



Findings of living donation experiences shared on a digital storytelling platform: A thematic analysis

Erica W. Ho^a, Ariana L. Murillo^b, LaShara A. Davis^c, Yaquelin Arevalo Iraheta^b, Shailesh M. Advani^a, Ashley Feinsinger^b, Amy D. Waterman^{c,*}

^a Terasaki Institute for Biomedical Innovation, 1018 Westwood Blvd, Los Angeles, CA, USA

^b David Geffen School of Medicine, 886 Tiverton Ave, Los Angeles, CA, USA

^c Center for Outcomes Research, Houston Methodist Hospital, 6565 Fannin St, Houston, TX, USA

ARTICLE INFO

Keywords:

Storytelling
Narrative communication
Patient education
Living donor kidney transplant
Health promotion
Patient-centeredness

ABSTRACT

Objectives: To identify common experiences and emotional changes shared by living donors and kidney recipients about their living donation experiences on a digital storytelling platform.

Methods: 82 donors and 36 recipients submitted prompt-guided videos to the platform. Two coders analyzed transcripts for motivations, common themes, and emotions expressed.

Results: Storytellers shared their stories to advocate for living donation and contribute to others facing similar challenges. Pre-surgery, recipients recalled their dialysis experiences and how they sought living donors while donors discussed their motivations and common fears. Post-surgery, recipients discussed changes in their relationship with the donor and quality life, while donors described how they benefited. Learning they needed a transplant, recipients reported feeling fear (33.3%) while donors felt sadness (48.8%). Post-transplant, recipients and donors reported feeling happiness (85.4%, 38.9%) and relief (29.3%, 22.2%).

Conclusion: Online digital storytelling libraries increase access to real-life living donation experiences. Since stories are highly personal, additional living donor kidney transplant risk-benefit education is needed.

Innovation: Stories can supplement traditional education and be incorporated into advocacy efforts; campaigns could capitalize upon the personal aspect of stories to gently introduce and encourage living kidney donation among the general public.

1. Introduction

For patients who suffer with chronic kidney disease and end-stage kidney disease (ESKD), living donor kidney transplantation (LDKT) is the preferred renal replacement therapy because of its better health outcomes compared to dialysis [1]. However, LDKT is underutilized, due to lack of awareness of both potential donors and kidney patients [2,3]. Several studies also show that disparities in LDKT accessibility are attributed to health literacy barriers and unavailability of culturally- and linguistically-sensitive health education resources [5-8].

Knowledge, language, and cultural barriers that contribute to LDKT inaccessibility and preventable ESKD-related deaths may be reduced by using digital first-person storytelling (FPS) as a health education resource [9,10]. FPS has been used to educate patients about many health topics, including cancer, diabetes, and hypertension [11], and has been shown to improve health behaviors [12], self-efficacy [13], attitudes towards the disease

and treatment [14], and knowledge [15,16]. FPS can also be an effective educational intervention to reach disadvantaged kidney patients, since unlike traditional didactic interventions, storytelling is more engaging for patients who are less ready to take health actions, are more mistrustful, and have low health literacy [17].

According to the Storytelling/Narrative Communication (SNC) theory [17], storytelling and narratives about personal experiences can be used to promote health behavior change among racial and ethnic minority groups. The findings Lee et al. [17] applied SNC to find that storytelling guides the target audience towards a specific health behavior through three means that may be beneficial for someone learning about LDKT: emotional engagement with another person, helping the viewer or listener relate personally with the narrative's plot, and providing a sense of ease when learning about an unfamiliar or uncomfortable topic. In addition, digital storytelling, especially when provided online through story libraries [10], has the unique aspect of being able to establish a visual connection

Abbreviations: FPS, first-person storytelling; LDKT, living donor kidney transplant; ESKD, end-stage kidney disease.

* Corresponding author at: Houston Methodist Hospital, 6565 Fannin St, Houston, TX 77030, USA.

E-mail addresses: ladavis@houstonmethodist.org (L.A. Davis), yarevaloiraheta@mednet.ucla.edu (Y.A. Iraheta), AFeinsinger@mednet.ucla.edu (A. Feinsinger), awaterman@houstonmethodist.org (A.D. Waterman).

<http://dx.doi.org/10.1016/j.pecinn.2022.100023>

Received 3 September 2021; Received in revised form 28 January 2022; Accepted 13 February 2022

2772-6282/© 2022 Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

between learner and storyteller. One study has shown that adults are better able to make connections with storytellers with whom they can personally or socially relate [18]. This connection has been shown to not only improve patients' receipt and retainment of health information, but also increases their health literacy, willingness to pursue necessary treatments, and overall knowledge of their disease [9,10,19].

Despite the successful application of FPS, it is only starting to be used in educational settings with potential living donors and kidney recipients. Since the value of digital storytelling relies heavily on the content of what storytellers communicate, this study qualitatively analyzed video transcripts with the goal of depicting common LDKT experiences for both donors and recipients and identifying emotional changes throughout our storytellers' LDKT journeys.

2. Methods

2.1. Sampling

This study (IRB #18-000515) utilized data collected through digital stories submitted to the Living Donation Storytelling Project [20]. The Living Donation Storytelling Project is a digital library of accessible, cost-effective, and culturally and linguistically diverse LDKT recipient and donor stories. We invited storytellers to share their stories via social media apps (e.g., Twitter, Instagram, Facebook, LinkedIn) and referrals from healthcare professionals and organizations from April 2019 to August 2020. Storytellers had to be 18 years or older to submit a video story to the website. At the time of this study in early 2021, only English stories were submitted and published on the website, though as of late 2021, the website includes stories in Spanish and French as well to serve a more diverse audience. This study includes 118 storytellers (82 donors and 36 recipients of LDKTs) who shared their living donation stories in response to a set of guided, open-ended prompts. Storytellers also answered a short survey that collected their demographic characteristics (e.g., age, gender, and race/ethnicity), type of story completed (e.g., recipient, living donor), and education level (Table 1).

Table 1
Storyteller characteristics.

Characteristics	Overall
N	118
Story Type, n (%)	
Recipient	36 (30.51)
Living Donor	82 (69.49)
Age Interval, n (%)	
18–30 Years	8 (6.78)
31–40 Years	18 (15.25)
41–50 Years	29 (24.58)
51–60 Years	33 (27.97)
61–70 Years	20 (16.95)
70 years or older	1 (0.85)
Did not respond	9 (7.63)
Gender	
Female, n (%)	76 (64.41)
Male, n (%)	35 (29.66)
Did not respond (%)	7 (5.93)
Race	
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)
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)

Video stories were filmed on personal devices including cell phones and computers. Storytellers completed a standard media release and were supported by trained staff to resolve any technical issues. Submitted videos were ethically reviewed to remove personal health information (PHI), medical inaccuracies, and overly persuasive statements (e.g., “If you don't donate your kidney you are selfish”), but were minimally edited overall before being posted to the library.

2.2. Content shared from prompts

Open-ended prompts were created by researchers and a patient panel based on common questions and concerns of people considering living donation (e.g., “Living without working kidneys meant that...”, “I ultimately decided to donate a kidney because...”) and grouped into two guides for prospective patients and donors [11]. The 17-prompt recipient guide invited discussion about life without working kidneys, feelings when talking about LDKT with family and friends, their recovery experiences, relationships between them and their donors, and what they learned from the entire experience. Additionally, donors were asked to share in response to 17 prompts that addressed their decision to donate; their worries, fears, regrets, and changes in lifestyle after donating; and what they learned about themselves post-donation. A complete list of donor and recipient prompts is included in Appendix A.

2.3. Emotional content

Two separate researchers coded the emotional content shared within each storytelling video at four stages of the donor and recipient journeys: 1) learning they or someone else needed a transplant, 2) matching with a donor/recipient, 3) before surgery, and 4) after surgery. The emotions coded as being “present” or “absent” at each stage were anger, fear, anxiety, hope, relief, guilt/shame/embarrassment, jealousy, sadness, happiness, pride, love, and “other”.

2.4. Analysis

Video stories were transcribed using the Otter.ai (v 2.3.86) and thematically analyzed by two coders using Dedoose (v. 8.3.35) a qualitative data analysis software. EH and AM read transcripts to develop initial codes and discuss common themes expressed by different storytellers in response to the guided prompts. Coders began the analysis on various kidney recipient and donor prompts (e.g., “A life without dialysis meant that I”, “The best moment after surgery was”, “The relationship that I have with (Donor) today, is”). The complete list of prompts can be found in Appendix A. EH and AM met weekly to revise codes, combine similar themes and reconcile differences, as well as for organization to ensure alignment with the study aims. The codes and themes were finalized in discussion with LD, an assistant professor, and YA, a qualitative researcher.

Positive and negative emotional responses were analyzed by two independent coders who rated whether each emotion was mentioned while the storyteller described their experience at one of the four key time points. Data on storytellers' emotions and demographics were analyzed using descriptive statistics.

3. Results

3.1. Storytellers' motivations

Storytellers had several motivations for sharing their story, including advocating for LDKT, connecting with others facing similar challenges, and motivating more people to become living donors. One recipient reported that they were sharing their story on the platform as one of the many ways they advocate for LDKT, saying, “I now educate the community, I educate the country, and I educate anyone I come in contact with on a daily basis about kidney disease, about transplantation, about living donation and about how we can all work together in trying to find a cure for kidney disease”

Table 2
 Recipients' Pre- and Post-Transplant Experiences.

Pre-Transplant Themes Identified	
<p>“Living without working kidneys meant that...” Theme: Struggling with dialysis</p>	<p>“I had to focus completely on just living and surviving and not really enjoying my life and it meant rearranging my entire schedule to just take care of myself the first time.” Recipient 7</p>
<p>“I found it ___ to talk about living donation with my family and friends, because...” Theme: Found it easy to talk to a potential donor</p>	<p>“I was exhausted, I could barely eat. And all I did was sleep, work and dialysis.” Recipient 38</p>
<p>Theme: Found it difficult to talk to a potential donor</p>	<p>“I found it easy for me to talk about trying to find a living donor because I was desperately in need of a kidney. My condition was getting worse by the day and there was no doubt that I would need a kidney... so I just started to try to the word as best I could amongst friends and family” Recipient 118</p> <p>“I found it difficult because I struggled with how to even ask someone to be a living donor. Initially I reached out to family who had their own personal situations to deal with, so then it was reaching out to friends who hadn't seen this slow decline in my health. It was very difficult to bring it up in a conversation like ‘Hey, you want to give me your kidney?’.” Recipient 146</p>
<p>“When [the Donor] first said they would think about donating a kidney...” Theme: Feeling guilty accepting a donation</p>	<p>“When my doctor told me that a living donor kidney transplant was my best option, I felt really, really sad... I found it difficult to talk about live kidney donation to family and friends because it's so weird to say hey man I'm sick I need a kidney and give me your kidney.” Recipient 47</p>
<p>Theme: Feeling happy when someone offered to donate</p>	<p>“I really struggled with accepting the donor because I was accepting the donor because I was so guilt ridden, but my doctor helped me up through this entire process counseled me about how it's not my job to carry their burden, but I had to decide for myself, if I wanted to live or die.” Recipient 111</p>
<p>Theme: Concerned for my donor's health when they offered to donate to me</p>	<p>“I was so happy and relieved... I found it easy to talk about living donation with my family and friends because I had a lot of support from my family and friends. I had a lot of people telling me that they were willing to donate to me.” Recipient 56</p> <p>“The first thing I was worried about was my wife, that she would be okay that she wouldn't have any complications. And that would be horrible if something bad happened while she was trying to give me a kidney. So that was the most important thing for me in the first place.” Recipient 73</p>
	<p>“I had a lot of questions about how the living donation process will affect the donor. You know, my biggest concerns were about insurance and how would it affect their health long-term.” Recipient 26</p>
	<p>“I had so many questions about how this would impact donor, including the cost and her recovery time, but once talking with the doctor and talking to my donor and talking the transplant team, they were able to assure me that she would be pretty quickly able to heal and go back to work within a reasonable time.” Recipient 16</p>
Post-Transplant Themes Identified	
<p>“A life without dialysis meant...” Theme: Being able to live a normal and active lifestyle without dialysis</p>	<p>“I'm back to my old self I'm doing the things I always loved to do: hunting, fishing, outdoor activities. I'm back to work full-time and overtime. Back to my normal life as I was before the kidney disease struck me. How I feel other than feeling great is inexpressible appreciation for this woman right here. I wouldn't be here making this video if it wasn't for her.” Recipient 118</p>
	<p>“I was able to start working towards exercise again. I was able to live a full and happy life again... I could live a full happy, healthy life again. It has now been four years since I received my kidney from my best friend. And I haven't felt better. I feel great. I'm active. I'm going out and doing the things that I love.” Recipient 22</p>
<p>Theme: Freedom from not being tied down with dialysis</p>	<p>“I wasn't tethered to the dialysis machine or the treatment or the hospital I can go to different places to travel. I can work out and do a lot more things in a day than I could when I was on dialysis. Since I've had my new kidneys, everything's great.” Recipient 73</p> <p>“Freedom of not being so dependent on a procedure to keep you alive anymore.” Recipient 118</p>
	<p>“A whole new freedom and I am now grateful for all the things that I took for granted before.” Recipient 24</p>
<p>“The relationship that I have with [Donor] today, is...” Theme: Closer relationship with donor post-transplant</p>	<p>“[Much closer after] this whole process. And we certainly have a greater appreciation for our time together now that we have more often, the relationship that I had with my wife, and donor is wonderful. We feel much stronger having gone through all the stress, and uncertainty in this process, and we certainly feel that we can make it through anything now.” Recipient 50</p>
	<p>“Obviously much closer than we were before. We talk, you know, every couple of days; we'll text all the time. Because of the distance and living in California and the traffic, we don't see each other as often as possible. But we talk all the time. And, you know, obviously social media helps. That way, I can see what she's been doing. We have a bond now. We will forever be tied together.” Recipient 38</p>
<p>“My recovery was...” Theme: What the recovery process was like</p>	<p>“[Slow the first week] because I was very sore. But I would say maybe within two weeks, you know, I could do pretty much anything. I was not able to drive until about maybe three weeks or so. But I really felt like myself again, I could go out, I could go shopping, I could walk around.” Recipient 24</p>
	<p>“A lot faster than what I thought it would be. I was excited to once again have the energy to do the things that I love doing like cooking meals and going for walks with my family bike riding. And, you know, going to the zoo going on hikes, going to the beach. There's so many things that I did not have the energy to do prior to the surgery.” Recipient 56</p>
<p>“What I learned from this entire journey was...” Theme: Grateful and motivated to live life because of their donor's generosity</p>	<p>“I think the most impactful way that I can show my gratitude is by living my life as fully as possible by taking care of this gift by trying to be as healthy as possible and by paying it forward just as she paid it forward to me. I can now take this gift pay it forward by hopefully working with diagnostic scientists and as well as the patient community in spreading advocacy and education about the beauty and the necessity of organ donation.” Recipient 146</p>
	<p>“That I really feel good... I feel like an active and contributing member to society.” Recipient 26</p>
	<p>“To be grateful for large and small moments of living is to be humbled by three individuals who gave me the gift of life. When I think about how I can repay these angels for their donation. I tried to live. I try to live my life to the fullest, so they can see their gift of life come to fruition.” Recipient 111</p>

(Recipient 39). One storyteller shared their desire to help guide others going through LDKT as well, saying, “[My transplant] was before the internet and I got all my information from people. I’m doing this recording because I felt like the interaction with people was really great” (Donor 34). Another stated that they filmed their story in hopes of inspiring others to participate in LDKT: “I get to talk about [transplant] and advocate for other folks to get or give kidneys” (Donor 131).

3.2. General content shared

Thematic analysis of storyteller transcripts identified a variety of themes commonly shared by recipients and living donors before and after their transplant and donation in response to key story prompts about their pre- and post-transplant and donation experiences (Tables 2 & 3).

3.2.1. Pre-transplant content shared by recipients

3.2.1.1. Negative dialysis experiences. When asked what living without working kidneys meant for their lives, recipients commonly discussed their struggles with dialysis prior to transplant. These narratives described poor quality of life due to dialysis and managing side effects of dialysis: “Living without functioning kidneys means my world was turned upside down. And I had a lot to learn. And a lot of lifestyles to change. My first time being on dialysis was very scary” (Recipient 22). Recipients also shared the lifestyle changes they made to accommodate their dialysis schedules, describing difficulties adjusting to a new lifestyle with limited knowledge, and disruptions to life goals.

3.2.1.2. Talking to potential donors. When asked how they felt talking about living donation with their loved ones, one recipient said, “Everyone stepped up to be tested...I actually [found] it very easy to talk about living donation with my family and friends” (Recipient 38). Other recipients shared about difficulty bringing up the topic with their family, with one saying, “I found it difficult to talk about live kidney donation to family and friends because it’s so weird to say, ‘Hey man, I’m sick. I need a kidney, and give me your kidney’” (Recipient 47). Some also struggled with feelings of guilt for asking such a large favor. One said, “I was really terrified to impinge on somebody’s life, and ask them for a body part. I didn’t know how to go about doing that” (Recipient 32). Overall, storytellers had varying experiences approaching their potential donors.

3.2.1.3. Asking someone to be their donor. When prompted about how they felt when a donor offered to be tested, some recipients expressed fear for their donor’s health/wellbeing and guilt for possibly imposing a burden on their donor. One said, “I was also a little scared that I would have to be a burden on someone else and ask them for such a huge favor that would potentially change their life” (Recipient 50). However, some recipients found the process to be easy and were grateful for the number of offers they received.

3.2.2. Post-transplant content shared by recipients

3.2.2.1. Recovery experiences. When asked to discuss what their recovery process was like, some storytellers were detailed about their recovery, describing the length of their recovery period and improvements to their physical and emotional wellbeing. A recipient reflected, “It took about four to five days before I really felt like myself again, and I had recovered from the surgery and I had my energy back. My body temperature returned to normal and I just I felt like a new person” (Recipient 36). Some recipients were candid about elements of recovery that they struggled with, recounting that, “Your eating habits change, your sleeping habits change, you’re not able to drive, and you have daily visits back to the transplant center. You’re very reliant on other people in your life to do that for you, so that was a big change” (Recipient 25).

3.2.2.2. Freedom from dialysis. When prompted about how life without dialysis has affected them, some talked about gaining freedom. One recipient expressed happiness about their ability to enjoy their daily life: “It’s just so

reassuring knowing that I’m not going to have to live on a machine. I’m going to feel good” (Recipient 33). Another expressed excitement in having the freedom to pursue goals that were delayed or unfeasible due to dialysis, recounting, “I could finally start my career as a public health professional, move out of my parents’ house, get a dog. Just do whatever I wanted and not have to worry about coming home and serving my dialysis machine” (Recipient 7).

Stronger relationship with donor. Prompted to talk about their relationship with their donor, several recipients mentioned how their relationship was strengthened post-donation and how they felt grateful for their donor’s generosity. One recipient shared, “I can’t even begin to describe the generosity, generosity of spirit, kindness, empathy, that it has taken her in my view to be able to donate a part of her body and literally saved my life. And for that I am forever grateful” (Recipient 32).

Altruism and appreciation. When prompted to reflect on the life lessons learned from their journey, recipient storytellers shared about how the generosity and selflessness displayed by their donor inspired them to be more altruistic or demonstrate their gratitude in some way.

I think the most impactful way that I can show my gratitude is by living my life as fully as possible by taking care of this gift by trying to be as healthy as possible and by paying it forward just as she paid it forward to me. I can now take this gift pay it forward by hopefully working with diagnostic scientists and as well as the patient community in spreading advocacy and education about the beauty and the necessity of organ donation. (Recipient 146).

3.2.3. Pre-donation content shared by donors

Reasons for donating. When asked why they decided to donate, donor storytellers expressed multiple reasons to donate a kidney. Most donors felt that their choice would help improve someone’s quality of life, with one saying, “He was in really bad shape and actually continues to struggle but the kids have been able to get him up a little bit more and having him around so that makes it all worth it” (Donor 75). After learning of a recipient’s need for a kidney, donors also spoke about how they were compelled to help avoid or lessen their struggle, the influence of their beliefs and spiritual ties on their decision, and how prior experiences with kidney disease motivated them to donate.

Family member’s reactions to storyteller’s decision to donate. When prompted to talk about what their family members worried about, most donors talked about having supportive family members, even if they had initial concerns about the donor’s safety during the process. Donors discussed educating their family members to quell donation fears. Other donors mentioned having family support for their decision and not needing to get approval. One said, “My immediate family was very supportive; it was mainly my wife that I spoke of initially as I considered donating. I would say as a whole they were supportive” (Donor 78).

3.2.3.1. Fears and challenges donors faced. When asked about moments that were scary or difficult, many donors shared about the possibility of being rejected during evaluation and fear of an invasive surgery. One recalled, “The only time it got harder and scarier for me was when I thought that I might be rejected as a donor, there was some question about one of my kidneys not being suitable” (Donor 79). Some fears stemmed from their lack of knowledge of the transplant process: “I did have fears and questions about the process... What are the odds that the surgery will work and that my dad’s body will accept my kidney?” (Donor 42).

3.2.4. Post-donation content shared by donors

3.2.4.1. No regrets from donating. When prompted to share about regrets they may have, several donors claimed they had no regrets other than not being able to donate again. One claimed, “Would I do it again? In a heartbeat. Any regrets? I do have one regret; I didn’t have three kidneys... I would give another one if I had three” (Donor 75). Others emphasized that donating a kidney was minimally impactful when compared to the experiences of recipients pre- and post-transplant.

Table 3
Living Donors' Pre- and Post-Donation Experiences.

Common themes pre-donation	
<p>"I ultimately decided to donate a kidney because..." Theme: Donation influenced by religion</p>	<p>"It's like God whispered in my ear he said you need to do more... I was reminded that I'm part of God's family I decided my mission was going to be able to donate a kidney" Donor 14</p>
<p>Theme: Donation influenced by prior knowledge of kidney disease/transplant</p>	<p>"I'm actually a member of a transplant team... And I truly believe in the importance of transplantation and registered as a deceased donor... I have seen the transformation that occurs when people move from being a place of terrible sickness to health again, and from feeling hopeless to feeling hopeful and excited about the future." Donor 125</p>
<p>Theme: Donated to save a loved one's life</p>	<p>"[My dad] needed one and I had to. It was really that simple and you know in the case of our relationship he's given so much to me to help me be Who I am and live the life that I do today it was really just a no-brainer to be able to pay back and give him back his ability to live a full and healthy life" Donor 48</p>
<p>"My family (children, spouse) worried..." Theme: Donor's family was concerned about the donor being harmed</p>	<p>"There was nothing I wouldn't do to save my daughter's life." Donor 89</p> <p>"Because they couldn't really comprehend why I would elect to have surgery for no reason. And especially because it wasn't particularly helping anybody that they knew. I couldn't even meet my recipient until after surgery. So it was something that they couldn't really understand. But I helped them to understand that it was very important to me." Donor 103</p>
<p>"It got harder or scary for me when..." Theme: Fears and challenges donors experienced during the evaluation process</p>	<p>"I learned about the evaluation and surgery process. I wanted to make sure that my parents my husband and my children were well informed and well educated about the process that they knew what to expect and that they were reassured that there would be as minimal a risk to my health and safety." Donor 15</p> <p>"I found out I was rejected as a kidney donor due to some pre-diabetic conditions that I didn't know. I went back to get retested and he said no you've been rejected so another month went by. This time, I was approved so you can improve your health in certain conditions to become a donor and improve your own life while you're doing it." Donor 76</p>
Common themes post-donation	
<p>"The only thing I regret is..." Theme: Donors don't regret their decision and would donate again if they could</p>	<p>"I don't have another kidney to give. It's been six years and I'm doing wonderful." Donor 84</p>
<p>"Looking back, the best part about donating a kidney was..." Theme: Donors feel happiness for changing a patient's life</p>	<p>"The cool feeling of being able to do this. Helping somebody in this fashion it's truly amazing. It's awesome, it makes you feel really good" Donor 101</p>
<p>Theme: Donors become more altruistic after donation</p>	<p>"I have become much more involved in volunteerism since I donated and I think that the donation has had a lot to do with that. I have become a platelet donor through the American Red Cross regularly, because I feel that that's also another way to be giving you know in a physical way." Donor 79</p>
<p>Theme: Donors taking better care of their own health</p>	<p>"My appreciation for how precious health and life really is. And it's not that I haven't been through my own hardships before. And certainly, after all these years of working in transplant, I have such sympathy for people who are really struggling to live and who have poor quality of life. This has enhanced it even more where I feel like I think so much more about how can I nourish myself? What can I do to take care of myself? How can I treat myself right?" Donor 125</p> <p>"My health getting better just because I'm more aware and I'm more conscious of, you know, what I did, and only having one kidney. But other than that, everything is 100% back to normal." Donor 98</p>
<p>"My recovery was..." Theme: Recovery challenges for donors</p>	<p>"Probably the hardest [after the surgery when I came home]. Coming home and not having anyone like you, I guess is the issue. Not having a network so much so created where you can connect with people who are like you very easily." Donor 36</p>
<p>Theme: Recovery was easy for donors</p>	<p>"Not exactly what I was expecting, but I think it was pretty normal. My first week I was in a lot of pain and discomfort and just really couldn't move, but by the following week, I was feeling somewhat normal and able to move a little bit more. And in the next few following weeks I was basically back to my normal self, and in the next few following months, it was like I didn't even have surgery." Donor 187</p>
<p>"The best moment after my surgery was..." Theme: Donors enjoyed seeing their recipient's health improving</p>	<p>"Walking into my recipient's hospital room and getting to see her, knowing that my kidney was in her body and it was working... She was going to be all right." (Donor 79)</p> <p>"Seeing [my recipient] for the first time and it was awesome. It looked like he had been to the beach. His color had returned. He was so happy; he was so excited. He looked great... I thought was really cool and it was just really powerful. It was a powerful moment to see somebody go from so sick to looking so much better in such a short period of time. I wasn't expecting that." Donor 62</p> <p>"Finding out that the kidney was doing great. That on the operating room table, it started functioning right away. And that all the doctors were so excited about it. And Liam's parents are so happy, so that made me relieved and made anything that physically I was feeling uncomfortable about better." Donor 126</p>

What donors gain from donating. When asked about the best part about donating, donors listed several benefits they gained from their experience. Donors commonly discussed how their altruism and charitable acts have extended beyond kidney donation. One said, "I have become more involved in volunteerism since I donated... I don't know that I would've become so involved if it hadn't been for the kidney donation" (Donor 79). Another major benefit donors experienced was becoming more mindful of their own health. One recalled, "I've lost weight since the operation and I exercise more and I'm much more conscious of the foods that I eat" (Donor 108).

Recovery experiences. When prompted to talk about their recovery process, some donors highlighted how they felt back to their normal self within a couple of months. Conversely, some donors experienced difficulties

during recovery. One donor was hesitant to be entirely candid with recovery pains: "What surprised me most, and I probably shouldn't tell you this, but I'm going to tell you, was how much the incision hurt like afterwards" (Donor 34). However, some donors were more willing to share unique struggles they faced during recovery. "My first 24 hours were really rough, if I'm to be completely transparent, the anesthesia hit my body hard... this isn't something that I hear many donors who have experience this" (Donor 86). Many donors were detailed in their narratives, recalling the amount of time it took to feel normal again and their emotional and physical hardships.

Seeing their recipient healthier. When asked about the best moment after their surgery, many donors elaborated on how it felt seeing or finding out their recipient's health was rapidly improving. One recalled, "The best

moment after surgery was when I woke up and I heard that my kidney was working in somebody else's body. I hadn't cried until then and then I just lost it" (Donor 75).

3.3. Emotions of storytellers

Emotions expressed at varying points throughout the living donation process were coded to understand the average storyteller's emotional changes and compare and contrast differences between donors and recipients. Living donors most commonly expressed happiness (85.0%) and relief (29.3%) after surgery and when they first matched their recipient (happiness: 48.8%; relief: 22%; Fig. 1). They were most likely to report negative emotions when they first learned someone needed a transplant (Sadness: 49%) and right before surgery (Fear: 12.0%). At many stages of their journey, donors were more likely to report feeling hopeful than did recipients. Recipients reported being fearful when they first learned they needed a transplant (33.3%), after they found a matching donor (13.9%), and before surgery (19.4%). They most commonly reported having anxiety right before surgery (30.6%). Recipients mentioned happiness (50.0%) and relief (47.2%) when they found a matching donor, as well as post-surgery.

4. Discussion and conclusion

4.1. Discussion

This study provided a rare opportunity to examine the organic content being shared on a digital storytelling platform by recipients and donors of LDKT to contribute to others' considerations. Storytellers were honest and vulnerable, sharing their challenges with seeking and providing organ donation and the emotional rollercoaster involved. At the end of their living donation journeys, the majority of recipients and donors spoke of the benefits they had received and the happiness and relief that were now present.

Most storytellers encouraged other kidney patients and potential donors to participate in LDKT by sharing the physical and psychosocial improvements to their lives post-surgery, with benefits such as being more

appreciative of their health, feeling pride in helping another person, or gratitude for getting to live a longer life. Our results, which show that storytellers are advocates for LDKT, align with other published research on storytelling for health promotion, which found that storytelling is useful to build social connections among people sharing a similar experience [10], and advocate for a cause [21].

As stated by Fitzgerald et al. [22], one of the core elements of stories is the emotional response they evoke in viewers and listeners, which may increase their effectiveness at motivating someone to take action, especially when there is a change in emotional flow [22]. Emotions expressed by recipients and donors ranged from fear and sadness to relief and hope. By being candid about the emotional hardships they experienced while pursuing living donation, storytellers were able to show how their lives and emotional wellbeing improved along the course of their LDKT journey. The content in these LDKT stories revealed common challenges early on, but mostly ended positively, which may be reassuring for those hesitant about LDKT.

By increasing interest in LDKT earlier, patients and potential donors have time to consider their options, make informed health decisions, and actively participate in their own health [23]. As we consider how to utilize stories optimally in health education settings, being sensitive to how storytellers deliver their messages and what they specifically discuss is critical for framing stories to best fit the educational or advocational space. Due to the lack of focus on concrete facts and statistics shared through stories, these shared personal experiences cannot replace traditional LDKT education. Instead, digital stories may be best utilized as a complementary educational and support tool to explain the nuances of real transplant journeys that traditional education delivered by a provider in a clinical setting may not be able to provide.

There are several limitations to this study. First, stories were qualitatively analyzed for themes in response to prompts previously deemed to be educationally important by the research team. Additional examination of other prompts should continue. However, any prompts provided are only meant to guide the storyteller in beginning to share, with stories still posted if prompts are not followed. There is also a possible bias in storytellers willing to upload stories to a public platform; for example, people who have had

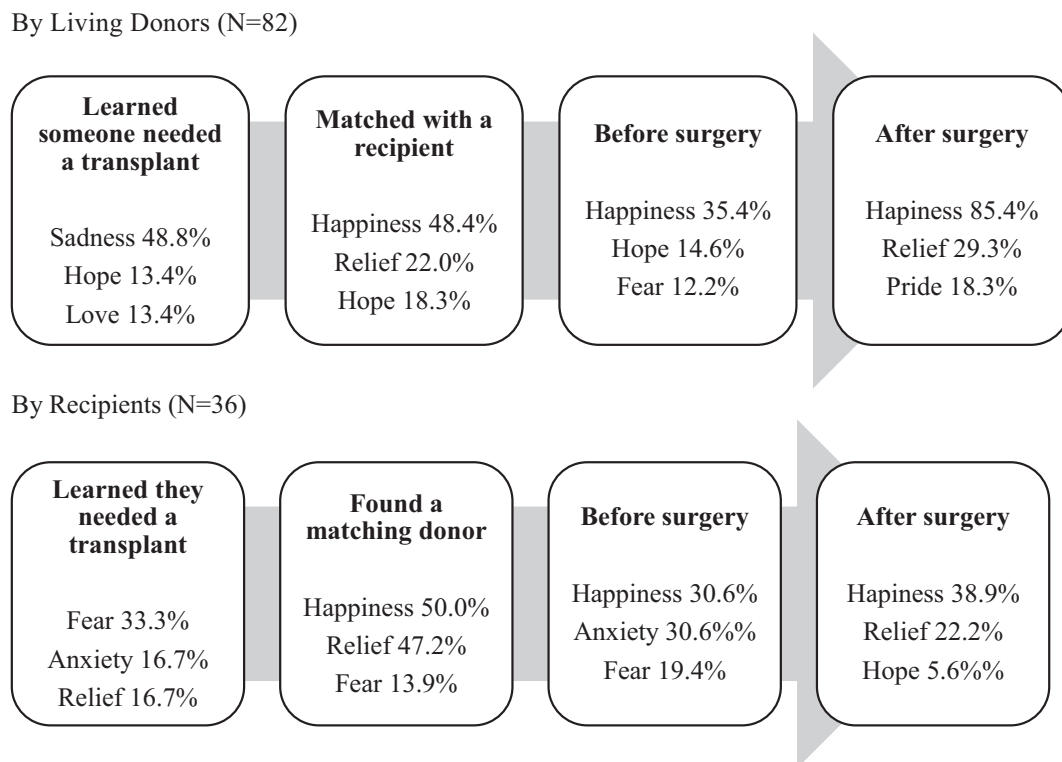


Fig. 1. Emotional changes experienced across the donation and transplant process.

profoundly positive experiences or others encouraging others to pursue LDKT may be more motivated to share and people who have had negative experiences may not feel comfortable sharing, or do not want to speak negatively about LDKT to discourage others. Storytellers were also predominantly female, white, and college-educated; future research should capture more stories in multiple languages and from diverse ethnic and racial groups to expand the generalizability of these findings [17].

4.2. Innovation

The results of this study show many opportunities for innovation and advancement in exploring FPS and a health resource tool. As demonstrated by the SNC theory, storytelling and narratives about personal experiences can be used to promote health behavior change among racial and ethnic minority groups [17]. As the Living Donation Storytelling Project Library expands to encompass a more diverse pool of storytellers to adequately reflect the diversity of LDKT recipients and donors, further research on differences in experiences between ethnic and racial minorities and White storytellers will undoubtedly be necessary. This may be particularly crucial for the nephrology field, as Black patients comprise 29% of the waitlist, but less than 14% receive a LDKT [4], and in 2019, only 5% of Latinx patients on the waitlist received a LDKT [5].

Further research may also be done on emotionality of storytellers. This study did not examine implicit emotional responses, as the research team only analyzed transcripts, but research on nonverbally expressed emotions in video stories may benefit the field of utilizing storytelling in healthcare [24]. Additionally, research that focuses on the reception of emotional changes throughout the journey by the viewer and how emotionality affects decision-making may also be explored. Since this study found that storytellers post their stories on a public forum to advocate for more people becoming living donors, the border between education and advocacy needs to be explored and clearly defined so that future education-based innovations can ethically fill the detected gaps. Studies introducing storytelling in multiple languages early in the LDKT education process should occur to assess whether patients or donors initially unreceptive to the idea of LDKT or those experiencing linguistic or cultural barriers to LDKT might be impacted. Also, additional research is needed to learn how emotions affect the receptiveness of the messages of these stories.

Aside from expanded research opportunities, the creation of a publicly available collection of video stories has several potential benefits for the LDKT community. Firstly, this is a method of community-building, where people who share a similar experience can meet and create a network of advocates with the same goal of promoting and spreading awareness about LDKT. This may encourage others to add their stories as well, thus expanding the library and offering the chance for higher engagement from the public and inclusion of more diverse stories. Additionally, storytelling can dispel common health myths [25], indicating that storytellers may be able to provide guidance to those with preconceived notions about LDKT.

Finally, storytelling can be a method of experiential learning for people new to LDKT. Experiential learning, as defined by Falloon and based off of Kolb's Experiential Learning theoretical model, is the process of learning through actions such as interacting with an experience, making observations of an experience, conceptualizing an experience, and experimenting and simulating the experience [26]. Studies have found that experiential learning is particularly impactful in resource-scarce settings and that the participatory-based nature of the method is beneficial for establishing community research partnerships [27]. This is promising for the future of the development of storytelling as a health resource tool, as this further shows the ability of storytelling to reduce barriers in information accessibility, thus helping more kidney patients and donors join the LDKT community and reducing the organ shortage.

4.3. Conclusion

If the use of storytelling can be optimized, this resource can help to ensure that more patients have equal access to LDKT resources, decrease

ESKD-associated mortality rates, help patients succeed with the processes and regimens required to have a long-lasting transplant, and initiate a larger movement for patient-centered interventions. Digital storytelling is an important experiential learning resource that can supplement traditional education, provide a personal touch that helps patients connect with the material they are learning, and help them feel less intimidated about an uncomfortable, lengthy, and invasive medical process that can ultimately save their lives. Stories can supplement traditional education and be incorporated into advocacy efforts, with campaigns capitalizing upon the personal aspect of stories to gently introduce LDKT to the general public and encourage more to explore the possibility of living donation. Further research is needed to understand the full potential of storytelling as a health resource tool.

Funding

Grant funding for this study was provided by One Lambda, Inc., and the Health Resources and Services Administration [grant number 5R39OT31888-03-00].

Declaration of Competing Interest

None.

Acknowledgements

We acknowledge Mindy Kim for contributing to literature searches, and Emily H. Wood, MPH and Rachyl Pines, PhD for participating in the preliminary formation of this study. We also thank Jacob M. Kolman, MA, ISMPP CMPP™, of the Houston Methodist Center for Outcomes Research for language and format editing.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2022.100023>.

References

- [1] Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, et al. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. *Am J Transplant*. 2011;11:2093–109. <https://doi.org/10.1111/j.1600-6143.2011.03686.x>.
- [2] United States Renal Data System. 2020 annual data report: epidemiology of kidney disease in the United States. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2020. <https://adr.usrds.org/2020/> (accessed December 16, 2021).
- [3] Deshpande PP, Jariwala S, Martin L, Golestaneh L. Impact of technology-based interventions on linking potential kidney donors and transplant candidates: a scoping review. *Transpl Int*. 2021;34:2781–93. <https://doi.org/10.1111/tri.14136>.
- [4] King EA, Ruck JM, Garonzik-Wang J, Bowring MG, Kumar K, Purnell T, et al. Addressing racial disparities in live donor kidney transplantation through education and advocacy training. *Transplant Direct*. 2020;6:e593. <https://doi.org/10.1097/TXD.0000000000001041>.
- [5] Gordon EJ, Romo E, Amorégui D, Rodas A, Anderson N, Uriarte J, et al. Implementing culturally competent transplant care and implications for reducing health disparities: a prospective qualitative study. *Health Expect*. 2020;23:1450–65. <https://doi.org/10.1111/hex.13124>.
- [6] King A, Lopez FY, Lissanu L, Robinson E, Almazan E, Metoyer G, et al. Renal replacement knowledge and preferences for African Americans with chronic kidney disease. *J Ren Care*. 2020;46:151–60. <https://doi.org/10.1111/jorc.12312>.
- [7] Zhou EP, Kiwanuka E, Morrissey PE. Online patient resources for deceased donor and live donor kidney recipients: a comparative analysis of readability. *Clin Kidney J*. 2018;11:559–63. <https://doi.org/10.1093/ckj/sfx129>.
- [8] Patzer RE, McPherson L, Redmond N, DuBay D, Zayas C, Hartmann E, et al. A culturally sensitive web-based intervention to improve living donor kidney transplant among African Americans. *Kidney Int Rep*. 2019;4:1285–95. <https://doi.org/10.1016/j.ekir.2019.05.771>.
- [9] McQueen A, Kreuter MW, Kalesan B, Alcaraz KI. Understanding narrative effects: the impact of breast cancer survivor stories on message processing, attitudes, and beliefs among African American women. *Health Psychol*. 2011;30:674–82. <https://doi.org/10.1037/a0025395>.
- [10] Briant KJ, Halter A, Marchello N, Escareño M, Thompson B. The power of digital storytelling as a culturally relevant health promotion tool. *Health Promot Pract*. 2016;17:793–801. <https://doi.org/10.1177/1524839916658023>.

- [11] Lipsey AF, Waterman AD, Wood EH, Balliet W. Evaluation of first-person storytelling on changing health-related attitudes, knowledge, behaviors, and outcomes: a scoping review. *Patient Educ Couns.* 2020;103:1922–34. <https://doi.org/10.1016/j.pec.2020.04.014>.
- [12] Nguyen HL, Ha DA, Goldberg RJ, Kiefe CI, Chiriboga G, Ly HN, et al. Culturally adaptive storytelling intervention versus didactic intervention to improve hypertension control in Vietnam- 12 month follow up results: A cluster randomized controlled feasibility trial. *PLoS One.* 2018;13:e0209912. <https://doi.org/10.1371/journal.pone.0209912>.
- [13] Adebayo AL, Davidson Mhonde R, DeNicola N, Maibach E. The effectiveness of narrative versus didactic information formats on pregnant women's knowledge, risk perception, self-efficacy, and information seeking related to climate change health risks. *Int J Environ Res Public Health.* 2020;17:6969. <https://doi.org/10.3390/ijerph17196969>.
- [14] Chiong-Rivero H, Robers M, Martinez A, Manrique CP, Diaz A, Polito K, et al. ARHMS investigators, Effectiveness of film as a health communication tool to improve perceptions and attitudes in multiple sclerosis. *Mult Scler J Exp Transl Clin.* 2021;7. <https://doi.org/10.1177/2055217321995947>.
- [15] Bertera EM. Storytelling slide shows to improve diabetes and high blood pressure knowledge and self-efficacy: three-year results among community dwelling older African Americans. *Educ Gerontol.* 2014;40:785–800. <https://doi.org/10.1080/03601277.2014.894381>.
- [16] Gubrium A. Digital storytelling: an emergent method for health promotion research and practice. *Health Promot Pract.* 2009;10:186–91. <https://doi.org/10.1177/1524839909332600>.
- [17] Lee H, Fawcett J, DeMarco R. Storytelling/narrative theory to address health communication with minority populations. *Appl Nurs Res.* 2016;30:58–60. <https://doi.org/10.1016/j.apnr.2015.09.004>.
- [18] Prins E. Digital storytelling in adult education and family literacy: a case study from rural Ireland. *Learn Media Technol.* 2017;42:308–23. <https://doi.org/10.1080/17439884.2016.1154075>.
- [19] Cueva M, Kuhnley R, Revels L, Schoenberg NE, Dignan M. Digital storytelling: a tool for health promotion and cancer awareness in rural Alaskan communities. *Int J Circumpolar Health.* 2015;74:28781. <https://doi.org/10.3402/ijch.v74.28781>.
- [20] Waterman A. Explore Living Donation - The Living Donation Storytelling Project. <https://explorelivingdonation.org/>; 2022. (accessed January 26, 2022).
- [21] D'Cruz K, Douglas J, Serry T. Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. *Neuropsychol Rehabil.* 2020;30:1409–29. <https://doi.org/10.1080/09602011.2019.1586733>.
- [22] Fitzgerald K, Paravati E, Green MC, Moore MM, Qian JL. Restorative narratives for health promotion. *Health Commun.* 2020;35:356–63. <https://doi.org/10.1080/10410236.2018.1563032>.
- [23] Waterman AD, Lipsey AF, Ranasinghe ON, Wood EH, Anderson C, Bozzolo C, et al. Recommendations for systematizing transplant education within a care delivery system for patients with chronic kidney disease stages 3 to 5. *Prog Transplant.* 2020;30:76–87. <https://doi.org/10.1177/1526924820913520>.
- [24] Siena FL, Vernon M, Watts P, Byrom B, Crundall D, Breedon P. Proof-of-concept study: a mobile application to derive clinical outcome measures from expression and speech for mental health status evaluation. *J Med Syst.* 2020;44:209. <https://doi.org/10.1007/s10916-020-01671-x>.
- [25] Soderlund PD, Martinez Hollingsworth AS, Heilemann MV. Participant engagement in a transmedia storytelling web-based app intervention for mental health of Latina women: qualitative analysis. *JMIR Ment Health.* 2021;8:e22575. <https://doi.org/10.2196/22575>.
- [26] Falloon G. Using simulations to teach young students science concepts: an experiential learning theoretical analysis. *Comput Educ.* 2019;135:138–59. <https://doi.org/10.1016/j.compedu.2019.03.001>.
- [27] Chamane N, Kuupiel D, Mashamba-Thompson TP. Experiential learning for primary healthcare workers in low- and middle-income countries: a scoping review protocol. *Syst Rev.* 2019;8:123. <https://doi.org/10.1186/s13643-019-1040-6>.