INTRODUCTION

Although kidney transplantation offers a superior prognosis for most patients who have kidney failure, the complex self-management regimen and life-long follow-up required to maintain optimal health and well-being remain challenging.1-4 eHealth is a valuable tool to support self-management for transplant recipients.5-8 eHealth can be defined as information and communication technology for health and health-related activities, mainly referring to health intellectual content; and provided final approval of the version to be published. All authors had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis. The data that support the findings of this study are available from the corresponding author upon reasonable request.

Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal’s Web site (www.transplantationdirect.com). Correspondence: James Tang, FRACP, Centre for Kidney Research, The Children’s Hospital at Westmead, Westmead, NSW 2145, Australia. (james.tang@health.nsw.gov.au).

Copyright © 2022 The Author(s). Transplantation Direct. Published by Wolters Kluwer Health, Inc. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

ISSN: 2373-8731
DOI: 10.1097/TXD.0000000000001404

James Tang, FRACP,1,2 Martin Howell, PhD,1,2 Simon Roger, MD,3 Germaine Wong, FRACP, PhD,1,2,4 and Allison Tong, PhD1,2

Perspectives of Kidney Transplant Recipients on eHealth: Semistructured Interviews

James Tang, FRACP,1,2 Martin Howell, PhD,1,2 Simon Roger, MD,3 Germaine Wong, FRACP, PhD,1,2,4 and Allison Tong, PhD1,2

Background. The acceptability and impact of eHealth on patient outcomes may be limited if their concerns and priorities are not addressed. This study aimed to describe the perspectives and experiences of eHealth among kidney transplant recipients. Methods. Face-to-face semistructured interviews were conducted with 30 adult kidney transplant recipients from New South Wales, Australia (urban and regional), in ambulatory clinics. We used purposive sampling to obtain a wide range of demographic and clinical characteristics. Transcripts were analyzed thematically. Ethics was approved by the Western Sydney Local Health District (6054-2019/ETH08718). Findings. Six themes were identified: seeking access to quality care (prioritizing and trusting clinician advice, better safety and timeliness, enabled by user-friendly content); supporting self-management (responsive to individualized informational need, empowerment through practical knowledge, encouraging connectedness); assessing reliability and trustworthiness (discerning information integrity, applying to own context, apprehensive about privacy and confidentiality); enhancing health system capabilities (synergy with routine consultations, essential to coordination, achieving goals by real-time monitoring); technology burden and limitation (uncertainty with navigation and comprehension, challenged by technical difficulties, requiring additional preparation, confrontation and distress); and lacking applicable value (diminished assurance of medical services, existing practice and procedures, hampered by low expectations and disininterest). Conclusion. Recipients felt eHealth could support healthcare delivery and self-management activities. However, they encountered challenges in navigating technology and were concerned about privacy, confidentiality, and misinformation. eHealth that is accessible, individualized, and secure may improve patient satisfaction and outcomes.

(Transplantation Direct 2022;8: e1404; doi: 10.1097/TXD.0000000000001404)
services and information delivery through the Internet and related technologies. During the COVID-19 pandemic, there has been a rapid growth of eHealth to minimize the risk of infectious exposure associated with in-person consultation. This is particularly relevant for kidney transplant recipients, who are at a much higher risk of infection from their immunosuppressed state with significant mortality and complication rates. Novel approaches to practice, including alternatives to face-to-face health delivery, may help to minimize such risks.

Prior studies have shown that digital technology can be leveraged to empower patients, promote self-management, and improve clinical outcomes. Patients with chronic kidney disease were found to have high user acceptability and satisfaction for eHealth self-management interventions, particularly when supported by clinicians. Although COVID-19 has seen a 22% to 35% increase in telehealth use in high-income countries, barriers to uptake remain, including technical difficulties, low expectations of eHealth among patients and clinicians, and privacy and confidentiality concerns. Little is known about the perspectives of kidney transplant recipients on eHealth. This study aims to describe the expectations, attitudes, and perspectives of kidney transplant recipients on eHealth.

MATERIALS AND METHODS

This study reporting is based on the Consolidated Criteria for Reporting Qualitative Health Research.

Participant Selection

English-speaking kidney transplant recipients aged 18 y and older were eligible to participate. Participants were excluded if they had cognitive impairment or deemed medically unsuitable by their treating nephrologist and unable to provide written informed consent. Participants were recruited from 2 local area health districts in New South Wales, Australia (Western Sydney and Central Coast), in ambulatory clinics urban and regional whereby their respective clinicians identified the participants. We used purposive sampling to obtain a wide range of participants, aged 58 and 72 y, 2 female participants, aged 58 and 72 y, and incorporated their feedback. Based on their recommendation, we also included the pictorial information sheet with examples, allowing the participants to better understand the discussion surrounding eHealth and digital interventions. Investigator JT conducted face-to-face semi-structured interviews from August 2019 to August 2020 until data saturation (when no new concepts were obtained from subsequent interviews). All interviews were conducted in English, audio-recorded, and transcribed.

Data Analysis

We drew from the principles of grounded theory to conduct this study. Thematic analysis was used to generate findings that address questions about participants’ perspectives and experiences on eHealth. This method involves inductively identifying, examining, coding, comparing, and grouping concepts within and across transcripts to develop descriptive and analytical themes. The transcripts were imported into HyperRESEARCH (Version 2.8.3; ResearchWare Inc) for coding the textual data.

To allow generation of analytical higher-order themes, JT read each transcript line-by-line and conceptualized and coded the data according to inductively identified concepts. Similar concepts were grouped into preliminary themes and subthemes on perspective, attitudes, and experiences of eHealth interventions in transplant care. The authors reviewed the preliminary coding structure (AT, MH, and GW) to enhance the analytic framework to ensure it captured the full breadth and depth of data collected (investigator triangulation). We identified and discussed conceptual patterns and relationships among the themes and developed an overarching thematic schema. Preliminary findings were sent to participants for feedback (member-checking). The themes were cross-tabulated to the pertinent digital health tools.

RESULTS

Participant Characteristics

Of the 32 transplant recipients invited to participate, 30 (94%) agreed to be interviewed. Five participants were interviewed with the support of their caregivers. Participant characteristics are shown in Table 1. Participants were 22 to 77 y of age (median 52 y), 15 (50%) were male, and the time since transplant ranged from 2 wks to 29 y (median 1.38 y). The majority of participants were current eHealth users (90%). The average duration of the interview was 47 min.

Themes

Six themes were identified: seeking access to quality care, supporting self-management, assessing reliability and trustworthiness, enhancing health system capabilities, technology burden and limitation, and lacking applicable value.
The themes and subthemes are described below. A selection of quotations for each subtheme is provided in Table 2. The patterns and relationships among themes are shown in the thematic schema (Figure 1). In addition, a cross-tabulation of themes with eHealth modalities (eg, telehealth, websites, mHealth) is presented in Figure 2.

### Seeking Access to Quality Care

**Prioritizing and Trusting Clinician Advice**

Participants prioritized and trusted their clinicians’ advice regarding websites and mobile applications (apps) for their transplant health. They sought guidance and clarification from their clinicians when searching for online information “if I’m not 100% sure, I’ll ask the doctor.” Others relied on their clinicians and avoided other sources for accessing transplant-related health data.

### Better Safety and Timeliness

Participants believed using eHealth, such as telehealth consultations and smartphone apps, to order medication or book clinician appointments online, may improve the efficiency in accessing care. Telehealth also reduced their exposure to health risks in hospitals and clinics, such as hospital-acquired infections and alleviated patients’ concerns as the community and health providers tackled the COVID-19 pandemic. For participants, websites provided instant access to health information, rather than paper-based booklets, as “nobody keeps the brochures or like they are going to keep for 1 mo or 2 mo and chuck it away.”

### Enabled by User-friendly Content

Digital technologies such as telehealth, apps, and websites (with medical information) presented in a simple format and layout were appealing to the participants. They preferred the content to be delivered in plain language with less “doctor words.” For example, they selected and chose the relevant content to be delivered in plain language with less “doctor words.” They also favored the apps that integrated the technologies they were already familiar with, such as health reminders within their pre-existing calendars on their smartphone devices as “it’s with you all the time.”

### Supporting Self-management

**Responsive to Individualized Informational Need**

Participants were motivated to use eHealth that incorporated personalized information that “can be tailored to the person” as “everybody is different...a case by case basis.” When faced with difficulties, “Googling” was a familiar way to find the answers, whereas some found access to other common languages helpful as it has diversified the reach to patient groups of different cultural and ethnic backgrounds. Some participants were active users of social media, but others were passive observers or preferred to read the posts of others that shared transplant specific health information.

### Empowerment Through Practical Knowledge

Participants felt more confident and mentally prepared to learn from websites containing information directly related to managing their transplant, such as medications, side effects, and dietary advice. They believed the Internet is a network of interconnected information “like having a massive

### Table 1

Participant characteristics (n = 30)

| Characteristic                              | n (%) |
|--------------------------------------------|-------|
| Age, y                                      |       |
| 18–44                                      | 10 (33) |
| 45–65                                      | 13 (43) |
| >65                                        | 7 (23)  |
| Sex (female)                               |       |
| Working (full-time, part-time)             | 11 (37) |
| Not working                                | 19 (63) |
| Marital status                             |       |
| Married or in a de facto relationship      | 24 (80) |
| Divorced/widowed/single                     | 6 (20)  |
| Highest level of education                 |       |
| Primary school                             | 1 (3)  |
| Secondary (high) school/professional degree| 22 (73) |
| (eg, diploma)                              |       |
| Tertiary—university degree                 | 7 (23)  |
| Ethnicity                                  |       |
| White                                      | 19 (63) |
| Indian                                     | 6 (20)  |
| Asian                                      | 2 (7)   |
| Other*                                     | 3 (9)   |
| English as a first language                |       |
| 18–60                                      | 18 (60) |
| Place of residence (urban)                 | 23 (77) |
| Donor type                                 |       |
| Deceased                                   | 17 (57) |
| Living (related/unrelated)                 | 13 (43) |
| Duration of transplant (mo)                |       |
| <6                                         | 7 (23)  |
| 6–12                                       | 7 (23)  |
| >12                                        | 16 (53) |
| Previous rejection                         | 11 (37) |
| Previous transplant                        | 2 (6)   |
| Previous RRT                              |       |
| HD                                         | 25 (83) |
| PD                                         | 15 (50) |
| CKD diagnosis or cause                     |       |
| Diabetes                                   | 10 (33) |
| Glomerulonephritis                         | 9 (30)  |
| Hypertension                               | 4 (13)  |
| Other*                                     | 9 (30)  |
| Medications including immunosuppressant (total daily number) | 10.3 |
| Current use of eHealth                     |       |
| Smartphone                                 | 27 (90) |
| Desktop/laptop                             | 26 (87) |
| IoT                                       | 25 (83) |
| Tablet                                    | 8 (27)  |
| Function of eHealth use                    |       |
| Websites                                   | 25 (83) |
| Apps                                       | 16 (53) |
| Reminders                                  | 15 (50) |
| Social media/forums                        | 12 (40) |
| Telehealth                                 | 12 (40) |
| Texting                                    | 7 (23)  |
| Email                                      | 7 (23)  |

*May not total 100 due to rounding.
Numbers may not total due to multiple categories or categories are not applicable to all participants.
*Other: Chilean n = 1 (3), Turkish n = 1 (3), Pacific Islander n = 1 (3).
*Other: polycystic kidney disease n = 4 (13), congenital anomalies of the kidney and urinary tract n = 2 (7), interstitial nephritis n = 2 (7), atypical hemolytic uremic syndrome n = 1 (3).
IoT, Internet-connected device.
| Theme                                      | Selected illustrative quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|-------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| **Seeking access to quality care**        | “Probably through their doctors, if the doctors approved or Kidney Health [Australia] approved. If you give them a little flyer of the thing you can post, have a look at more information and go there wwwID04                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I’ll take the doctor’s advice at the end of the day. I believe the doctor over technology; they are specialized in their field. You have to put your trust in them.” ID15                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I’m not going to Do Google, I’m sure things are far more accurate now, but if I want an answer to something, I go to the expert.” ID29                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| **Prioritizing and trusting clinician advice** | “If you give them a little flyer of the thing you can post, have a look at more information and go there wwwID04                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|                                           | “I’ll take the doctor’s advice at the end of the day. I believe the doctor over technology; they are specialized in their field. You have to put your trust in them.” ID15                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I’m not going to Do Google, I’m sure things are far more accurate now, but if I want an answer to something, I go to the expert.” ID29                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| **Better safety and timeliness**          | “Probably through their doctors, if the doctors approved or Kidney Health [Australia] approved. If you give them a little flyer of the thing you can post, have a look at more information and go there wwwID04                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I’ll take the doctor’s advice at the end of the day. I believe the doctor over technology; they are specialized in their field. You have to put your trust in them.” ID15                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I’m not going to Do Google, I’m sure things are far more accurate now, but if I want an answer to something, I go to the expert.” ID29                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
| **Enabled by user-friendly content**      | “Better safety and timeliness “It’s [eHealth] pretty convenient… not like the old fashion encyclopedias. It’s something that the latest news items should always be up to date, if it’s relevant and gives you a bit of an idea what’s happening in the world in that area.” ID04                                                                                                                                                                                                                                                                                                                                 |
|                                           | “He said we’ve got a new app… it really was so much easier. It made my life, my wife’s life, cause it was hell before that because, you drive all the way… to get one packet, one small packet of tablets. It was a nightmare.” ID05                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I prefer [eHealth], I’m so scared of COVID. I don’t want to get sick, so I’m happy to do the online, video calls and things like that.” ID15                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|                                           | “We’re going to do the consultation over the phone… you don’t have to go and drive to your appointment, sit and wait. Generally your doctor will be late, its just nature of the beast, drive home and you lose half a day, whereas you can be doing stuff. My phone is going to ring at such and such a time.” ID17                                                                                                                                                                                                                                                                                                                                 |
| **Supporting self-management**             | “Level of language, get the language to layman’s point of view. Doctors would understand what it was and so does the person that’s reading it… [or else] they would go away from it.” ID05                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
|                                           | “He just sent us a link and then… before 11 when we do it we just dial it though. There is a link through email and click it… it’s pretty straightforward.” ID22                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|                                           | “It’s really user friendly. It’s easy to use, understand how to use it. You get the text reminders from it saying your appointment is coming up and it gives you an option to put it straight into your calendar on your phone.” ID25                                                                                                                                                                                                                                                                                                                                                                                                 |
| **Responsive to individualized informational need** | “… there is stacks of information online… it needs to be a generic sort of application, but something that can be tailored to the person. You put your parameters in there and then it helps you down the track.” ID17                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I look up my own symptoms because other people don’t get diarrhea or can handle the phosphate tablets, but you just want answers, but everybody is different and it’s a case by case basis.” ID15                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “When you go through something and you find to look up this before the transplant, that’s only since the transplant happened. It’s like, how am I going to track my pills? How am I going to do this? How am I going to do that?” ID15                                                                                                                                                                                                                                                                                                                                                                                                 |
| **Empowerment through practical knowledge** | “If I don’t understand something I find out about it. The net is like having a massive encyclopedia at just at your fingertips.” ID19                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
|                                           | “It’s broadened your knowledge… you read and you know this is for me or just read. Build up your knowledge.” ID13                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               |
|                                           | “When you get into the website like Kidney Australia and you can start looking at some recipes and healthier lifestyles, what exercises you should be doing… I find that really informative.” ID14                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “I got my friend, my very good friend Google. I get information from there when I want to know something.” ID12                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| **Encouraging connectedness**             | “Transplant support groups… you could chat about your experiences and what things to expect… the community aspect is very important and technology is great for that. It’s more about finding someone who understands, because a lot of people are tired and don’t have the energy to meet each other as they live far away from each other. Having someone that can pick up the phone and they are there in your pocket is kind of nice to know.” ID09                                                                                                                                                                                                                                                                 |
|                                           | “Doctors know this stuff, but they don’t know the pain that you’re going through… so it’s really good to hear from somebody who has experienced the pain and got through the pain, because the doctors are there to fix you up and they do an awesome job, but they don’t understand the emotional side.” ID15                                                                                                                                                                                                                                                                                                           |
|                                           | “At the moment with all the restrictions around us, you can only have one person in here at a time visiting at a time. So there are a lot of families, who want to be here for you, but they can’t, they sort feel isolated. They could access that sort of help, like an app or something on the internet as well.” ID17                                                                                                                                                                                                                                                                                                                                 |
| **Assessing reliability and trustworthiness** | “There are basically commercial sites which are looking to make money…. If there was any truth to it, yes, there are other things out there that people claim. However, there is no information to back their claims up or not enough information to back their claims up.” ID01                                                                                                                                                                                                                                                                                                                                 |
|                                           | “You’ve got to be careful because not everything is going to be true and correct. Doctor Google doesn’t know everything… these people, because most of them are not doctors so you have to be careful what you take on board.” ID04                                                                                                                                                                                                                                                                                                                                                                                                 |
|                                           | “Some based on research, like in US, have the papers and references and everything. At the end, [if] they say this is all new information and it hasn’t been approved by anything, I don’t consider that thing and just read it. But some of them [have] the research and the papers and the reference, so I just checked them and read them.” ID10                                                                                                                                                                                                                                                                                                                                 |

**continued**
| Theme                                      | Selected illustrative quotes                                                                                                                                                                                                                                                                                                                                                       |
|-------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Applying to own context                   | “Forums or any sort of online blogs or whatever, you’ve got to understand that everybody has different ideas. You’ve got to understand that some people are very negative, some people are overly positive, some are realistic and down the line.” ID17  
“Try to relate it to myself. If I can find parts of it that relate to what I’ve been through, then I’ve got a pretty good idea that what they are saying isn’t buck.” ID05  
“I filter myself with everything. I think to myself...I see it’s ok, and then after make myself decide…[or] no, this is not for me.” ID10 |
| Apprehensive about privacy and confidentiality | “I just want it to be private and confidential. When you get on the internet, I don’t like giving out my name and email addresses or anything like that.” ID05  
“Hearing about hackers and you don’t want your records and things like that when you subscribed to these sites and things. You’re putting yourself at risk and your whole medical history at risk. There are things in my medical history that I don’t want people to know.” ID15  
“There is always the threat out there that someone is going to access the information and do all of that, it’s not like I’m going to have my credit card details on this information.” ID17 |
| Enhancing health system capabilities      | “Anything to do with medication or an improvement in medication or something that you find out recently about medication and side effects that would be good thing to broadcast.” ID02  
“I think texting is quite easier. And then people can give you the answer in their time when you’re trying to get a hold of them. If it’s not urgent text, if it’s urgent, then I phone.” ID02 |
| Synergy with routine consultations        | “For me its easier, you can check your diet, you can check your things, medications, your doctor appointments its everything through the internet.” ID18  
“[App], that’s how I order my tablets and everything… you would just tap to refill, and if I want something, I just tap that there tap, then I send it to the chemist and sometimes I’ve got to wait a day or so for the Tacrolimus to come and the Myfortic.” ID05 |
| Essential to coordination                 | “One of the big things at the moment is the amount of medications...just trying to keep a track of them. And the times that you’ve got to have medications and what you’ve got to have with the medication, like do you have this one with food?...I’ve seen what people do with apps.” ID17  
“...just gives me information on what I’ve done during the day or tell me whether I’m active or less active certain days than the others. It’s an indicator of how my day is really.” ID09  
“There should be some device or something wearable or any detection [to tell you the] kidney is going down...put 3-4 [staff] there to monitor so anyone with a code number goes wrong it just beep, beep, beep red sign like that if you can click that is the problem patients are going to face straight away inform them.” ID10 |
| Technology burden and limitation          | “If I’m looking at something online and you’re talking above my IQ level, I’ll just lose interest I won’t continue, whereas you’ve got to engage the person.” ID17  
“So I think if you get that wrong, you could potentially cause yourself a lot of stress at the least. Maybe if you went to try to self-medicate or something, you can do some harm.” ID06  
“I was ordering medications online, but it’s still confusing…and then I have to look through my script. What is available? What is not available? It was a bit difficult. Then I said, no more ordering online. I will bring the script and then you just give me what I want.” ID13 |
| Uncertainty with navigation and comprehension | “A lot of the apps are not very useful. I feel too hard to use… I couldn’t get there or something. It’s got to be virtually properly debugged and all that sort of thing.” ID18  
“Fingers are too big and haven’t got the patience. I’m half blind. I want an eight, I’ll end up with some other number or some other word.” ID16  
“My biggest fear technology wise is sort of glitches of it not working. If the system goes down or something like what happens here quite often, when they’re trying to access your blood results.” ID17 |
| Challenged by technical difficulties      | “Now you’ve got to do everything online, but for the elderly people, they can’t do that. They may not have a computer at home. They may not have the internet. For the elderly people or the people that don’t speak English, they don’t understand.” ID14  
“I had this with my doctor, telehealth, which was quite good, but it was the first ever so I missed most of the information because you’re not very used to it.” ID20  
“I remember once I missed the call and then I had to call back and he wasn’t ready again. So then I had to wait another 15-20 min. I just got that call, if you’re face to face you will not miss the call. The lead up to that was a bit clunky because I missed the original call…then you get moved on.” ID25 |
| Requiring additional preparation          | “I went on the Internet and I was horrified because I saw these pictures of these gross polycystic kidneys. Thousands and thousands of cysts in them. I was shocked and that was a shock. So that was getting an idea of what was happening to the kidneys.” ID04  
“People who read too much, they can get themselves into a big panic, terrible! Everyone is diagnosing themselves, it’s pretty bad really.” ID14  
“Sometimes it got a bit depressing...it was like really a bit of a mental burden as well, just like constantly getting notifications about this message and that message and someone dying. Sometimes when you’re in a difficult headspace it can be really hard to be confronted with that 24/7.” ID25 |
| Theme | Selected illustrative quotes |
|-------|-----------------------------|
| Diminished assurance of medical services | "Telehealth can’t take your blood pressure… and they can’t take a look at your wound or check you or examine you, or weigh you. Sitting down I could have gained 25 kilos, but no one would know." ID14 |
| | "There are still times when you’re going to need to see [your doctor] face to face. I think that’s still very, very important otherwise all you become is a phone number to someone… every, so many sort of visits, you actually need to go and see him so that he knows who you are and sort of all that sort of stuff. Otherwise, I think it will be start to become too impersonal." ID17 |
| | "I was actually disappointed in kidney site a few years ago. I didn’t think much of their site. I hadn’t really had a look at it lately, but I’m sure it’s improved over the years anyway." ID04 |
| Existing practice and procedures | "I take the medications right in front where I see it. My blood pressure tablet, my glucose machine, everything. My blood pressure machine. They are in front of me so I know my time." ID11 |
| | "I’ve always carried a large diary when I’ve worked. And I wrote everything down and then I got a tablet and thought it was a pain in the ass. It was quicker for me to write a note." ID22 |
| | "So when I go for a walk you don’t remember because, I don’t put usually it [wearable] on… generally like when I walk in park, that’s a walking track in a big circle, so I know roughly how much I’ll walk. I just usually do the five rounds." ID10 |
| Hampered by low expectations and disinterest | "I’m fairly basic with these things. I can take 10 min to type of text to my daughter. Then in three seconds I’ll get three pages back… I’m an old person we’re not right up with this modern day encyclopedia just at your fingertips." They were also proactive in searching pertinent health information online “you got to look it up and see it, and you got an idea of what is going on.” |
| | "There is a few people who go onto the kidney websites and Kidney Australia and look through that. I don’t particularly do that." ID02 |

**Encouraging Connectedness**

Participants used eHealth to seek support from their peers by finding like-minded interest groups who shared common transplant experiences, which was deemed particularly relevant during the COVID-19 “stay-at-home” orders and restrictions. Some formed support networks through online transplant communities, which also provided valuable information by sharing their transplant journey and health information from a group “who has been through it” and “made it [rejection] more comprehensible and a lot less terrifying.”

**Assessing Reliability and Trustworthiness**

**Discerning Information Integrity**

Participants approached online transplant information with doubt—“I just sort of didn’t take anything for real” and “would rather trust the doctor than Facebook.” Participants searched for reliable information supported by evidence from credible and trustworthy sources (eg, Mayo Clinic, National Institute of Health)—“they need to be reputable… from the kidney organization… that is legitimate because there is too much information out there.” App users also assessed user ratings to gauge the level of confidence they should place on the website and the information provided.

**Applying to Own Context**

Participants were aware that the various opinions posted on websites and social media represented diverse views and that they needed to assess the consistency, content reliability and relevance judiciously—“you have to read a couple [websites] to judge which one is better. It’s not like you can go onto one, you need to go to a couple. It’s just like you write essay with references.” Many found online information challenging to apply to their health situation and make decisions.

**Apprehensive About Privacy and Confidentiality**

Participants felt telehealth was an opportunity to support standard transplant care—“Instead of coming in here once a month, I go get the blood test and read you the results and you have a chat [over telehealth].” However, face-to-face consultation was seen as the default when vital issues were discussed, including transplant complications and changes to management. Those who used emails for nonurgent issues felt this had improved clinician workflow and the efficiency in

**Enhancing Capabilities of the Health System**

**Synergy With Routine Consultations**

Participants felt telehealth was an opportunity to support standard transplant care—“Instead of coming in here once a month, I go get the blood test and read you the results and you have a chat [over telehealth].” However, face-to-face consultation was seen as the default when vital issues were discussed, including transplant complications and changes to management. Those who used emails for nonurgent issues felt this had improved clinician workflow and the efficiency in
the delivery of care. For example, for routine blood tests “I can just email her and when she sees it she'll know I had it at 7 am rather than just having to call throughout the day I don’t know if she is busy in clinic or whatnot…it’s just more direct just as an email.” Participants believed the hospital system would best disseminate transplant education through texting and websites to reinforce their clinicians’ recommendations.

Essential to Health Coordination
Participants relied on smartphones or smartwatches to remind them of transplant-related tasks such as medication taking, supplies, and online appointment bookings. They felt this helped organize their day-to-day activities, particularly when they transitioned back into the workforce after fully recovering from the transplant surgery. For example, participants found online booking was “more convenient because…they show the doctor’s schedule and what time slots they still have available…it’s easier to relay that type of information online.”

Achieving Goals by Real-time Monitoring
Participants preferred personal tracking eHealth tools and wearables to monitor their overall health status. Some found these invaluable tools to have provided the incentives to keep up with their exercise regimens, improve sleeping patterns, and lose weight. Reaching personal goals, such as achieving daily exercise and fitness goals, motivated them to stay on track and provided a measure of how well they were doing—“I’ve got MyFitnessPal [app], so I could track because losing weight is all about calorie intake…I think it's a better tracking of what you eat.” One participant suggested that real-time monitoring of kidney function using a wearable device would help detect problems earlier and provide patients better control of their transplant health.
Technology Burden and Limitation

Uncertainty With Navigation and Comprehension
Accessing transplant specific health information websites and apps were difficult at times—“sometimes if they don’t know how to research, they don’t know what to look for.” Some found that the transplant-related websites were too generic or country specific. They were frustrated when the online information was incongruent with the information provided by their clinician and felt uninformed—“non-medical professionals on there [websites and forums] and other people giving advice and then taking that for gospel.” They indicated that it could potentially lead to harm, confusion, and undermined the patient-clinician relationship.

Challenged by Technical Difficulties
Some participants encountered difficulties in accessing and using various websites, particularly when they did not fulfill their purpose or had glitches that need to be “debugged,” such as incorrect recording of medication supplies or “couple of [app] notifications of nothing.” Other participants had issues with their Internet connection or hardware where the “connection drops out,” difficulty pairing apps and wearables, or software issues. Participants with physical disabilities and comorbidities experienced considerable problems when interacting with eHealth. In particular, older patients with poor vision preferred larger text sizes and screens. They also favored laptop keyboards rather than the smaller keypads on smartphones and tablets.

Requiring Additional Preparation
Participants believed eHealth use may impose additional resources and expenses (such as smartphones, accessories, and Internet connection) for patients and families. Some required assistance from their family members in accessing the health app and telehealth—“I have to be shown first. Show it to me and I have to have a look and see what’s good, easy to put on, easy to use.” Sometimes, telehealth consultations required extra preparation such as pre-charting of the upcoming patient visits to avoid disruption. This involved additional communication and outreach by clinical nurse practitioners or medical assistants to review and update patient information before the consultation. In some cases, patients needed to arrange remote monitoring of their vital information such as blood pressure, temperature, and heart rate in advance.

Confrontation and Distress
Some who searched online for health information felt distressed by the large quantity of information “reading too much, they can get themselves into a big panic, terrible.” Participants using social media such as Facebook or online transplant forums were taken aback by negative patient experiences—“that could be me, what if that happens to me? What if the kidney rejects. I don’t think I’ll go do dialysis again.”

Lacking Applicable Value
Participants believed eHealth use may impose additional resources and expenses (such as smartphones, accessories, and Internet connection) for patients and families. Some required assistance from their family members in accessing the health app and telehealth—“I have to be shown first. Show it to me and I have to have a look and see what’s good, easy to put on, easy to use.” Sometimes, telehealth consultations required extra preparation such as pre-charting of the upcoming patient visits to avoid disruption. This involved additional communication and outreach by clinical nurse practitioners or medical assistants to review and update patient information before the consultation. In some cases, patients needed to arrange remote monitoring of their vital information such as blood pressure, temperature, and heart rate in advance.

Existing Practice and Procedures
Participants developed certain habitual behaviors and patterns when managing their transplant health. For example, some used paper diaries/calendars; others preferred in-person visits to the pharmacy to deliver and pick up medication scripts—“I always carry a piece of paper with all the current medication and the meds I got to take. I always carry this. It’s always up to date.” Participants who were followed by their healthcare providers routinely every 3 mo or had regular outpatient visits found little benefit from personalized eHealth or telehealth.

Hampered by Low Expectations and Disinterest
Participants believed younger recipients had greater flexibility and adaptability in engaging new technology, whereas older recipients felt they were “like dinosaurs” and would find it difficult to learn the skills to adapt—“I’m not very good in technology. I’m not that fast with the younger generation.” Those who had limited health literacy and digital health literacy felt they could not keep up with technological advancements—“If the technology changes slowly, I will be together with technology. If it changes very quickly, then I will be a bit lost.” Some were unaware of eHealth use and therefore put less value and emphasis on it, as their clinician had not encouraged its use.

DISCUSSION
Kidney transplant recipients believed eHealth could support the existing healthcare system by improving accessibility to routine telehealth consultations, coordinating self-management tasks such as medication taking and appointments, and helping to achieve health goals such as exercise and weight targets. They expected that digital health technologies would further assist individualized needs, facilitate practical knowledge, and encourage discussion between patient groups through online forums. However, they also wanted reassurance in the form of endorsement from their clinician to ensure eHealth tools are trustworthy and reliable. Participants were concerned about the perceived threats to the security and privacy of patient health data, whereas some experienced technical difficulties using eHealth. Some believed that eHealth would not be useful for them as they already had well-organized routines or had low expectations of their understanding of eHealth or skills to use it.

A “digital divide” among patients based on age and socioeconomic factors such as educational attainment may affect eHealth adoption. Older participants and participants with lower eHealth literacy expressed uncertainty and reluctance to use eHealth because they were unfamiliar with the technology. Furthermore, those with limited physical abilities such as poor vision or impaired hand dexterity may experience difficulties operating eHealth devices. Long-term
transplant recipients and those with a prior transplant were less reliant on eHealth for self-management. On the contrary, participants who had greater experiences with technology (such as regular social media users) were open to using the same platform to search for health information. This helped their ability to understand their health concerns better but did not replace the in-person interaction with their clinicians. Participants favored using eHealth to prevent the risk of infectious exposure, during health crises such as acute rejection. As shown in the cross-tabulation of the matrix of themes and subthemes, recipients expressed that the use of telehealth was secure, not confronting, and did not cause extreme distress. Similarly, recipients felt that communication through email was secure, simple to use, and may improve health-related communication.

There were similarities in perspectives and experiences of patients with other chronic conditions who also used eHealth to support self-management, so long as it was regarded as reliable and user-friendly.23,37,38 They valued eHealth that could be individualized to their needs, such as providing health information, personalized reminders, self-tracking health measures (eg, spirometry for asthma), and pertinent information for family/caregivers.23,37,38 Concerns of technical issues, low eHealth literacy, and privacy and confidentiality have also been previously documented.23 However, some aspects may be unique to the transplant community. For kidney transplant recipients, eHealth facilitated safe, convenient, and timely access to quality medical care. eHealth was particularly useful in certain contexts, including routine, nonurgent follow-up for telehealth, Internet and apps for reliable information, and patient–clinician communication through email. Kidney transplant recipients trusted and gave high priority to the advice provided by their clinicians and sought their support for using eHealth. However, the patient–clinician may be complicated by the communication technology because of the change in dynamics in the delivery of care.

This study has several strengths. eHealth encompasses a wide range of digital technology each with its own unique features, benefits, and pitfalls. This study aimed to understand patient experiences and perspectives on digital healthcare in kidney transplant recipients. These perspectives and experiences have been mapped to categories of digital interventions to better understand how interventions align with specifics of each intervention group. It has provided valuable insights on eHealth in transplantation among transplant recipients. Purposeful sampling was used to obtain diverse sociodemographic and clinical characteristics among the participants. The Unified Theory of Acceptance and Use of Technology model was used to guide the design of the interview guide to ensure relevant topics were addressed. However, this study has some potential limitations. Because of the wide range of digital technology discussed, the detail of patient experiences may be limited. The transferability of findings to low-income countries is not clear as participants were from a single high-income country. Participants were recruited from an ambulatory outpatient setting, and therefore not acutely unwell, who

| TABLE 3 | Suggested strategies to improve eHealth utilization in kidney transplant recipients |
|-----------------|-------------------------------------------------------------------------------------------------|
| Strategy | Suggested action or interventions |
| Tailoring to individual user needs | • Establish aculturally sensitive and multilingual program to educate, train, and provide ongoing support resources to equip recipients to use and navigate eHealth (eg, develop a patient-focused “how to guide” for telehealth to prepare for teleconsultations) |
| | • Assess the level of personalization to health management needs based on socioeconomic status, comorbidities, age, and eHealth and health literacy (eg, providing large font to those with poor vision, enabling voice-activation software/apps/websites for those with limited finger dexterity) |
| | • Provide additional education and training for recipients who are screened as low eHealth literacy, minority groups, non-English speaking |
| Promoting reliability and trustworthiness | • Establish a searchable library of trusted, accurate, and regularly updated endorsed websites, telehealth platform, apps, software recommended by clinicians, hospitals, and governing bodies such as FDA/TGA (eg, medical devices) |
| | • Promote and encourage eHealth awareness as an accessible, supportive tool for self-management (eg, order medications, booking medical appointments, health tracking) and health service delivery (eg, telehealth) to recipients to reduce disease transmission |
| | • Provide a user-friendly checklist and flowchart to discern the integrity and accuracy of website information about transplant health websites, apps, and telehealth appointments |
| Address technical, privacy, and confidentiality concerns | • Conduct regular “debugging” and updates of software/apps to ensure capture of technical issues, and availability of email/call software provider for troubleshooting |
| | • Provide contingencies to missed telehealth appointed by rescheduling at a convenient time and availability of contact person (eg, call back function) |
| | • Develop protocols for data sharing, consent to keep privacy, and confidentiality and breach issues |
| | • Provide secure eHealth tools with clear consent if collecting private and personal information online such as via logging into websites, apps, and telehealth appointments |
| Engaging clinicians in digital care | • Clinicians to openly discuss about eHealth, such as advice on eHealth-related tracking parameters, online health information concerns, and how it may affect health (eg, online sites, apps) |
| | • Conduct face-to-face consultations when health management is not suitable for telehealth (eg, breaking bad news, examinations), and screening for health activity that would be suitable eHealth (eg, nonurgent results, routine follow-up) |
| | • Ask for patient feedback about the appropriateness and improvements of eHealth (eg, user testing) |
| | • Develop guidelines for the clinician to improve the quality of health provisions and personal interaction via telehealth (eg, checklist of best practices) |
| Enhancing community supports | • Encourage and promote peer support transplant communities for recipients who lack support and are isolated (eg, online transplant groups, forums, blogs) |
| | • Develop guidelines for developers to enable user-friendly interface layout and layman language for eHealth tools that can integrate and connect to existing technology with the ability to share content with family/caregivers/clinicians |
| | • Assist in eHealth costs (eg, equipment and ongoing costs Internet) via social worker through government initiatives and subsidies |

Suggestions are based on authors’ synthesis and review of study findings (in need of further study).
may have different perspectives. In addition, participants who spoke English were interviewed, and non-English-speaking participants were excluded.

Our study findings have provided practical solutions to bridge the gap of diversion between policy and practice. Recommendations for implementing eHealth services in post-transplant care are provided in Table 3. We suggest a personalized approach to the delivery of eHealth service to the relevant patient groups. There is also a need to establish a culturally sensitive and multilingual program to navigate eHealth services. To promote the reliability and trustworthiness of eHealth, we recommend the provision of a trusted library of online resources and the involvement of clinicians to champion eHealth awareness. A reliable troubleshooting platform will address the malfunctions concerns experienced by patients and caregivers. Direct engagement with healthcare professionals to discuss the nuances of eHealth utilization may improve the uptake of this technology among our transplant recipients. Furthermore, recipients should be encouraged to build community networks to support transplant care, share information, and experiences about eHealth use.

Future research may explore how eHealth use may influence the hospital health systems at the organization and infrastructure levels. Capturing the eHealth experiences and perspectives of relevant stakeholders, including clinicians, will ensure the intervention meets the users’ needs and addresses usability concerns.

In conclusion, our study findings highlighted the benefits of eHealth interventions for self-management in transplantation, but there are limitations to this concept. Clinicians, health professionals, patients, and caregivers should be cognizant about the privacy of the medical information, the relationship (or the lack of personal interaction) between the patients and the healthcare professionals, and the associated technological challenges of eHealth care delivery. Sustainable technology-enabled healthcare will need to encompass an accessible, high quality, and equitable health service that will ultimately improve patient-centered care and outcomes, patient satisfaction.

REFERENCES

1. Wolfe RA, Ashby VB, Milford EL, et al. Comparison of mortality in all patients on dialysis, patients on dialysis awaiting transplantation, and recipients of a first cadaveric transplant. N Engl J Med. 1999;341:1725–1730.
2. Axelrod DA, Schnitzler MA, Xiao H, et al. An economic assessment of contemporary kidney transplant practice. Am J Transplant. 2018;18:1168–1176.
3. Tonelli M, Wiebe N, Knoll G, et al. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. Am J Transplant. 2011;11:2093–2109.
4. Neuberger JM, Bechstein WO, Kuypers DR, et al. Practical Recommendations for Long-term Management of Modifiable Risks in Kidney and Liver Transplant Recipients: A Guidance Report and Clinical Checklist by the Consensus on Managing Modifiable Risk in Transplantion (COMMIT) Group. Transplantation. 2017;101:S1–S56.
5. Fleming JN, Taber DJ, McColligott J, et al. Mobile health in solid organ transplant: the time is now. Am J Transplant. 2017;17:2263–2276.
6. Hollander JE, Carr BG. Virtually perfect? Telemedicine for Covid-19. N Engl J Med. 2020;382:1679–1681.
7. Keesara S, Jonas A, Schulman K. Covid–19 and health care's digital revolution. N Engl J Med. 2020;382:e82.
8. Tang J, James L, Howell M, et al. eHealth interventions for solid organ transplant recipients: a systematic review and meta-analysis of randomized controlled trials. Transplantation. 2020;104:e224–e235.
9. WHO. World Health Organization, global diffusion of eHealth: making universal health coverage achievable. Report of the third global survey on eHealth. Geneva, Switzerland. 2016.
10. Steinhul SB, Musa ED, Topol EJ. Can mobile health technologies transform health care? JAMA 2013;310:2395–2396.
11. Webster P. Virtual health care in the era of COVID-19. Lancet 2020;395:1180–1181.
12. Tanne JH, Hayasaak E, Zastrow M, et al. Covid-19: how doctors and healthcare systems are tackling coronavirus worldwide. BMJ 2020;368:m1090.
13. Fontanarosa PB, Bauchner H. COVID-19-lookng beyond tomorrow for health care and society. JAMA 2020;323:1907–1908.
14. Akalin E, Azzi Y, Bartash R, et al. Covid-19 and kidney transplantation. N Engl J Med. 2020;382:2475–2477.
15. Lurie N, Carr BG. The role of telehealth in the medical response to disasters. JAMA Intern Med 2018;178:745–746.
16. Keshavarzost S, Bahaaadinbeigi K, Fathie F. Role of telehealth in the management of COVID-19: lessons learned from previous SARS, MERS, and Ebola outbreaks. Telemed J E Health. 2020;26:850–852.
17. Hollander JM. The transition from reimaging to recreating health care is now. NEJM Catalyst 2020.
18. Shachar C, Engel J, Elwyn G. Implications for telehealth in a postpandemic future: regulatory and privacy issues. JAMA. 2020;323:2375–2376.
19. Donald M, Beanlands H, Strauss S, et al. Preferences for a self-management e-health tool for patients with chronic kidney disease: results of a patient-oriented consensus workshop. CMAJ Open 2019;7:E713–E720.
20. Shen H, van der Klei R, van der Boog PJM, et al. Electronic health self-management interventions for patients with chronic kidney disease: systematic review of quantitative and qualitative evidence. J Med Internet Res. 2019;21:e12384.
21. Mobile Fact Sheet. 2021. Available at https://www.pewresearch.org/internet/fact-sheet/mobile/. Accessed April 4, 2021.
22. Internet/Broadband Fact Sheet. 2021. Available at https://www.pewresearch.org/internet/fact-sheet/internet-broadband/. Accessed April 4, 2021.
23. Akashmi MF, Fitzpatrick B, Davis E, et al. Features of a mobile health intervention to manage chronic obstructive pulmonary disease: a qualitative study. Ther Adv Respir Dis. 2020;14:1753466620951044.
24. Walker RC, Tong A, Howard K, et al. Patient expectations and experiences of remote monitoring for chronic diseases: systematic review and thematic synthesis of qualitative studies. Int J Med Inform. 2019;124:78–85.
25. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19:349–357.
26. Stevenson JK, Campbell ZC, Webster AC, et al. eHealth interventions for people with chronic kidney disease. Cochrane Database Syst Rev. 2019;8:CD012379.
27. Tang J, Kerklaan J, Wong G, et al. Perspectives of solid organ transplant recipients on medicine-taking: systematic review of qualitative studies. Am J Transplant. 2021;21:3369–3387.
28. Venkatesh V, Thong J, Xu X. Consumer acceptance and use of information technology: extending the unified theory of acceptance and use of technology. MIS Quarterly 2012;36:157–178.
29. Hoque R, Sorwar G. Understanding factors influencing the adoption of mHealth by the elderly: an extension of the UTAUT model. Int J Med Inform. 2017;101:73–84.
30. Alwashmi MF, Fitzpatrick B, Davis E, et al. Features of a mobile health intervention to manage chronic obstructive pulmonary disease: a qualitative study. Ther Adv Respir Dis. 2020;14:1753466620951044.
31. Veer A PJ, Brabers A, Schellievis F, et al. Determinants of the intention to use e-Health by community dwelling older people. BMC Health Services Research. 2015;15:103.
32. Koivumaki T, Pekkarinen S, Lappi M, et al. Consumer Adoption of eHealth. 2020. Available at: http://www.pewresearch.org/internet/fact-sheet/mobile/. Accessed April 4, 2021.
35. Strauss A CJ. Basics of Qualitative Research Techniques. Sage Publications; 1998.

36. Latulippe K, Hamel C, Giroux D. Social health inequalities and ehealth: a literature review with qualitative synthesis of theoretical and empirical studies. J Med Internet Res. 2017;19:e136.

37. Zulman DM, Jenchura EC, Cohen DM, et al. How can eHealth technology address challenges related to multimorbidity? perspectives from patients with multiple chronic conditions. J Gen Intern Med. 2015;30:1063–1070.

38. Sarkar U, Gourley GI, Lyles CR, et al. Usability of commercially available mobile applications for diverse patients. J Gen Intern Med. 2016;31:1417–1426.

39. Wannheden C, Revenas A. How people with Parkinson’s disease and health care professionals wish to partner in care using eHealth: co-design study. J Med Internet Res. 2020;22:e19195.

40. De Vito Dabbs A, Myers BA, Mc Curry KR, et al. User-centered design and interactive health technologies for patients. Comput Inform Nurs. 2009;27:175–183.