

Living Kidney Donation Stories and Advice Shared Through a Digital Storytelling Library: A Qualitative Thematic Analysis



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Rationale & Objective: Despite the development of numerous educational interventions, there has been limited change in actual living donor kidney transplant (LDKT) rates over time. New strategies, such as the inclusion of patient stories in patient education, show promise to inspire more people to donate kidneys. This study identified the challenges faced, coping strategies used, and advice shared by transplant donors and recipients.

Study Design: Qualitative thematic analysis.

Setting & Participants: One hundred eighteen storytellers across the United States and Canada, including 82 living donors and 36 kidney recipients of living donor transplants who shared their stories on the Living Donation Storytelling Project (explorelivingdonation.org), an online digital storytelling platform and library.

Analytical Approach: A poststorytelling survey assessed participant demographics. Two coders conducted tool-assisted (Dedoose v.8.3.35) thematic analysis on narrative storytelling videos and transcripts.

Results: Storytellers were predominantly White (79/118, 66.95%), female (76/118, 64.41%), and non-Hispanic (109/118, 92.37%) with college/vocational education (50/118, 42.37%). Common themes were found related to living donation challenges for donors and recipients (eg, the fear of not being able to complete the LDKT process, of unsupportive family or rejected donation requests, and of unknown or adverse surgical outcomes and graft rejection) and recommended coping strategies (eg, seeking LDKT information, using prayer, and relying on a support network). Recipients provided advice that included being proactive and staying hopeful, whereas donors recommended seeking support, researching LDKT to comprehensively learn, and building a community of support.

Limitations: Limited representation of diverse demographics.

Conclusions: Although supplementary to traditional education about LDKT, digital storytelling provides a source of peer support that can enhance the experience of donors and recipients and encourage autonomy and self-management after transplant.

Complete author and article information provided before references.

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Approximately 15% of US adults have some stage of chronic kidney disease.¹ The number of patients with full kidney failure in the United States exceeded 130,000 in 2018.² More people die of kidney failure each year than of breast or prostate cancer.³ The best treatment option for kidney failure is a living donor kidney transplant (LDKT). Patients who receive a LDKT live years longer and have a better quality of life than those who continue receiving dialysis or wait years for a deceased donor kidney transplant.⁴ Although there are many generous people who could donate kidneys in the United States, less than 6,500 people donate when alive each year.⁵

The need for kidney transplants is especially prominent in racially and ethnically diverse communities. Compared to White patients, patients who are Black or Hispanic have higher rates of kidney failure because of higher rates of diabetes and hypertension, the 2 main causes for kidney failure.⁶ Minorities are more likely to have kidney failure and are less likely to present to transplant centers for evaluation, complete transplant evaluation, and receive transplants.⁷

Despite LDKT being possible for all patients on the transplant waiting list, thousands of patients die of kidney failure every year without their families and friends being

aware that they could have become living donors. Furthermore, some may never have had the opportunity to meet an LDKT recipient or donor, particularly one of their own race/ethnicity. Disseminating LDKT information more broadly to the public has the potential to reach more potential living donors and reassure additional patients with kidney failure, especially those with higher medical mistrust or fears about allowing others to donate, that LDKT is a viable treatment decision for them.⁸

Researchers have developed various educational interventions to reduce transplant disparities⁹; however, there has been limited change in actual LDKT rates. Storytelling is one educational technique that has not yet been fully studied in LDKTs; however, it has shown promise in improving other health-related behaviors.¹⁰ Published research on storytelling application has ranged from exploratory studies in health contexts, including midwifery,¹¹ cancer,^{12,13} hypertension management,^{14,15} smoking cessation,^{16,17} exercise adherence,¹⁸ human papillomavirus vaccination,¹⁹ mental health,^{20,21} and maternal health,²² to pilot-feasibility studies on the application of storytelling as an intervention in particular health contexts.^{13,23-25}

PLAIN-LANGUAGE SUMMARY

We analyzed the content of donor and recipient stories in the Living Donation Storytelling Project for common themes. We found that participants often discussed challenges of the living donation process, coping strategies, and advice to help others through the process. Challenges included fear of the process, rejection, lack of family support, and bad outcomes. Coping strategies included learning more about living donation, prayer, and relying on a support network. Recipients advised others to be proactive and stay hopeful, whereas donors recommended seeking support, researching donation, and building a community of support. These stories can supplement patient education and offer an accessible source of support for people considering or currently pursuing living donation and living donor transplant.

Storytelling supplements traditional educational approaches by providing those who are considering taking health actions with the opportunity to access unique experiential expertise through real-life patient stories. According to narrative theory, stories help change attitudes and behaviors of listeners by “breaking down cognitive resistance through transportation and identification” to “emotionally and cognitively engag[e]” the audience into becoming “more open and accepting of the information presented.”²⁶

Storytelling is especially useful to convey scientific information to lay audiences.²⁷ Health information can often be complicated and fraught with medical jargon that is challenging for populations with limited literacy to understand, process, and act upon. The benefits of storytelling include getting answers from someone who has gone through the experience, providing reassurance and encouragement, increasing confidence, helping the listener make or confirm treatment decisions, and providing hope for the future. Storytelling may also help contextualize and clarify patients’ concerns as they review health information. In addition, by sharing personal stories, patients who have already faced a health challenge can help reduce fears and educate others who are going through similar experiences.²⁸

Web-based storytelling platforms have been shown to be a convenient and cost-effective way to increase interest and further engage the public in learning more about LDKTs.^{29,30} Although storytelling has been applied to blood or marrow transplantation³¹ and allogeneic hematopoietic stem cell transplantation,³² limited research exploring the value of storytelling in solid organ transplantation is available. Although ventures into this topic date back to the early 2000s,³³ until recently, few studies have examined the content being shared about the transplant experience.^{10,29,34} Educationally beneficial information

provided in an accessible format to diverse communities can offer insight into what increases trust and improves connection with hard-to-reach patient populations.²⁸

To address this research gap, the present study describes donor and recipient experiences with LDKTs as shared through storytelling. Thematic analysis of the stories presented in the Living Donation Storytelling Project was conducted to understand the challenges that living kidney donors and recipients report facing when exploring LDKTs, assess the strategies used to overcome challenges during the LDKT process, and discuss the advice and recommendations given to others considering LDKTs.

METHODS

Storytelling Capture Procedure

The Living Donation Storytelling Project (explorelivingdonation.org) is a free, publicly available, online digital library that contains real-life stories of kidney recipients and living donors from diverse communities across the United States and Canada.³⁵ The research team identified and invited storytellers via referrals from health care professionals and organizations and through social media (Twitter, Instagram, Facebook, and LinkedIn) from April 2019–August 2020. Potential storytellers were invited on the basis of their previous experience with living donation or an expressed interest in exploring the topic as evidenced through social media posts or living donation–related group membership. The research team directed the interested participants to explore the living donation storytelling website, where they received instructions on how to record their video, including strategies for effective recording (eg, lighting and camera placement), and specific tips to help them avoid disclosure of protected health information. The website allowed storytellers to conveniently and privately film their story using a device (ie, a cell phone, tablet, or computer) and location of their choice. The study protocol was approved by the University of California, Los Angeles, institutional review board (IRB #18-000516). Grant funding for this study was provided by One Lambda and Health Resources and Services Administration grant 5R39OT31888-03-00. Informed consent requirements were waived for the research use of deidentified information. At the time of data analysis in early 2021, only English stories were submitted and published on the website; however, as of late 2021, the website includes stories in Spanish and French as well to serve a more diverse audience.

Donor and recipient storytellers were presented with a set of open-ended prompts (see [Table 1](#)) that provided starting points to help storytellers share important aspects of their experience with others, including the challenges faced during the living donation process, strategies used for overcoming those challenges, and advice to help others navigate the process. Storytelling prompts were designed by a research team that comprised a social psychologist

Table 1. Sample of Storytelling Prompts

	Storytelling Prompts
Donors	"Hello, my name is (Name). I donated a kidney to (recipients; ie, Dad, sister, etc)"
	"When I started to research living donation, the most surprising thing I learned was..."
	"I had many private & personal fears and questions about the process, the main ones were..." ^a
	"Different sources of information helped me learn and kept me informed, like..."
	"I ultimately decided to donate a kidney because..." ^a
	"My family (children, spouse) worried that...I helped them understand..." ^a
	"It got harder or scary for me when...What helped me get through it was..." ^a
	"Leading up to the procedure, I coped with the stress by..."
	"When I share my story, I am often asked the question of..."
	"Looking back, the best part about donating a kidney was..."
Recipients	"What I discovered about myself during/after this experience was..."
	"The best advice I could give someone else who is considering being a Living Donor is..." ^a
	"Hi, I'm (Name), I received a living kidney donation from... (eg, Dad, Sister, Stranger, etc) about (X) months/years ago."
	"My kidney failure began when I was (X) years old. At that time, I was doing (common activities for you before the transplant) ... but then I started to notice (changes that affected your daily life)"
	"Living without working kidneys meant that... The first time I had a dialysis treatment was ... (explain how it felt)"
	"I found it...(difficult/easy) to talk about living donation with my family and friends, because..."
	"Even with my fears, I decided to try to find a living donor because..." ^a
	"When... (Donor) first said they would think about donating a kidney, I felt..."
	"On the day of the procedure, when I was being rolled into the operating room, I was thinking... and feeling..."
	"The relationship that I have with... (Donor) today, is... What I learned about myself/others is..."
"Looking back, this is what I didn't expect. The only thing I regret is..."	
"What I learned from this entire journey was..."	
"My advice to others who need a kidney is..." ^a	

^aIndicates prompts selected for the qualitative thematic analysis of this study.

(ADW), a social worker (LA), public health professionals (EWH, YAI, and EW), and a health communication expert (LAD), who all had extensive experience in developing patient education on LDKT. Storytellers responded to each prompt individually, could skip prompts, and could rerecord until they were satisfied with the recording. When complete, the software spliced the prompts together into a seamless story.

Transplant educators and social workers reviewed the completed stories to ensure that the content and presentation were appropriate for public sharing. This process included an ethical review of each story to ensure that no protected health information was shared and to identify foul language or misinformation about donation or transplantation. Problematic content was redacted from the final videos. Approved stories were uploaded into the digital library with a link sent to the storyteller to share with others.

Viewers of the digital storytelling library can find the most relevant stories by using search categories including sex, location, race/ethnicity, language (English, Spanish, or French), key transplant-related topics (eg, asking for a kidney and thinking about donation), and living donation story type (eg, recipient, donor, family, and those in need of a kidney). At the time of data collection, stories were only available in English; thus, the focus of the analysis is on English narratives.

The website also allows visitors to read information on living donation and post stories to their own social media accounts.

Survey Instruments and Analysis

Demographic Assessment

Through a poststorytelling survey, storytellers reported their demographics (eg, gender, race/ethnicity, and age), level of education, and type of story completed (eg, donor, recipient, or family member). Participant demographics were analyzed and summarized using descriptive statistics.

Story Coding and Analysis

Storytelling content from the video library was transcribed using the Otter.ai (v 2.3.86) virtual transcription service. Two coders (LAD and YAI) watched each donor and recipient video and reviewed the corresponding transcripts. Both coders were trained in qualitative method analysis, with a PhD in Health Communication and Research Methods and a BS in Biological Sciences, respectively. The researchers had no prior relationship to participants; however, YAI was involved in the recruitment and instruction, as noted in the aforementioned storytelling capture procedures. For this article, we first examined 7 key storyteller prompts (Table 1). After the initial review of the key prompts, the entire stories were reviewed a

second time to ensure the capture of the thematic content. Analyses of additional prompts for distinct themes related to the emotional content of the stories have also been reported elsewhere.³⁶

Transcripts were then uploaded into Dedoose (v 8.3.35), an online qualitative data analysis tool, to conduct a thematic analysis of qualitative data on the basis of the techniques of Braun and Clarke.³⁷ Themes were generated using a combination of inductive and deductive coding and interpreted using a phenomenological approach that focused on the experiences of the storytellers. LAD first analyzed transcripts by identifying instances where the participants referenced challenges they faced while pursuing a living donor transplant, the strategies they used to overcome those challenges, and the advice given to those pursuing a living donor transplant. Using this process, a set of 5 interviews was independently coded by LAD and YAI to identify and refine the additional broad themes and sub-themes generated from the data. LAD and YAI met twice a week to reconcile differences. The final groupings of themes were undertaken by LAD and YAI.

RESULTS

Participants

From April 2019-August 2020, a total of 118 storytellers, including 82 (69%) living donors and 36 (38%) kidney recipients of living donor transplants, shared their stories. Story duration ranged from approximately 2-15 minutes, with most stories being around 5 minutes. Storytellers were primarily White (66%) and female (64%) (Table 2). The analysis of the stories revealed that both donors and recipients faced challenges, identified and utilized effective coping strategies to overcome those challenges, and offered advice to those considering a LDKT.

Common LDKT Challenges/Concerns

Both donors and recipients expressed concerns about graft rejection and worried that the donor's health might be harmed because of medical complications after surgery (Table 3). In addition, donors expressed concerns about not being able to donate and being ruled out during the evaluation process. One donor stated,

The only time it got harder and scarier for me was when I thought that I might be rejected as a donor, for instance there was some question about one of my kidneys not being suitable because they thought they saw something on one of my kidneys, that scared me and then there they thought they saw something on one of my lungs and that might rule me out. (Donor #79)

Similarly, recipients dealt with the fear of not finding a match and being rejected if they asked someone to donate.

Table 2. Storyteller Characteristics (N = 118)

Characteristics	Overall
N	118
Age interval, n (%)	
18-30 y	8 (6.78%)
31-40 y	18 (15.25%)
41-50 y	29 (24.58%)
51-60 y	33 (27.97%)
61-70 y	20 (16.95%)
70 y or greater	1 (0.85%)
Did not respond	9 (7.63%)
Gender, n (%)	
Female	76 (64.41%)
Male	35 (29.66%)
Did not respond	7 (5.93%)
Race, n (%)	
White	79 (66.95%)
Black	10 (8.47%)
Asian	3 (2.54%)
American Indian or Alaska Native	3 (2.54%)
Multiracial	3 (2.54%)
Other	4 (3.39%)
Did not respond	16 (13.56%)
Ethnicity, Hispanic, n (%)	9 (7.63%)
Story type, n (%)	
Recipient	36 (30.51%)
Living donor	82 (69.49%)
Education, n (%)	
High school or GED	4 (3.39%)
College or vocational school	50 (42.37%)
Graduate or professional	32 (27.12%)
Did not respond	32 (27.12%)

Abbreviation: GED, General Education Development.

Finally, some donors' families and friends did not understand the process and were unsupportive of their decision to donate. Even close family members struggled to accept the donor's desire to donate. A donor shared,

When I told my mother, I wanted to do this for my father...nobody listened to me, they would ignore me. My father would ignore me. They were gonna have a meeting at the hospital, and they told me to stay at home. (Donor #105)

LDKT Coping Strategies

Donors and recipients coped with the challenges of LDKT before and during donation and transplantation in different ways. Many reported the value of seeking and learning more about LDKTs through internet research. One donor said,

I was fine there's a lot of reliable sources of information out there...in addition my favorite all-time website has lots of information free webinars and all kinds of workshops that are also complementary is the living

Table 3. Challenges to Donation or Transplantation

Themes	"It got harder or scary for me when..."
Donors	
I became afraid I wouldn't be able to donate	"...there were all these tests to do, and if I didn't pass them, it wasn't like there was something wrong with me, I would just feel so bad that I wasn't able to, to do what I wanted to do for somebody..."
My family was unsupportive or worried	"...my family worried about quite a bit of things in regards to the donation...the rest of my family along with my wife just thought I was crazy. And they were worried that I that I didn't know what I was doing, that I was doing it for the wrong reasons."
Recipients	
I feared that I wouldn't find a match	"I was scared that I wouldn't find a match because I didn't have a family that was alive or close to me."
I became worried that I would get rejected if I asked someone to donate	"Honestly, I didn't have the courage to do so (ask anyone to be my donor). I didn't know where to start. I didn't know what to say or even ask. I was so ashamed when I was so afraid that I, if I asked that I would just be rejected. And I didn't think that I would be able to handle that."
Donors and Recipients	
I became worried that the kidney wouldn't work posttransplant	"I worried a lot about it (the kidney) failing because he needed it so badly...It was kind of his last shot and I thought, gosh, if this doesn't work after everything we've been through..." -Donor "What if my kidney didn't work?" -Recipient
I began to worry about the donor having medical complications after surgery	"Can I live on just 1 kidney? What are the repercussions for me donating? What are the risks involved? Will this end my life? Or will my life expectancy I should say be impacted by this? How long will it take to heal? Do I have to change my diet or my lifestyle?" -Donor "I had many questions about how this would impact [donor's] life, including was the surgery safe for him? What were the long-term consequences be for him and his health? Was his family okay with doing this?" -Recipient

kidney donor network. These resources really help me.
(Donor #59)

Another donor spoke of how impactful the hospital staff was in helping them gather more information to address their concerns. They shared that,

...the doctors and...the folks at the hospital where we did the transplant were really remarkable in helping both of us kind of understand what it looked like, what the risks were, what the benefits to them were, and just really kind of, for lack of a better term really held our hand through the process. (Donor #131)

Having adequate social support was another crucial component to coping and managing life through the LDKT and recovery process. Recipients commonly talked about the emotional support received from their support network before the transplant. One recipient spoke about the emotional support he received from his wife, stating, "My wife and I talked about it a lot, and she was very reassuring, and she shared in my hope that we could go through this together and return to a normal life that we had before" (Recipient #50). Donors reported receiving tangible support, such as assistance with childcare and meal deliveries, during their recovery after donation. One donor who was accustomed to providing support to her community recalled that giving the kidney was easy,

...but then to receive...support from my friends and family was pretty incredible. It was kind of hard, the first week being totally dependent on my husband to receive that kind of care. And I mean, totally dependent

for everything and anything. And then ...the church calls me when people need meals and suddenly, I'm the one who needs meals, and my husband needs meals because he's trying to wrangle the kids...and he certainly needed help. So, it was amazing to see.
(Donor #86)

Throughout the LDKT process, faith, hope, and prayer proved key to coping with stress and the uncertainties of how a LDKT would go for both donors and recipients. A recipient storyteller shared that she "turned it all over to the Lord, [because] He was in total control at that point" (Recipient #18). This reliance on faith was echoed by a donor who recounted, "...what helped me get through it was, for me, prayer, just asking and relying on God's strength" (Donor #121).

LDKT Advice

After sharing about the challenges faced and the coping strategies used to overcome them, donors and recipients offered advice to help others navigate the LDKT process and find living donors (Table 4).

First, donor and recipient storytellers encouraged others not to lose hope; a recipient said, "my advice to others who need a kidney is to never lose hope. Sometimes hope was the only thing that I had, and they really hung onto that and it worked out" (Recipient #7). They also recommended that others donate or pursue LDKTs, if possible, because of the positive impact of an LDKT on one's overall life and the specific health improvements over other treatments. One recipient noted that they learned that transplant,

Table 4. Advice Given by Living Donors and Recipients

Themes	“The best advice I could give someone else who is thinking about getting a living donor transplant or being a living donor is...”
Recipients	
Stay hopeful while on dialysis	“...never lose hope sometimes hope was the only thing that I had and they really hung on to that and it worked out I also encourage everyone to try not to let dialysis get in the way of things.”
Share your need for a kidney as widely and as much as possible	“...don't be afraid to announce your need, let other people know that you have this disease. It doesn't mean that you're actually asking someone for a kidney, but as you announce your need and that you have kidney failure, just let the need be out there.”
Be your own advocate for living donation	“...keep learning about kidney disease. Go on all the different websites, talk to people, talk to kidney donors, if you know any, talk to people who have received a kidney, and when you learn more about the disease, you will be in better control of your health... Those things will give you a sense of control and will put you in a better place mentally and I think when you're stronger mentally, your body will be stronger um as you're fighting disease and as you're waiting and the better your outcome will be. So, keep going, keep staying strong and get connected with people.”
Donors	
Do your research to stay informed about living donation	“...do your research, research the hospital that you're thinking about going to and then just research all of the statistics on living kidney donation stories of other people, support groups get as much information as you can.”
Build a community to support you through LDKT	“But gosh, just talk to people. I would talk to recipients. I would talk to donors. There's a really great living kidney donor network out there. There's a social media component of it, Facebook, whatnot. And really, we're all there to answer questions and walk people through it...there are some mentoring programs that I've been involved in, that you get to sit down and talk to folks who are getting ready to go in for that surgery about what your experience was like, and so many resources there.”

Abbreviation: LDKT, living donor kidney transplant.

...is by far better than dialysis and having lived through both...a year of dialysis and 2 years since I've had my transplant, my transplanted life is far better. And then I learned that living donor transplant was even better than [a] deceased donor for a bunch of reasons. (Recipient #24)

Recipient storytellers encouraged potential LDKT recipients to take charge in their pursuit of a kidney. They also cited the importance of remaining positive and hopeful throughout the process. One recipient stressed the need to be courageous when seeking a donor:

“...don't be afraid to announce your need, let other people know that you have this disease. It doesn't mean that you're actually asking someone for a kidney, but as you announce your need and that you have kidney failure, just let the need be out there and you'll be surprised who steps forward. (Recipient #24)

Donors encouraged those considering donation to do their research and build a community of support to help them throughout the LDKT process. One donor stressed the importance of a support network and their success; he stated,

Having a support network going into this is so important I think often when we are feeling vulnerable we might find it difficult to ask for help and when you are recovering from this experience you need to focus on your recovery...don't be afraid to ask for it and don't be afraid to leverage the support that's available to you. (Donor #48)

DISCUSSION

When patients face living donation challenges, insight from actual living donors and recipients may offer unique, experiential expertise and recommendations that are functional, useful, and effective. In this study, after reviewing content that was shared publicly on a digital living donation storytelling platform, we found that transplant recipients and living donors commonly shared their vulnerabilities, including fears of not finding a match, failing to match as donors, or having their request for a kidney rejected. When providing recommendations to others earlier in the LDKT process, these digital storytellers recommended staying positive, becoming well prepared to pursue living donation, and building and relying on strong faith and support networks.

When examining the motivation behind sharing their stories, many of the storytellers suggested that they wanted to provide others with the type of information that would have been helpful for them. Digital storytelling can serve as a type of remote peer mentoring to reassure and guide others, providing instructions on how to avoid pitfalls and sharing best practices for success through LDKTs. Research on the benefits of peer mentoring generally has found increased discussion about self-management techniques and coping strategies.^{38,39} Participants in a recent exploratory study on peer mentorship for posttransplant patients reported that peer support provided a convenient and user-friendly way to address transplant-related concerns.⁴⁰ Peer mentorship has also been shown to be a valuable way of creating a community to help alleviate loneliness and isolation, which is common among posttransplant

patients.⁴⁰ Digital stories do differ from traditional peer mentoring because of the unidirectional nature of the communication. However, in a world of remote telemedicine and difficulty matching real-life mentors with patients or family members/friends in person, viewing these stories may be a valuable starting point, particularly for those who cannot come to a transplant center to meet others.

The adequacy of social support has been used to determine suitability for transplant.^{41,42} Some living donor storytellers reported facing challenges in donating because others did not support their decision. If the entire social support network views these digital stories, family members and friends may be better oriented to support people undergoing transplant or donor evaluation.

There is still a need for additional research on the ethical implications of using first-person stories in the context of LDKTs, both to understand the general impact of these stories on viewers and their decision-making process and to examine the specific impact of hearing experiential challenges, solutions, and advice. Although hearing the vulnerabilities of potential LDKT patients and donors, particularly in underrepresented communities, may be motivating, these types of stories might also be manipulative, particularly if true risk-benefit information is not provided. As health systems and patient advocates work toward increasing LDKT rates through stories, practices should be in place to ensure that the challenges, obstacles, and advice shared are discussed and meaningfully understood alongside more aggregate information.

The online digital library used for this study can be accessed free of charge by nearly anyone regardless of financial resources or educational needs. Although the advice shared encourages potential donors and recipients to discover more information, talk with family and doctors, and advocate for themselves, more research is needed to see how helpful the shared information is for viewers and what actions the viewers take as a result of viewing these stories. Although research has examined conceptual models of digital storytelling effects,⁴³ the impact of digital storytelling on the storytellers,⁴⁴ and the perceptions of characters within stories,⁴⁵ few studies have assessed the effectiveness of storytelling in educational trials.

This study has several limitations. Although diverse storytellers are being actively recruited, the library currently consists of individuals who are predominantly White, female, and English-speaking. Additional outreach through community groups, social organizations, and key trusted resources in diverse communities is necessary to engage more diverse storytellers. There was also a limited number of and content on prompts. Donors and recipients could choose from up to 15 prompts while recording their story. Relatedly, recruitment strategies and prompts were not as readily well-suited to those who considered but did not complete a LDKT, either opting for dialysis or deceased donor, or because of medical reasons. A broader focus to capture more wholistic experiences of LDKTs could

improve relevance to additional audiences. Finally, to expand the reach of this library, outreach to Spanish-speaking patients and patients who speak languages other than English is needed.

In conclusion, digital storytelling can extend traditional transplant education by supporting populations who have lacked access to the best type of kidney replacement therapy—living donation. If storytelling is positioned in an ethical and equitable way, it has the potential to engage patients with kidney failure of all races/ethnicities and greater numbers of potential living donors from their communities. Digital storytelling can also help reduce critical LDKT barriers, including bypassing reading difficulties, reducing fears of allowing others to donate, and overcoming language or cultural barriers. Although the Living Donation Storytelling Project cannot replace standard transplant education, it can offer a source of remote peer support to enhance the experience of donors and recipients and encourage autonomy, empowerment, and pursuit of living donation by more patients with kidney failure and potential donors.

ARTICLE INFORMATION

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Data Sharing: We will share individual participant data that underlie the results reported in this article after deidentification (text, tables, figures, and supplementary material). Study Protocol, Statistical Analysis Plan, and Analytic Code will be made available beginning 3 months and ending 5 years after article publication. Data will be made available to investigators whose proposed use of the data

has been approved by an independent review committee (“learned intermediary”) identified for this purpose. Analyses will be permitted to achieve aims in the approved proposal.

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