	43%	3.5	0.59	0.012
Dialysis ≥1 year (n=13)	5.92±1.89	8.38±1.19	42%	3.1	0.61	0.024
Dialysis <1 year (n=15)	5.47±1.96	7.40±1.96	35%	3.0	0.54	0.036
<Median technology access (n=12)	6.17±1.59	8.33±1.37	35%	3.0	0.60	0.036
≥Median technology access (n=16)	5.31±2.09	7.50±1.86	41%	3.1	0.55	0.024
Attended transplant education (n=8)	6.00±2.07	7.63±2.33	27%	2.0	0.51	0.492
Did not attend transplant education (n=20)	5.55±1.88	7.95±1.43	43%	3.8	0.60	0.012

SD – standard deviation. \* Wilcoxon Signed-Rank test Bonferroni correction for multiple comparisons; \*\* Effect size,  $r=Z/N$ ;  $r$ =Point biserial correlation. Interpretation: 0.10=small effect, 0.24=medium effect, 0.37=large effect.



**Table 8.** Comparison of participant evaluation-listing understanding and concerns before and after viewing the videos.

Characteristic*	Pre-test score	Post-test score	P value**
Understanding the evaluation process	25.0 (7/28)	60.7 (17/28)	<b>0.002</b>
Understanding confirmation of waiting list placement	32.1 (9/28)	85.7 (24/28)	<b>&lt;0.001</b>
Understanding how to contact the transplant center	60.7 (17/28)	96.4 (27/28)	<b>0.002</b>
Concerns about the evaluation process	7.1 (2/28)	0.0 (0/28)	0.500
Concerns about determining waiting list placement	32.1 (9/28)	7.1 (2/28)	<b>0.039</b>

\* Participants who answered 'agree' or 'strongly agree' to the willingness question; \*\* McNemar's test p value.

### Understanding and concerns

Participants reported increased understanding after video exposure about the evaluation process (25% before video to 61% after video;  $P=0.002$ ), confirming waiting list placement (32% to 86%;  $P<0.001$ ), and method of contacting the transplant center (61% to 96%;  $P=0.002$ ). The proportion of patients who reported being concerned about the evaluation process was 7% before and 0% after ( $P=0.5$ ) watching the videos. Concerns about determining waiting list placement decreased from 32% before the video to 7% after the video ( $P=0.039$ ) (Table 8).

### Acceptability

The majority of participants agreed that they felt comfortable learning from the animations (96%); the animations were easy to understand (96%) and watch (89%); the animations were interesting/engaging (93%); they could trust the information in the animations (96%); and they would personally use the animations in the future (89%) and recommend them to a friend (93%).

### Discussion

The results of our study describe the development and testing of 2 educational videos about the evaluation and waiting list process for kidney transplantation. Patient perceptions of messages received from the videos included facilitative themes of provider resources and support, caregiver inclusion, bidirectional communication, and following through with testing. Preliminary results support the high acceptability of the videos by participants and the feasibility of the videos to improve knowledge about the kidney transplant evaluation and waiting list process. Although our results are promising, further research is needed to confirm our findings using a control group and to determine if viewing the animations can improve outcomes, such as completion of the transplant evaluation and maintenance of active status on the list.

Our findings suggest that the animations improved participants' knowledge overall, including among older persons and

those with lower health literacy, indicating the potential for the broad applicability of the materials. These promising findings may be attributable to our using 2 formats for learning, imagery and audio, and other health communication best practices, such as using common language, active voice, and conversational style. To reduce the known disparities in patient access to transplantation [40], effective educational strategies must be accessible across age, culture, and health literacy level.

We found that concerns about the evaluation and listing processes were reduced after animation viewing. It is possible that concerns were reduced because the videos provided information in an emotionally reassuring way. Positive communication is important since the transplant waiting period has been identified as the most psychologically stressful time of the transplant experience [41,42]. Stress contributes to emotional barriers to learning and difficulties in navigating health-care systems [18].

The animations positively impacted the self-reported level of understanding about the evaluation and listing process, with a similar effect size in knowledge increases among participants, whether or not they had previously attended the transplant center's education class. These findings suggest that the video can be impactful for individuals who have not met with transplant providers, such as members of social networks and dialysis patients considering transplantation. Social network members help patients with decision-making and remembering information [43], and the patients' informational needs may therefore not be met by routine education delivery practices [32]. Delivery of transplant education to individuals already on dialysis is important because 80% of dialysis patients are not on transplant waiting lists [2,3], and some may not have received sufficient education. Most dialysis providers spend very little time providing transplant education to patients [44] and report many barriers to delivering transplant education, including having limited time and competing work priorities, and having poor transplant knowledge themselves [45]. These barriers may be overcome with easily available stand-alone educational materials.

It is important to note that we tested the videos using an on-line study format because the COVID-19 pandemic precluded the conduct of face-to-face research during the timeframe of the study. It was also an opportunity to use a simple trial design to measure how much transplant candidates are willing to watch videos that are emailed to them. Our findings suggest that implementation of the program via the Internet prior to transplant evaluation is possible by providing patients with the program's Internet link and an individualized password to access the software. The majority (80%) of the consented patients completed the intervention. The main logistical challenge that we faced was that some patients lacked email. In future studies, delivery of the program via text message should be available. In terms of clinical implementation, linkage to an electronic medical record system that could transmit patients' concerns and preferences to the transplant team prior to the consultation would provide valuable information to the patient about the upcoming evaluation, and would allow providers to tailor the information provided more closely to meet patients' needs.

### Limitations

Our study has the limitation of being a single-arm, nonrandomized study with a small sample size; therefore, efficacy was not evaluated. We did not assess knowledge retention since we expect participants in the future trial to have online access with repeated viewing options. Generalizability of our results are limited in this single-center study that employed the use of email and included patients who were English-speaking and largely a non-Hispanic and White sample; however, the study population was heterogeneous in terms of sex and education level.

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### Conclusions

Using established principles developed by health communication scientists, we created 2 educational animations about the kidney transplantation evaluation and listing process that are contextual, relevant, easily accessible, engaging, and self-directed. The results of our single-center pilot study in potential kidney transplant recipients, prior to their presenting for medical evaluation, support the acceptability of our educational animations and their feasibility to improve patients' knowledge and understanding of the process of kidney transplant evaluation and listing, even in patients with low health literacy. In busy transplant centers, in which providers have little time to deliver education and patients have varying degrees of health literacy, innovative approaches that require less supervision are needed to carry out transplant education.

### Institution where work was done

Work was performed at the Transplant and Kidney Care Regional Center of Excellence at Erie County Medical Center in Buffalo, NY, U.S.A.

### Statement

The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).

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