Austin Medical Sciences

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Research Article

Using Interviews of Lay Caregivers in the US to Identify Modifications to a Single Website for Kidney Transplant Access

Handmacher M[1], Solbu A[1,2], Keller M[1,2]*, Jackson N[1], Inoue M[3], Koizumi N[4] and Kayler LK[1,2]

[1]Jacobs School of Medicine and Biomedical Sciences, The University at Buffalo, SUNY, Buffalo, NY 14203, USA

[2]Transplant and Kidney Care Regional Center of Excellence, Erie County Medical Center, Buffalo, NY 14226, USA

[3]Department of Social Work, George Mason University, Fairfax, VA 22030, USA

[4]Schar School of Policy and Government, George Mason University, Fairfax, VA 22030, USA

***Corresponding author:** Keller M, Jacobs School of Medicine and Biomedical Sciences, The University at Buffalo, 462 Grider St., Buffalo, NY, 14215, USA

Tel: 1-716-898-3394;

Email: mkeller1@ecmc.edu

Received: September 18, 2025

Accepted: October 14, 2025

Published: October 17, 2025

Abstract

Background: Although educational and behavioral interventions are effective to facilitate kidney transplant access, most are offered at physical sites on a scheduled basis, limiting reach by patients and supporters. Websites are increasingly used to promote patients' kidney transplant (KT) navigation and living kidney donor search but no website exists for caregivers to support KT-seekers. Our study aimed to assess caregivers' perceptions of the website in the KidneyTIME intervention to aid in future intervention refinements to meet caregivers' needs.

Methods: Individual interviews and post-interview surveys were conducted with 20 lay caregivers of KT-seekers after they viewed at least 6 videos on the website. Questions gathered caregivers' perspectives pertaining to the websites' usability, topics, shareability, positive and negative aspects, and possible future features for supporting caregivers.

Results: Qualitative analysis resulted in 5 themes: (1) caregivers supported using the site to find information; (2) caregivers became more comfortable with living kidney donation; (3) caregivers were interested in sharing the content; (4) caregivers had varying preferences for other features that could support them; (5) forgetting may limit use of the website. Website acceptability ratings on 10 items were positive regarding appeal, usability, and helpfulness.

Conclusion: The KidneyTIME website was well regarded by caregivers who recommended additional features. Future research should modify the website to address issues valued by caregivers and assess how this website within the context of the full digital intervention could supplement usual care to increase KT access.

Keywords: Education; Kidney Transplantation; Kidney donation; Health services and outcomes research; Digital intervention; Caregivers; Website; Access to care; Mobile phone

Abbreviations

KT: Kidney Transplant; KT-Seekers: Kidney Transplant Seekers; CAB: Community Advisory Board.

Introduction

Over 800,000 individuals in the United States have kidney failure [1] and is expected to increase to one million in 2030 [2]. Kidney transplantation is the best treatment for kidney failure, yet least accessed [3]. Challenges of patients to navigate the transplant process and communicate their need for caregiving and kidney donation demand innovation by transplant programs [4,5]. Findings from randomized controlled trials and quasi experiments positively link educational and behavioral interventions using educational classes, donor outreach skills building, social support, and navigators in facilitating kidney transplant access [6-15]. These interventions have been traditionally delivered at physical sites and may lack the flexibility necessary for those who have jobs or live at a distance, limiting the extent of individuals that can be reached. Furthermore, clinicians, such as doctors and nurses, may have limited time during or after clinic visits to support kidney transplant pursuit.

As advanced kidney disease becomes increasingly prevalent, the use of digital technology for accessible self-learning has enabled more patients to understand how to navigate the transplant process and conduct donor outreach [16]. An essential component of transplant navigation is the engagement of lay caregivers to support patients [17]. However, caregivers may not be optimally empowered in pre-transplant care [17,18], hindering patients' access to kidney transplantation. Increasing transplant access can be addressed by interventions that use digital technology to scale transplant access information delivery, such as websites. Websites for enhancing transplant access may provide information and strategies that promote self-learning and outreach to the social network for awareness raising, education, and stimulating conversation about the topic, yet few digital evidence-based sites exist [19,20].

Citation: Handmacher M, Solbu A, Keller M, Jackson N, Inoue M, et al. Using Interviews of Lay Caregivers in the US to Identify Modifications to a Single Website for Kidney Transplant Access. Austin Med Sci. 2025; 10(1): 1080.

The website in the *KidneyTIME* intervention leveraged shareable animated videos as an educational and outreach strategy to provide education to patients and their social network members, thereby scaling knowledge distribution and addressing barriers of explaining kidney transplantation and donation to others who may be interested in donating a kidney or supporting a patient or donor. Animated video is particularly effective for delivering information about kidney transplantation given patients' limited health literacy about the topic, the challenge of explaining transplantation and donation, and the need to reach a broad social network to find a potential living kidney donor [16,21]. The video content on the *KidneyTIME* website was previously examined in several feasibility studies, demonstrating high acceptability and significant knowledge improvement among patients [21]. The intervention is currently being trialed to assess additional outcomes related to its effect on living kidney donor transplant cognitions and behaviors. However, accumulating evidence in longitudinal follow-up suggests low dissemination of the site content by some study participants [16,22,23]. The intervention could also be used by lay caregivers for the purposes of supporting patient use of the intervention as well as transplant navigation and donor outreach. That said, adaptation of the intervention to the caregiver population may be challenging, and there is a need to ensure that caregivers find the content relevant and useful, as well as possibly supporting them in other ways. To date, no studies have explored caregivers' perspectives of websites for kidney transplant access.

Like other digital intervention researchers, we follow a model of numerous iterative cycles based on user feedback to continue refining the product to increase potency and usability, following the IDEAS framework [24] of strategies for the development of more effective digital interventions to change health behavior. As such, our research team investigated caregivers' perceptions and desired modifications to the existing intervention website that is currently being tested in a randomized controlled trial among transplant candidates to ultimately enhance its relevance among caregivers with an interest in supporting kidney transplant navigation.

Materials and Methods

Study Design

This mixed methods study involved individual interviews and post-interview surveys of caregivers of kidney transplant seekers (KT-seekers) about the *KidneyTIME* website. Our study was conducted as part of a larger study that evaluates the adaptation of a technology-based user-centric intervention for promoting participation in kidney transplantation and live donation at a kidney transplant center in an Eastern United States city. The study was approved by an Eastern state university (IRB# 00002771). We used the Consolidated Criteria for Reporting Qualitative Research checklist to report this study [25] (see Supplement).

The *KidneyTIME* Intervention Website

The *KidneyTIME* website is a feature of the *KidneyTIME* digital intervention that includes 3 key components: (1) proscribed core animated video education, (2) optional website for viewing and sharing videos from the entire video curriculum, and (3) time-based electronic (email or text) messages describing specific videos and providing links to access the intervention, described in detail elsewhere [16,21,26]. The website hosts 25 short (2-3 minutes) educational animated videos (total duration 55 minutes) organized into 4 modules in which participants are taught about the kidney transplantation and donation process, risks, benefits, and expected outcomes. The educational content implicitly includes family members and supporters by showing their roles in all aspects of the transplant and donation process. The intervention is based on the reality that patients' access to kidney transplantation is diminished by misconceptions and fears about the kidney transplant and donation process and outcomes, as well as discomfort in communicating their need to potential donors. The video curriculum addresses essential knowledge, reduces fears rooted in misinformation, and improves their ability to conduct donor outreach by sharing the intervention videos through ubiquitous technologies (email, text, Facebook, X) and by having knowledgeable conversations.

KidneyTIME Intervention Adaptation

The *KidneyTIME* intervention is being adapted to optimally engage lay caregivers using a 4-phase iterative-design strategy. Phase one used individual interviews with lay caregivers of KT-recipients to assess caregivers' informational and support needs of the pre-transplant process [18]. Phase two used a community advisory board (CAB) to develop a foundational educational animated video for caregivers of KT-seekers with successive iterative refinement from interview feedback [27]. The third phase (current study) used interviews with lay caregivers and post-interview surveys to focus on the acceptability of the *KidneyTIME* website to gain insight into future improvements. In phase 4, we plan to adapt the *KidneyTIME* website as part of a multicomponent and multilevel intervention to engage KT-seekers, their caregivers and other social network members towards kidney transplant access with an emphasis on finding a living kidney donor.

Data Collection

Eligible individuals included English-speaking adults (age 18+ years) who self-identified as a caregiver for someone pursuing KT. Recruitment flyers were posted in the clinic rooms and research personnel approached caregivers in clinic rooms between June 2023 and August 2024. Exclusion criteria included lack of internet access and caregivers of patients currently participating in any educational intervention study. All participants provided consent.

After returning home, caregivers received an email invitation with a link to the study survey that included electronic consent, baseline sociodemographic and support role readiness questions, and the caregiver-specific video embedded in the survey. Those who viewed the video were given instructions to view the intervention website. The first five participants completed paper-based consent, survey

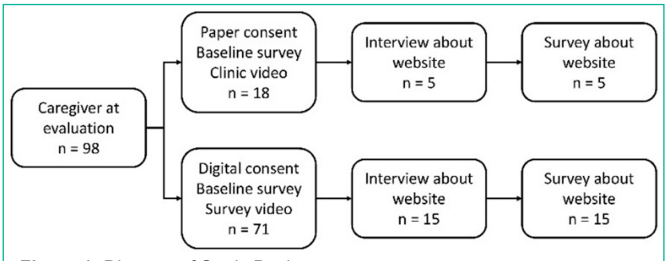

Figure 1: Diagram of Study Design.

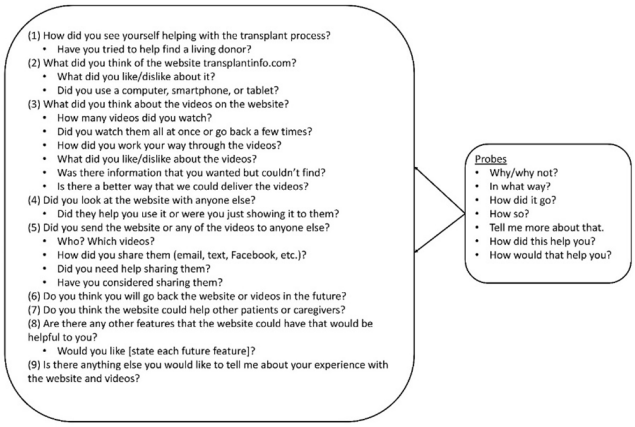

Figure 2: Participant Interview Guide.

questions, and a caregiver video viewing in the clinic on their own device; this approach was switched to the online method due to difficulty ensuring video viewing in the busy clinic. Illustration of the flow of participants, including sample sizes, is found in Figure 2. After participants indicated they viewed at least 6 videos on the website, we then invited participants to telephone interviews of initial impressions about their experience. Recruitment ended when thematic saturation was achieved. Individual interviews were conducted over the phone by a female researcher [CH] trained in qualitative research who had no prior relationship with the participants. The interviewer used a semi-structured guide (Figure 2) to gather caregivers' perspectives pertaining to the *KidneyTIME* website's usability, topics, shareability, positive and negative aspects of the website, and possible future content or features for supporting caregivers to succeed in their preferred roles. Questions also asked participants for feedback on ways to improve the intervention, including additional features (real video, one long video, a mobile app, supplemental written information, reminders to use), other ways to support donor searches (conversational tips, sample writing and advertisements, coaching, role-play), donor decision-making (talking to a kidney donor) and caregiving (opportunity to share personal problems, talk to a caregiver or recipient, support group). The interviewer also asked participants: (1) whether they would continue to use the intervention, (2) why or why not. Each telephone interview lasted an average of 13 minutes [range: 9-29 minutes] and was audio-recorded. Participants were compensated with a $25 debit card for their time.

At the end of the interview, participants completed questions electronically to assess usage and acceptability of the site as well as potential future features. Website usage was assessed by applying questions from our current research (device used, number of website visits, time spent, video sharing). Website acceptability was assessed by a custom survey informed by the Theoretical Framework of Acceptability [28] including the experience of the website (topics

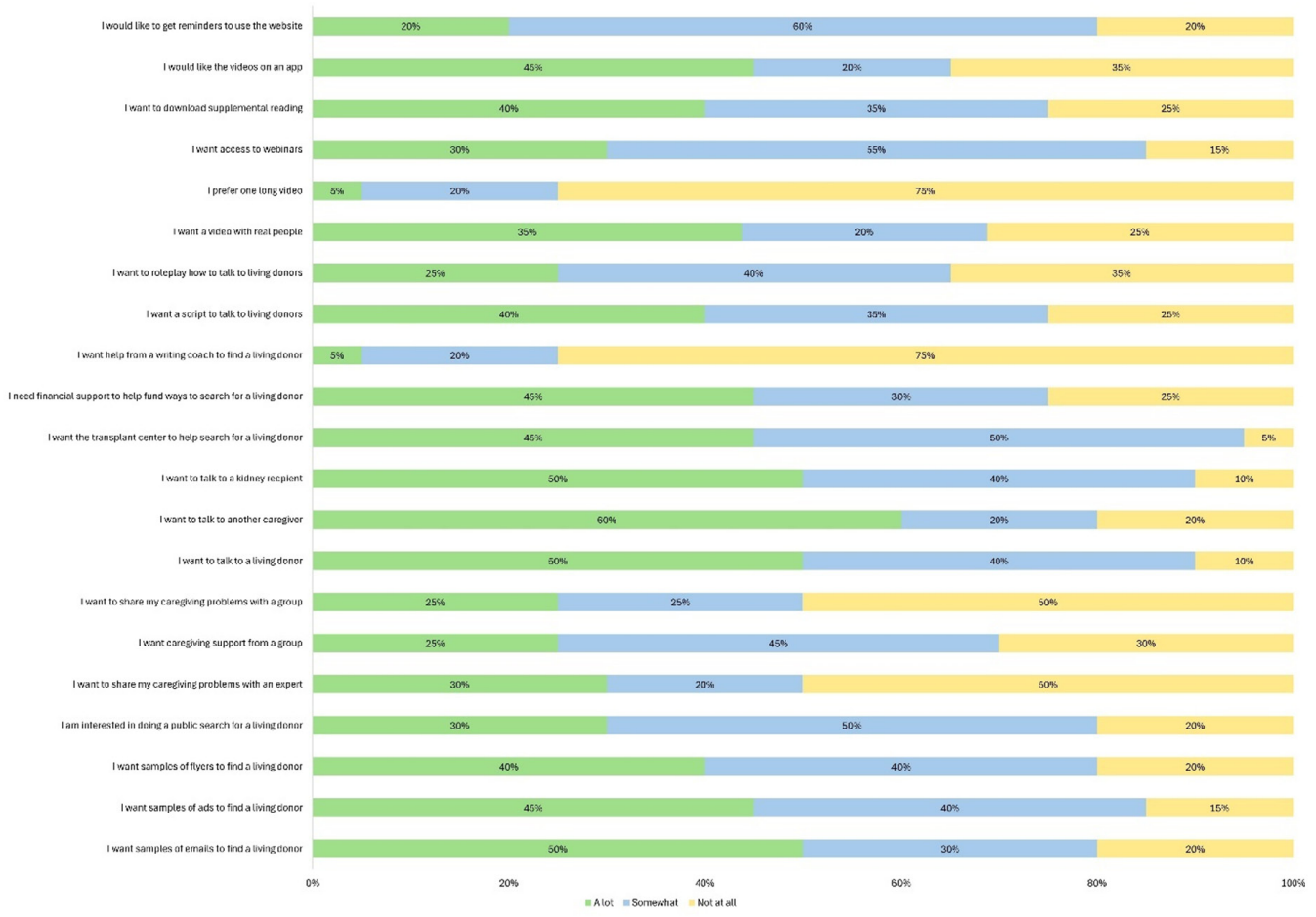

Figure 3: Acceptability of future features: post-interview survey responses of participants (n=20).

and extent to which participants found the website appealing, usable, and helpful) using 4-point Likert-type scales, (1=strongly disagree to 4=strongly agree) and anticipated acceptability of future features of the website using 3-point Likert-type scales (a lot, somewhat, not at all). Future features included the same questions asked during the interview (30 total). We also asked one open question for qualitative analysis (What other ways could we support you as a caregiver?). Participants received another $25 for completing the survey. The surveys were formatted in a large font to increase readability for older participants.

Data Analysis

Survey and sociodemographic data were reported using frequencies and percentages or medians and interquartile range. Individual interview audio recordings were transcribed verbatim. Transcripts and answers to the open-ended question were analyzed for emergent themes using inductive and deductive coding and constant comparison methods. A list of defined codes corresponding to interview questions was developed [LK, MK]. All responses were coded using Dedoose qualitative software (version 9.2.12). Three researchers [MK, SP, MH] used a rapid iterative process to independently review and openly code the first set of transcripts and open-ended question responses. Thereafter, the research team revised the coding scheme by adjusting for new responses with modified codes applied to prior transcripts, until reaching thematic saturation (when no new themes emerged). The themes were then reviewed by a researcher with qualitative expertise [MI] and a transplant surgeon [LK] for confirmation, where all sources of the data were systematically reviewed by the two authors until agreement for the final themes. We reviewed all segments pertaining to each code to develop analytic summaries that synthesized emergent patterns and to integrate the qualitative data with the quantitative data about future features.

Results

Twenty individual interviews were conducted with caregivers of KT-seekers. Most participants were white race (70%), female (90%), spouses or partners (55%), and knew the patient for ten or more years (95%) (Table 1). Participants were equally split between earlier and later stages of readiness to help someone navigate transplantation and conduct donor outreach. Most (60%) were not considering becoming living kidney donors themselves (Table 1). Forty percent of participants indicated they had used a phone to access the website and 60% used larger screens.

Thematic Findings

Five themes were identified about caregivers' perceptions of the *KidneyTIME* website: (1) caregivers supported using the site to find information; (2) caregivers became more comfortable with living kidney donation; (3) caregivers were interested in sharing the content; (4) caregivers had varying preferences for other features that could support them; and (5) forgetting may limit use of the website.

Theme 1. Caregivers Supported Using the Site to Find Information: Caregivers found that the *KidneyTIME* website was informative, simple to use, and convenient. The educational videos were reported to be easy to understand and the animated format

Table 1: Caregiver interview participant sociodemographic characteristics and role readiness (n=20).

Characteristic	% (n)
Age, 18-49 years	30% (6)
Age, 50-60 years	30% (6)
Age, 60+ years	40% (8)
Sex, Female	90% (18)
Black or African American	25% (5)
Non-Hispanic White	70% (14)
Hispanic or Latino	5% (1)
Employed full- or part-time	50% (10)
Annual income less than $30,000	10% (3)
$30,000 to $50,000	25% (5)
More than $50,000	45% (9)
Prefer not to answer	15% (3)
Education, College degree	45% (9)
Relationship to patient:	
Spouse or partner	55% (11)
Child	5% (1)
Sibling	15% (3)
Parent	15% (3)
Other Relative	5% (1)
Friend	5% (1)
Has known patient 10+ years	95% (19)
Has working internet-capable cell phone	90% (18)
Has working computer	90% (18)
Sends or receives text messages	85% (17)
Uses email	100% (20)
Watches videos online	85% (17)
Has active Facebook account	70% (14)
Follows YouTube channels	80% (16)
Device used for video viewing:	
Computer	15% (3)
Cellphone	55% (11)
Tablet	40% (8)
None	10% (2)
Uses social media:	
Never	16% (3)
Less than once a week	5% (1)
Once a week	16% (3)
More than once a week	63% (12)
Has 1-3 close friends and relatives	35% (7)
Has 4+ close friends and relatives	65% (13)
Thoughts about helping someone navigate the transplant process	
Helped someone before	10% (2)
Understand	40% (8)
Beginning to understand	45% (9)
Not sure	5% (1)
Thoughts about helping someone find an living kidney donor	
Helped someone before	0% (0)
Understand	40% (8)
Beginning to understand	35% (7)
Not sure	20% (4)
Patient does not want an living kidney donor	5% (1)
Thoughts about donating a kidney	
Been approved	0% (0)
Being evaluated	20% (4)
Seriously considering	15% (3)
Beginning to think	5% (1)
Not thinking about it	60% (12)
I have all the information I need to start a conversation about living kidney donation	
Strongly Agree	15% (3)
Agree	45% (9)
Neutral	5% (1)
Disagree	25% (5)
Strongly Disagree	10% (2)
I am comfortable discussing living kidney donation with other people	
Strongly Agree	40% (8)
Agree	40% (8)
Neutral	0% (0)
Disagree	15% (3)
Strongly Disagree	5% (1)

Table 2: Themes and representative quotes.

Theme 1. Caregivers supported using the site to find information	
Convenient	"I was able to do it on my own time." "[There was] downtime at work, so I kind of just watched it." "Sitting in a car waiting for someone to come . . . I could do a quick pick one and watch it quickly."
Simple to use	"You can just click and go right where you need to go." "Very simple, very basic, very easy to read." "Straightforward once you clicked and you watched it."
Easy to understand	"I liked the simplicity . . . I never felt overwhelmed." "It's presented in a very plain language, common way, I think almost anybody can understand." "They got right to the point, and yet there was, It felt a good explanation."
Engaging	"It was kinda more flashy, so it kept your attention." "Fun and interactive." "The cartoon aspect because it kind of wasn't just so like blah, blah."
Efficient	"The fact that it's three minutes or under . . . you're getting all that information on that topic right then and there." "It was easier to watch a shorter clip of a video than to have a long, drawn-out, two-hour orientation." "If I had to sit and watch a long video, I probably wouldn't have been too much interested in it."
Theme 2. Caregivers became more comfortable about living kidney donation	
Overcoming misperceptions	"It's mind boggling, but the bottom line is you don't have to be a perfect match in order to donate." "I found that it didn't have to be a relative to be a donor." "I just think that a lot of people have like a thought that of what donation is like but I think that you do these videos, you start to see that it's not like as scary as you thought it was."
Feel more comfortable about LD	"The video states right in there that the recipient's insurance pays for it because I think that would help ease them into actually donating." "It's nice to learn I'm not going to have so much downtime [after I donate]." "I think it's a resource especially the donors . . . I don't think the donors really know a lot of it. And I think that's what makes a lot of people not wanna donate because they're scared."
Theme 3. Caregivers were interested in sharing the content	
Reasons for sharing	"I know my aunt and father will wanna help in some day, so we'll certainly be sharing [the link] with family members who will be more involved." "I will probably send the website link because some of the ladies at church are interested in [donating], so I think it would be educational for them to see what they're getting themselves into." "I did do one on Facebook to my own page . . . it was just like, if anybody's interested, here's some information and I think it was the living donor video."
Reluctance to share about LD	"I don't know. It just seems, it seems kind of like such a personal thing to ask for." "We're discussing [finding a living donor] now because at one point he didn't want anyone to know that he needed it." "You always find yourself in different social situations and you're not sometimes not sure how to present [living donation]."
Theme 4. Caregivers had varying preferences for other features that could support them	
Comprehensive	"I liked that they had a lot of different topics that were on there . . . it's always nice to look at the videos because you don't know what tidbit you might get out of 'em that you wouldn't get from just looking at websites." "I like the way when you come on the website, it showed the different areas of the videos, so if you're the person who needs a kidney, if you wanna donate, how you can help be a caregiver." "I thought you, it pretty much reached everything that you needed to know."
Request for other topics	"I just wanted to know what to expect when he comes home. Like, what am I gonna be changing bandages? Is there gonna be a nurse coming?" "Maybe just understanding different coverages that employers have, so if people have questions and how they can reach out to their HR." "The medication part is what threw me because they're saying like, she's gonna be on all these pills and then it says that the caregiver just has to make sure of that."
Other ways to support caregivers	"Links to social work or like care coordination . . . transportation, that sort of thing." "We talked about with the doctors what it would mean to be a caregiver, but real-life experiences would certainly help." "Everybody's dealing with some sort of like mental health issue, depression. This type of situation just is gonna exacerbate that, so I think that people need to at least know that there are options to speak with somebody if they need to." "If you said to me . . . you're assigned to go find someone and tell them you want them to be a donor, I would have no idea. And I would not feel comfortable as I said earlier about initiating that conversation, so if I did have something to go by, that would be very helpful."
Theme 5. Forgetting may limit use of the website	
	"I did get busy and forgot about 'em." "That's like, that's the next step in the process or something, like something that reminds you to go back and look at it, that would be helpful." "Probably just a reminder cuz I did get busy and forgot about 'em until you called."

was engaging such that the videos "kept your attention," "softened emotions," and provided information efficiently by being "short," "right to the point," and "not too wordy." Caregivers noted that finding information on the site was "simple" and "self-explanatory" by clicking and going "right where you need to go." Caregivers found value in convenient access to the website and liked being able to view the content anytime anywhere such as "on my own time" and "whenever you feel like." They anticipated that they would return to the site as the patient progresses through the transplant process.

Theme 2. Caregivers became more Comfortable about Living Kidney Donation: After viewing the website, participants noted overcoming misperceptions and feeling more comfortable about living kidney donation. Topics mentioned by caregivers that they realized they didn't fully understand until watching the study videos covered donor eligibility, kidney exchange, how matching worked, donation expenses, and recovery after donation.

Theme 3. Caregivers were Interested in Sharing the Content:

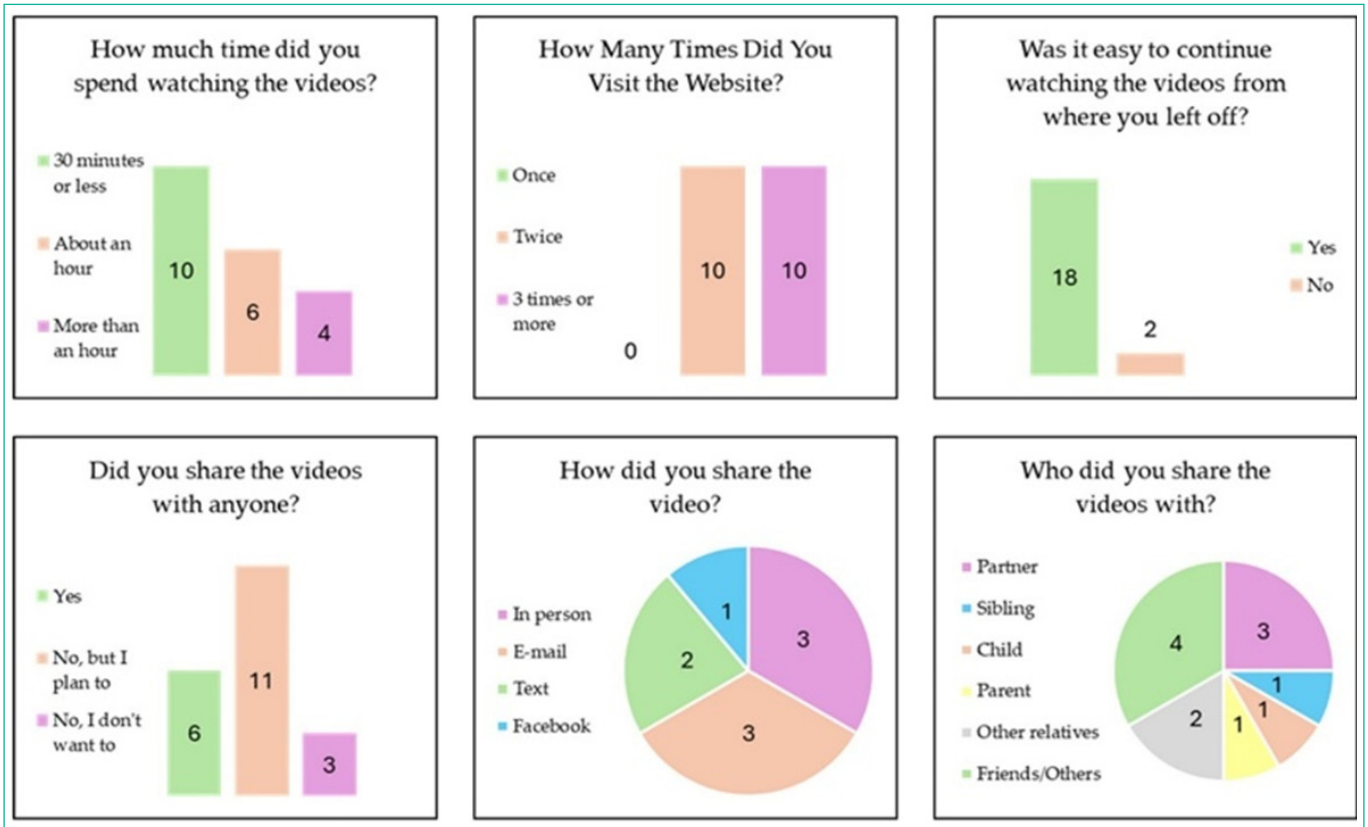

Figure 4: Caregivers' usage of the KidneyTIME website (n=20).

By the time of the interview, some caregivers had already shared the website content and some said they would share it in the future. They described various preferred ways for sharing the site including calling, emailing, texting, and putting the information on a "church bulletin," "passing the phone at the dinner table," and posting on Facebook. Reasons for sharing included to inform "backup caretakers" how to help and be involved, to elicit possible donors, to provide information to potential donors who might "change their mind" about donating after viewing the videos, and to inform people who are considering donating so they "understand what's involved." Some indicated they would only share in certain circumstances, such as if the patient remains eligible for a kidney transplant and if others asked for information. Caregivers viewed the patients' reluctance to consider living kidney donation as a barrier to sharing the videos, although some caregivers thought the patient may be interested later.

Theme 4. Caregivers had Varying Preferences for Other Topics and Features that could Support Them: Most caregivers found the content to be comprehensive as it allowed them to "know all the options for helping" and "answered my questions." They recognized roles of supporters in the videos: "I liked how people got together and helped each other out." Some caregivers requested other topics or clarification (family medical leave). Caregivers additionally recommended a variety of ways to support them. They desired more feedback and advice from the transplant program, contact information to center staff, such as social workers and care coordinators, and awareness of resources for both patients and caregivers (mental health experts). Although many mentioned the benefit of sharing the animated videos to reduce personal barriers when asking others for a kidney, participants desired other types of outreach materials and interactions with other caregivers as well as donors and recipients.

Theme 5. Forgetting may Limit Use of the Website : Caregivers mentioned the propensity to forget about the site, stating they are busy and not always in front of their phone or other devices. They recommended sending reminders about the site.

Ratings of Future Features of the *KidneyTIME* Website

Quantitative Findings with Qualitative Integration: When asked for their opinions of specific features that they might be interested in to support them, caregivers had a range of opinions. Their opinions were also quantified by caregivers in post interview surveys. Participant ratings of future features of *KidneyTIME* indicated that additional adaptations were warranted (Figure 3). At least one half of caregivers agreed "a lot" that they would like the opportunity to talk to other caregivers, donors and patients, and would like samples of emails to find a donor.

Several other features were considered highly desirable by at least 40% of participants, including mobile app delivery, supplemental downloadable reading, donor search samples for conversations, writing, and real or electronic media (flyers, yard signs, websites etc.), help from transplant center in donor search, and financial support to fund ways to find a donor. The lowest graded potential features were one long video, real video, role-playing how to talk to possible donors, writing coaching, access to webinars, and sharing personal problems with an expert or group. Several quotes from the interviews related to future features reinforce these findings (Table 3).

Table 3: Representative quotes relating to future features.

Feature	Representative quote
Videos on an app	"If you had the app you like, it'll show you where you stopped . . . So you don't have to re-go through 'em all again." "If I am in a setting like dinner with a group of family members, I can like pass my phone around and say, oh, here's the app. You can download it, you can watch the video." "If they're put on an app meant for the mobile phone, they'd probably be easier to get in and out of."
Download supplemental reading	"If there was something I really wasn't sure about and wanted to read over again or, you know, look it over and write, jot down notes with it and so that would be a good option."
Prefer one long video	"I would much rather just see one video that's like two hours long versus one that's like multiple because when I started. When I was going through I was like, man, I don't know if I'm gonna have time to keep clicking on all these different ones. It would be easy just to kind of pause it and then come back." "If I had to sit here and watch a long video, I probably wouldn't have been too much interested in it." "I liked the little, short ones because if for some reason you have to walk away or stop, it's not that long of a time span."
Video with real people	"I think real people are more relatable." "I thought that the animation was not as distracting as real people." "Easier to describe things and show things like that than to use real people in the videos."
A script to talk to living donors	"it's very important to have something that you can lean back because you always find yourself in different social situations, and you're sometimes not sure how to present it." "You're assigned to go find someone and tell them, tell them you, you want them to be a donor, I would have no idea. And I would not feel comfortable as I said earlier about initiating that conversation. So, if I did have something to go by, that would be very helpful."
Financial support	"I would like to learn like ways that people fundraise for that. My husband and I, we can cover most of his costs while we're here, but I don't even know what that looks like to do like a billboard for a kidney."
Talk to someone whose been through it	"I would like to know how other people deal with certain things and maybe get an insight how to handle something or to be aware of something that might come up, or just their feelings on how they feel felt going through the process." "Yes, very interested in 'cause I don't know anybody who's donated a kidney."
Samples for a public donor search	"I think just to give 'em an idea of like where to start or what things they can do is a very good idea." "I would wanna know all the options and all the things that I could do to try to help."
Samples of emails to find a living donor	"It would be nice to see kind of like an outline of what kind of is important to touch on in the email." "[The email sample can] have all the information on there, and not necessarily do you need to have the same specific conversation with everyone that you know."
Samples of social media	"If there was a social media sample or prompt or something like that we can post, I think that would be easier than having, you know, necessarily having the conversation with individuals about it."

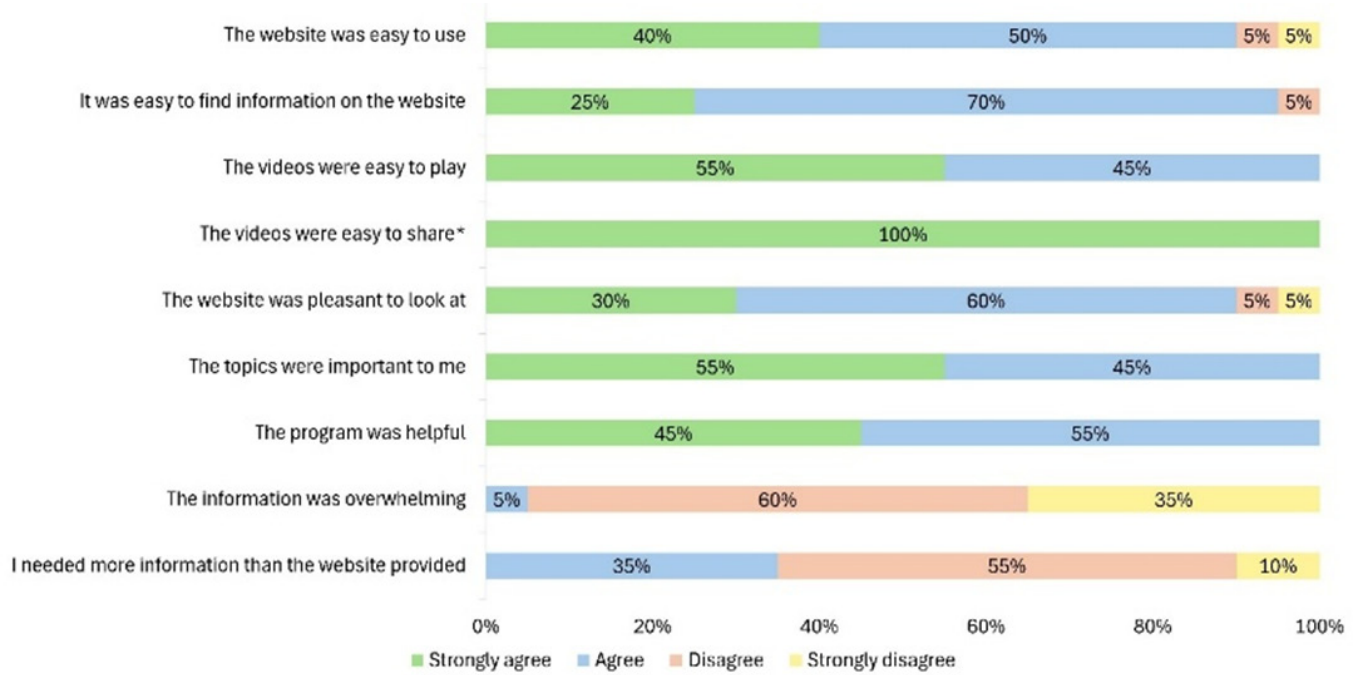

Figure 5: Caregivers' experience with the KidneyTIME website (n=20).
*Percentage based on n=6 who responded affirmatively to sharing a video.

Intervention Website Use

In post-interview survey conducted a median of 2.9 days (range: 0 to 13 days) after the interview, all caregivers indicated that they had visited the website more than once, and 50% spent at least an hour on the site (Figure 4). A large fraction (85%) of respondents shared the intervention or indicated interest in engaging other family and support network members in using the website (30% had already shared and 55% planned to share). Video sharing was conducted with multiple methods, including in-person, email, text, and Facebook and with a range of social network members.

Intervention Website Satisfaction

In post-interview survey, satisfaction ratings were high (Figure 4). Over 90% agreed or strongly agreed that the website was appealing, easy to use without assistance (including playing videos, sharing videos, returning to were left off, easy to find information), helpful and not overwhelming; however, 35% would have liked more information than the website offered.

Discussion

Using individual interviews supplemented by surveys, we elicited inputs from caregivers of kidney transplant seekers to assess the acceptability of an existing website within the *KidneyTIME* intervention for self-learning about kidney transplantation and donation, as well as for donor outreach. Results will inform refinement of the *KidneyTIME* intervention (that includes the website and other components) and provide value to other transplant center programs in engaging caregivers to increase KT access. We found that caregivers were highly receptive to *KidneyTIME* for informing themselves and others about transplant-navigation, donation decision-making, and donor-search issues. The results of this report identified five themes that explain caregivers' acceptability and utility considerations of the website. Overall, caregivers reported being satisfied with the website and being comfortable finding information and disseminating information from the site. Acceptability ratings were overall positive implying that caregivers found the *KidneyTIME* website appealing, easy to use, and helpful. Comments indicated improvements for usability, including reminders and a mobile app. Key future features to increase donor outreach and decision-making were donor search samples for conversations, writing, and real or electronic media (flyers, yard signs, websites etc.) and the opportunity to ask questions from donors. Key future features for transplant navigation were more communication with transplant staff and the opportunity to ask questions from caregivers and recipients. We plan to incorporate feedback of caregivers, alongside other users, to modify the *KidneyTIME* website and other components of the intervention's digital system and delivery in the future and will be reported separately.

Discussion of Themes

Themes highlight several tactics that may enhance transplant center websites and digital interventions for engaging caregivers in kidney transplant access activities. Theme 1 highlights that caregivers valued information provided as videos, preferably short in duration. Short videos were considered to be an efficient way to learn, enabled choosing content of interest, and allows to control the pace of information delivery better than longer videos. On demand access was important to overcome time constraints and meet evolving information needs as the patient progresses through the transplant process. Theme 2 indicated that the videos made participants more knowledgeable and comfortable about living kidney donation. In Theme 3, caregivers were interested in sharing the website and anticipated a variety of ways to share. They reiterated that sharing would help build social support, donor awareness and for donation-decision making. In Theme 4, a key finding was that the content directed to potential recipients and donors is acceptable as long as it includes topics important to caregivers. Caregivers recognized that the videos were implicitly showing the role of caregivers in the transplant navigation process; however, they had specific information needs that were not covered and desired more personal support from transplant staff and access to other caregivers. We also found the intervention should include content addressing local resources to be relevant to patients, donors, and caregivers. Theme 5 related to remembering to use the website, indicated that it would be easy to forget about the website, and reminders were requested.

Comparisons to Other Studies

Compared to other studies, video content in combination with human educators has been found useful to strengthen learners' knowledge about transplantation and donation and how to approach or find donors [8,10,21,29,30]. Only a few studies provide effective education that can be accessed as standalone [19,21,31,32]. Some interventions that include videos have also motivated behaviors to access transplantation if presented in combination with a human educator [8,10,13]. It's been suggested that the human element is relevant for gaining motivation and skill building to become more comfortable approaching others [30]. However, the importance of including human interaction as an intervention component to influence outreach behaviors is unknown since standalone interventions have not yet evaluated these behaviors. There is concern that many individuals who could benefit are not receiving kidney transplant and donation information [33], and transplant center websites require an advanced level of education [34]. Interactive platforms, such as a tablet web app for viewing videos and holding video chats, showed promise but faced implementation challenges due to technology concerns [30,35]. The availability of high-quality, easy-to-understand medical information is crucial to provide accurate information and influence attitudes toward transplantation and willingness to donate [9,36-38]. Recommendations from the 2014 AST Consensus Conference on Best Practices in Live Kidney Donation and other data suggest that effective patient education should include a patient's "family and friends" [39-41]. Therefore, alternative media such as animated video may be necessary for designing easy to use systems for delivering information and skill building to improve communication between the patient's team, inclusive of caregivers, and potential donors.

Limitations

Our study has several limitations. Findings from this convenience sample of 20 participants from a single urban geographic region in the United States are not intended to transfer to all caregivers, and the specific characteristics of this sample (female and white race) may have influenced the findings, including some factors we did not measure such as prior exposure to transplant information and the caregiver video. Many caregivers who consented to the study did not complete the study interview, possibly resulting in selection bias. Because we decided not to include KT-seekers in this study, findings do not represent views of people with kidney failure. However, participants were recruited from the settings where the intervention will be evaluated and are likely to represent the views of caregivers who frequent those settings. We acknowledge the subjective nature of qualitative analysis of transcripts, which we sought to minimize by using three independent coders. The high ratings on the survey could possibly represent participants giving socially desirable responses, but the written nature of the survey should have minimized this effect. Psychometric differences may have existed between the written and electronic versions of the surveys.

Future Considerations

Data suggests future improvements of the *KidneyTIME* website are warranted to increase overall exposure among the intended audience, such as reminders about the site, a variety of donor search promotion materials and strategies, and human connections (e.g., peers, transplant staff). Adapting the intervention for suitability by caregivers will involve ensuring that health communication specifically speaks to caregivers within a single intervention approach for a population group that is based on the shared interest of KT navigation by the subgroup as well as other members of the larger group including patients, peripheral social network members, community advocates, and medical professionals with an interest in supporting kidney transplant navigation.

In terms of clinical practice, there are missed opportunities to incorporate the support of caregivers to facilitate kidney transplant access [17,18,42]. Interventions that train a natural support person to increase donor search (often named donor champions) have shown evidence to impact live donor referrals and transplants [6,8,9,11-13,15,43,44]. However, these programs are only offered in-person at physical sites over 1 to 6 sessions and have low uptake by families. Between 20% to 56% of candidates were unable to bring a friend or family member to participate [8,11-13,15,45]. Lacking a donor advocate to attend educational sessions approached 68% among African American candidates in one study and was significantly associated with living in neighborhoods with greater community vulnerability and being unmarried [45]. Non-participants universally cited distance to educational sessions as a barrier [12]. Providing accessible and user-centered strategies for training about kidney transplant access to patients and natural supports is critically important to improve kidney transplant access for a wide range of individuals.

Conclusion

In conclusion, we used mixed methods research, in the form of interviews and surveys, to gather perspectives of caregiver members of the community of interest about an existing intervention website designed to improve access to kidney transplantation within the context of a larger intervention. We found the website and video content was acceptable to caregivers who identified future features that may enhance the relevance and impact of the intervention. Web-based interventions for kidney transplant access that include animated videos have potential to enhance delivery of content to informal caregivers.

Author Contributions

LK: conceptualization, methodology, data curation, formal analysis, writing—original draft preparation, and writing—review and editing; AS, MK, and MH: Participated in data curation, formal analysis, and writing—review and editing; MI and NK: Participated formal analysis and writing—review and editing. All authors have read and agreed to the published version of the manuscript.

Funding

This research was funded by National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health, award number R01DK129845-01.

Institutional Review Board Statement

The study was approved by the University at Buffalo Institutional Review Board. The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of the University at Buffalo, SUNY (protocol code 00002771; date of approval 09/08/22).

Informed Consent Statement

Informed consent was obtained from all subjects involved in the study.

Data Availability Statement

The qualitative data used and analyzed in the study is not publicly available because the data contain personal and potentially identifying information. Quantitative data is available from the corresponding author upon reasonable request.

Acknowledgments

We are thankful for the data collection and entry assistance, consultation, and collaborative efforts we received from several individuals, including Sydney Pelino, Colleen Hagler, and members of our community advisory board, named Kidney Health Together.

Conflicts of Interest

The authors declare no conflicts of interest. The funding organization played no role in the collection of data, analysis, interpretation, or the right to approve or disapprove publication of the finished manuscript.

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