



Designing an App for Immunosuppression Adherence and Communication: A Qualitative Approach

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Abstract

Background: Immunosuppression nonadherence may be the most important factor limiting long-term allograft survival.

Objective: Following user-centered design, we explored the essential priorities and preferences of kidney transplant recipients and healthcare providers (HCP) to inform development of a smartphone app to improve immunosuppression adherence and communication.

Design: A qualitative descriptive research design was used.

Setting: The University of Alberta Hospital adult kidney transplant program in Edmonton, Canada.

Participants: Participants were recruited by convenience sampling and included 32 kidney transplant recipients and 11 HCPs.

Methods: Seven focus groups (5 with recipients and 2 with HCPs) were conducted to inform app development. Sessions were recorded, and transcripts were coded to elucidate themes.

Results: App development to improve adherence was not a priority for HCP. Recipients prioritized choice: that all features be optional. Recipients preferred support while traveling; access to laboratory results; and use by younger or newly transplanted recipients. Both recipients and HCP preferred linkage to pharmacy; and self-management and accountability.

For the app to improve communication, HCPs believed the priorities to be addressed included: clarity on scope of app; legal, ethical, and professional obligations; and charting. Both recipients and HCP prioritized HCP workload, and broader medication and health concerns. Healthcare providers preferred tech support; both recipients and HCPs preferred app access for nontransplant HCP.

Limitations: Limitations include underrepresentation of physicians, recipients with racial/ethnic diversity, and potential selection bias of transplant recipients who perceived themselves to be adhering to immunosuppression medications.

Conclusion: Future research is needed for the app to become a comprehensive, secure platform for broader communication between recipients and HCP, pharmacies, and nontransplant clinicians while streamlining HCP workload.

Abrégé

Contexte: La non-observance du traitement immunosuppresseur pourrait s'avérer le facteur limitant ayant la plus grande incidence sur la survie à long terme de l'allogreffe.

Objectifs: Suivant une conception centrée sur l'utilisateur, nous avons exploré les préférences et les priorités essentielles des receveurs d'une greffe rénale et des fournisseurs de soins de santé (FSS) afin d'orienter le développement d'une application pour téléphones intelligents visant à améliorer les communications et l'observance du traitement immunosuppresseur.

Type d'étude: Un plan de recherche qualitatif et descriptif a été utilisé.

Cadre: Le program de transplantation rénale pour adultes du University of Alberta Hospital à Edmonton (Canada).

Participants: Les participants ont été recrutés par échantillonnage de commodité. L'étude a inclus 32 receveurs d'une greffe rénale et 11 FSS.

Méthodologie: Sept groupes de discussion (5 avec les receveurs, 2 avec les FSS) ont été organisés pour guider le développement de l'application. Les séances ont été enregistrées et les transcriptions ont été codées afin de préciser les thèmes.



Résultats: Le développement d'une application pour améliorer l'observance au traitement n'était pas une priorité pour les FSS. Les receveurs d'une greffe priorisaient d'avoir le choix : ils souhaitaient que toutes les fonctionnalités soient facultatives. Les receveurs d'une greffe avaient une préférence pour une application qui offrirait du soutien lors de leurs déplacements, qui permettrait un accès aux résultats de laboratoire et qui soit utilisée par les nouveaux greffés et les receveurs plus jeunes. Tous les participants préféraient que l'application propose un lien vers la pharmacie et qu'elle favorise l'autogestion et la responsabilisation. Pour que l'application améliore la communication, les FSS étaient d'avis qu'il fallait s'attarder aux priorités suivantes : la clarté de la portée de l'application; les obligations juridiques, éthiques et professionnelles; et la tenue des dossiers. Tant les receveurs d'une greffe que les FSS accordaient une priorité à la charge de travail des professionnels de la santé et aux préoccupations plus générales en matière de santé et de médicaments. Les FSS préféraient une assistance technique; et tous les participants avaient une préférence pour que l'application soit accessible aux FSS ne travaillant pas en transplantation.

Limites: Parmi les limites figurent la sous-représentation des médecins, l'absence de receveurs issus de la diversité raciale/ethnique et un possible biais de sélection des receveurs d'une greffe qui se perçoivent comme adhérant à leur traitement immunosuppresseur.

Conclusion: D'autres recherches sont nécessaires pour que l'application devienne une plateforme complète et sécurisée qui facilite la communication entre les patients, les professionnels de la santé, les pharmacies et les cliniciens ne travaillant pas en transplantation, tout en allégeant la charge de travail des fournisseurs de soins.

Keywords

immunosuppression, communication, transplantation, eHealth, mobile health

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What was known before

- Poor immunosuppression adherence may be the most important factor limiting long-term graft survival.
- The transplant community has identified that development of effective interventions to improve adherence is a priority.
- Technology may help improve medication adherence for kidney transplant recipients

- Kidney transplant recipients prioritized choice, independence, and greater access to their health information over potential monitoring.
- Healthcare providers and recipients together imagined use of a comprehensive platform for broader communication between themselves, pharmacies, and non-transplant clinicians while upholding security requirements and streamlining HCP workload.

What this adds

- While we explored development of a smartphone app to improve immunosuppression adherence, we found this was not a priority to HCP. HCP-recipient communication to improve overall experience within transplant care was prioritized over immunosuppression adherence.

Introduction

Poor immunosuppression adherence may be the most important factor limiting long-term graft survival.¹⁻⁴ Immunosuppression nonadherence is common, with estimated prevalence up to 36%⁵ in kidney transplant recipients. Development of effective interventions to improve adherence has been identified as a priority by the transplant community.^{6,7}

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Several trials demonstrated that technology may help improve medication adherence for kidney transplant recipients⁷⁻¹¹ McGillicuddy et al⁸ demonstrated that an app-based reminder system to self monitor blood pressure and provide blood pressure measurements resulted in better adherence and more medication adjustments by the healthcare providers (HCP). The TAKE-IT trial⁹ showed that individualized coaching, adherence monitoring and feedback using an electronic pillbox, and dose reminders using text messages, resulted in a 66% greater likelihood of adherence compared with monitoring alone. Nguyen et al¹⁰ also explored strategies and challenges to improve medication adherence, including opinions on usage of and electronic pill box along with a supplemental website and features such as reminders and longitudinal pill box data tracking. While electronic ingestible pills are now available, the long-term research into acceptability in the transplant settings are still needed.⁷

In today's world of extensive smartphone use and a culture in which "there is an app for that," the feasibility of integrating app technology to improve adherence in transplantation is growing.¹¹ While most reviews found that while the evidence for using mobile technology is moderate, they concur that there is great opportunity to promote therapeutic adherence using mobile health interventions.¹²⁻¹⁹ Among transplant recipients, smartphone ownership and interest in using medication apps have doubled in the past 5 years.²⁰ While a variety of medication apps are available commercially, even the top performing apps curated by medappfinder.com require motivated individual users to actively sign up with the apps and then allow the apps to share information with their physicians.^{7,20} None of the available apps were designed to be integrated as part of a transplant center's electronic medical record (EMR), nor intended to be employed on a program-wide basis.^{7,20-22} Therefore, we plan to build an integrated app within an existing Health Insurance Portability and Accountability Act-compliant EMR, with the intention of programmatic implementation to improve medication adherence and communications between patients and HCP. We employed a user-centered design^{23,24} to explore the following research question: What are kidney transplant recipients' and HCP's essential priorities and preferences to inform the development of a smartphone app to improve immunosuppression adherence and communication? This approach will improve app acceptability and usability as it is "designed" by the users.

Methods

Study Design

Following a qualitative descriptive research design,²⁵ we conducted 5 recipient focus groups and 2 HCP focus groups to collect qualitative data, and applied thematic analysis.^{26,27}

Participants

Participants were recruited by convenience sampling²⁸ from the University of Alberta Hospital adult kidney transplant

program located in Edmonton, Canada.²⁹ Transplant recipients were informed about the study when they attended clinic appointments (between June to August 2018). Nonclinical research staff followed up with interested participants to provide additional information and obtain informed consent. The inclusion criteria for recipients included: age over 18 years; and being a kidney transplant recipient followed by the program. Recipients were excluded if they had significant cognitive impairment or language barrier. The inclusion criteria for HCP included both physicians and allied health transplant care team involved in patient care, and all were verbally invited to participate

Data Collection

Focus groups (1-1.5 h, 4-9 participants per group) were undertaken to elicit group discussions.²⁸ They were conducted by an experienced facilitator (L.E.L.) who had no prior relationship with participants and guided by a semi-structured discussion tool (see Supplementary File 1). Of the 5 recipient focus groups, 4 were conducted in a conference room at the hospital, outside of the clinic setting; one was stratified for younger recipients (<40 years) and conducted via Skype. Healthcare providers focus groups were conducted in a conference room, outside regular work hours. All focus group discussions were audio-recorded.

Data Analysis

Field notes were used to record initial impressions and contextual details. Focus group transcripts were coded inductively and independently by the facilitator (L.E.L.) and a research associate not present during data collection, using NVivo 12. They created "memos" to note analytic reflections and met to discuss coding differences and reach consensus. To compare and contrast priorities and preferences, recipient and HCP data were first coded and analyzed separately, then combined, compared and contrasted between groups to elucidate thematic²⁶ commonalities and differences in their priorities and preferences in app design. K.S.M., L.E.L., and K.W. reviewed emerging findings, and through consensus agreed on the final thematic structure. App features were defined as "priorities" when participants discussed the feature as essential. App features were defined as "preferences" if they were discussed as optional. Through this analytic approach, inductive thematic saturation was achieved.³⁰ The Consolidated Criteria for Reporting Qualitative Research guidelines were followed.³¹ (See Supplementary File 2).

Ethical Approval

This study was approved by the University of Alberta Health Research Ethics Board and Alberta Health Services. All recipient and HCP participants provided written informed consent.

Results

Participant Characteristics

Thirty-two kidney transplant recipients and 11 HCP who worked in the transplant clinic participated (Table 1).

Themes

Development of an app to improve immunosuppression adherence entailed one essential priority identified by recipients only: that all app features be optional. Five preferences to improve immunosuppression adherence were identified. Recipients' preference was that the app could provide (1) support while traveling, (2) access to laboratory results, (3) benefit to younger or newly transplanted recipients; both recipients and HCP preference was for the app to provide, (4) linkage to pharmacy, and (5) self-management and accountability (see Figure 1).

Development of an app to improve communication entailed 5 essential priorities. HCP prioritized (1) clarity on scope of the app, (2) legal, ethical, and professional obligations, (3) charting; both recipients and HCP prioritized, (4) HCP workload, and (5) broader medication and health concerns. Two preferences to improve communication were identified. While HCP preferred (1) tech support, both recipients and HCP preferred and (2) app access for nontransplant HCP (see Figure 2). (See illustrative quotes in Table 2).

App Development to Improve Immunosuppression Adherence: One Essential Priority

All app features be optional (recipients). Development of an app to improve immunosuppression adherence was prioritized by recipients only. Healthcare providers, unexpectedly did not prioritize development of an app toward this goal, particularly in comparison to prioritization for communication (outlined below). Recipients framed this within individualized choice. Recipients consistently stated the importance of ensuring all app features were optional; that is, anyone using the app could choose whether to activate any feature (such as alarms). Most recipients were not interested in using the app as a device to track medication adherence; sharing that information with the transplant clinic team was perceived as unnecessary "monitoring." These recipients suggested that receiving a kidney transplant gave them freedom (from dialysis) and control over their own health; being monitored through an app was perceived as contrary to that gain.

App Development to Improve Immunosuppression Adherence: 5 Preferences

Support while traveling (recipients). When discussing development and design of the app to improve immunosuppression adherence, recipients preferred using the app for support while traveling. One unique aspect of this preference was for

Table 1. Characteristics of Recipient and Clinician Participants.

Demographic information	
Kidney transplant recipients—total	32
Current age—years	
Mean age (SD)	45.9 (15)
Range (min-max)	22-79
Age at transplant—years	
Mean age (SD)	39.1 (14.5)
Range (min-max)	18-71
Sex	
Female	8
Male	24
Ethnicity	
Caucasian	30
African	1
Asian	1
Marital Status	
Married	21
Never married	11
Number of transplant	
First transplant	28
Second transplant	4
Type of kidney donor	
Living donor	19
Deceased donor	13
Years since transplant	
Mean (SD)	6.3 (6.1)
Median	4
Range (min-max)	<1-20
Interquartile range	5.5
Cause of end-stage renal disease	
Diabetes mellitus	4
Polycystic kidney disease	2
Glomerulonephritis	16
Congenital	3
Unknown	7
Co-morbidities and complications	
New onset diabetes after transplant	7
Coronary artery disease	5
Stroke	0
Recurrence of native kidney disease	1
Post transplant lymphoproliferative disorder	1
T-cell-mediated rejection	2
Antibody mediated rejection	2
Healthcare providers—total	11
Age—years	
Mean age (SD)	47.5 (5.3)
Range (min-max)	41-58
Sex	
Female	11
Male	0
Ethnicity	
Caucasian	9
Asian	2
Occupation	
Transplant coordinator—registered nurse	8
Dietitian	2
Pharmacist	1
Years in practice (SD)	22.5 (5.6)
Years in transplant practice (SD)	8.6 (5.7)

App Development to Improve Immunosuppression Adherence		
	Priority	Preference
Recipients	All app features be optional	Support while traveling Access to lab results Benefit to younger or newly-transplanted recipients
Agreement Among Recipients & HCP	-	Linkage to pharmacy Self-management and accountability

Figure 1. Priorities and preferences for app development to improve immunosuppression adherence.
Note. HCP = healthcare providers.

App Development to Improve Communication		
	Priority	Preference
HCP	Clarity on scope of the app Legal, ethical, professional obligations Charting	Tech support
Agreement Among Recipients & HCP	HCP workload Medications and health concerns	App access for non-transplant HCP

Figure 2. Priorities and preferences for app development to improve communication.
Note. HCP = healthcare providers.

the app to help with medication timing when crossing time zones. Another preference was to be able to use it for healthcare advice while traveling if local HCP were unfamiliar with the kidney transplant context of care.

Access to laboratory results (recipients). A design feature that recipients raised spontaneously (ie, unprompted through the question guide) was having access to laboratory results (specifically blood work) on the app. Many recipients stated they closely monitored laboratory results and sometimes struggled for access to this information. Having laboratory results available through the app was of strong interest, an opportunity for greater control of their own health data.

Benefit younger or newly transplanted (recipients). Also unsolicited through the focus group questions, recipients shared their preference about the app's intended users. Recipients commonly stated the app would be most useful for "younger" generations whom they assumed would be more likely to use an app. Recipients recalled their early days posttransplant as

being physically challenging and tumultuous in terms of medication management. They suggested that an app would have been most helpful to them at that time and would likely be so for other recipients immediately posttransplant.

Linkage to pharmacy (recipients and HCP). Both recipients and HCP preferred linkage to pharmacy be included in app development. They shared the desire to have the app link to the clinic's pharmacy as well as other retail pharmacies for medication management. Both groups perceived tracking medication supply, ordering medications, managing prescription changes and medication safety (eg, alerts for allergies or drug contraindications) would be easier and more efficient if managed through the app. Healthcare providers also stated that the app could be used to house insurance coverage of medications. Recipients' preferences were that all medications would be listed in the app (ie, not limited to immunosuppression medication). While recipients wanted greater access, there was inherent conflict here with HCP who highlighted concerns about workload, accuracy, safety, and

Table 2. Illustrative Quotes.

App development to improve immunosuppression adherence	
Theme	Focus group participants
Priority: 1. All app features be optional Recipients only	Recipient 9: I just echo what was said [about not using the app to record taking medication]. You know even just having some control over your situation too. I mean it feels like you're kind of in a Big Brother situation if they're looking out, you know 5 minutes late on this one and stuff like that. Recipient 8: Yeah, that's a good point. Recipient 9: You know the great part about a transplant is you've got freedom and control over your own situation. A lot more than you had before that's for sure. All: Yeah, yeah. Recipient 9: So just losing some of that [through the app] is kind of contradictory. Recipient 7: That's the whole part of the transplant right is freedom.
Preference: 1. Support while traveling Recipients only	Recipient 7: I travel a lot so what I run into sometimes, something will happen—the flu or whatever. You go in and they look at you but they're unaware of what it means to have a transplant . . . I got into situations where I need a pill but the real clinic is closed, I can't call them and they're not too sure whether the pill that they are recommending will be a good fit or a mismatch. Recipient 8: Yeah, to have that access just on your App 24 hours a day no matter what would definitely be [beneficial] . . .
Preference: 2. Access to laboratory results Recipients only	Recipient 12: When the lab sends the blood work results, they [could] come through the App too. Recipient 14: 'Cause I've asked the doctors say can I get these results? Can I have graphs, can I see what's happening? I like looking at the numbers. [And they say], 'oh we can't send this through email. It's private . . . ' I have to call in to find it, unless there's something way out of whack, [then] I get called at 10 or 11 at night. Every time I do blood work I'm looking at the phone waiting for something to go off.
Preference: 3. Benefit younger or newly transplanted Recipients only	Recipient 21: I'm sorry, I just kind of think it almost sounds like it's trying to gamify, it's like, 'oh you took your meds, you get a trophy. Ooh.' Recipient 24: Exactly. Recipient 19: But for younger ones, absolutely. Recipient 25: Anybody under the age of 25, is going to love it. Recipient 29: Yeah. Especially when you are starting out. When you had your transplant, you start off with quite a few medications and you take them all day and it's quite easy to forget what they are and what the doses are too. So it [the app] would be very helpful for the people who are just starting off with their new medications and how frequently they are changing.
Preference: 4. Linkage to pharmacy Recipients & HCP	Recipient 20: Linking it [the app] to your pharmacist would be kind of a cool thing too . . . If you got all your medications listed on the App as well as the renewals. So the pharmacy can just go straight there or we can send it straight to the pharmacy from the App rather than having to go through the doctor. Recipient 18: Just having the transplant pharmacist as well as the outpatient pharmacy contact information, having that available. Recipient 19: Having them work as a team. HCP 10: I was wondering if the App has the capability if patients go to family physicians and something gets prescribed, they go to pharmacy, pick up their prescription, if they can with the cellphone take a picture of the new medication and then we would be able either to see the new medication or the name would pop up on the healthcare professional site.
Preference: 5. Self-management and accountability Recipients and HCP	Recipient 24: I kind of wondered if by taking responsibility away from the individual, what else that individual is going to be expecting the staff to be doing for them. And then it gets to the point where those who are perhaps less motivated to take control of their own health, they just start offloading that and expecting the App to do everything for them and not really making conscious effort. HCP 4: [If] they [recipients] are too reliant on us entering things for them, that could cause confusion for the patient because they might expect us to change these meds, what they see on the app says one thing but the doctors changed it, that could just cause confusion.
App development to improve communication	
Theme	Focus group participants
Priority: 1. Clarity about scope of the app HCP only	HCP 1: A lot of the changes are not necessarily made by our program. So I really would not want to be responsible for updating a patient's app separate from our chart on meds that aren't even the ones that we are changing or prescribing.

(continued)

Table 2. (continued)

App development to improve communication	
Theme	Focus group participants
	HCP 3: All of the medications are reviewed not just the transplant immunosuppression, transplant meds. I mean these patients are usually seen by multiple people. Another example would be the combined organ transplant so you got a liver-kidney, they are adjusting medications . . . Just going to your family doctor, because they could be co-managed by the program, the nephrologist suggests the blood pressure [meds] here, asks them to go see the family doctor in a couple weeks and follow up, they could be adjusting things, so we won't necessarily even know that unless the patient has good communication and calls us back and said this thing was adjusted.
Priority: 2. Legal, ethical, and professional obligations HCP only	HCP 2: My biggest question is also the confidentiality and the privacy and the storage of the information. I know there are some apps out there, but I just cannot recommend them to a patient 'cause I don't know where the information is being stored. And for us, even communication through email, emailing us the medication list and if I reply and they are not in the secure network with the proper firewalls, we are breaching patient confidentiality. So I just want to see how this app—where the information is stored and how we go about doing that part.
Priority: 3. Charting HCP only	HCP 5: Like [no] double entry. I would want it [the app] to be linked to their online chart. Because you have more potential for error if you are having to enter it into OTTR [Organ Transplant Tracking Record] and enter it into an app. HCP 2: That would be time consuming. Some of these patients have many, many, many medications and that would take a long time, especially initiating things. Maintaining it might not be so much but still, that is an extra step. Especially if it is not part of the current workflow, [it] could cause some problems of inaccuracies, and then the patients are going to be confused on all levels.
Priority: 4. HCP workload Recipients and HCP	Recipient 17: The staff are so busy, they have so many duties already and the patient load is so heavy that my concern is with all this input [into the app] that maybe would be asked of them with all this changing medications . . . is that going to cut down our chances of ever being able to reach them by phone and having any feedback from them? I like to talk to them in person. I like to be able to phone and I hope for a phone call back. I'm in charge of my medications. As I said before, I'm not an App person. Recipient 18: So I guess the question is how much of this App would we want to be more of me, myself and I—personal for me to use . . . [and] how much of it do we want the staff to be worrying about having to communicate with? . . . Recipient 24: Really if they can't support it, then it's really not worth having the feature. HCP 3: It's just the extra steps. If it's going to be—we update it in our current system, plus then we update it in the app—all of that adds extra time to your day. HCP 3: I guess the hard part is, now this is another avenue I have to remember to check. Not only do I get phone messages and sometimes e-mails from patients, but now I'm going into a third portal to make sure that I'm not missing something . . .
Priority: 5. App as communication tool—medication and health concerns Recipients & HCP	Recipient 29: I have to admit that my inspiration for being even more interested in this App is . . . I find trying to get a hold of the nurses at the Kidney Clinic incredibly aggravating and very difficult and I actually think that I would use the App primarily for . . . communication, to be honest, [more] than anything else. HCP 4: And it would have to be part of the medical record somehow too . . . HCP 3: We also have people who cross cover your portfolio so that communication on who's doing what, I just think there could be recipe for a problem or inaccuracies with multiple steps.
Preference: 1. Tech support HCP only	HCP 4: Just limitations of technology too, if they [the recipients] have somewhere more remote and they are not always getting wifi access, can't update it, or they're getting frustrated with this and they are going to ask us questions about that. HCP 1: That's true, some tech support. Cause I won't be able to help with that.
Preference: 2. App access for nontransplant HCP Recipients and HCP	Recipient 4: Going forward from today's date, everything is technology driven. If a nurse needs to make a change, the doctor sees that change on the prescription, the pharmacist sees that change. You don't get this little hiccups. The patient sees it, he logs in, you're seeing it right away. Or a result from the blood work. Everything is all in one location, it's a little bit easier for newcomer . . . 'Hey we need to do this, we can order meds, we know what we're taking, oh we're going the wrong way'. Everybody knows about it right up front . . . The ultimate goal with this is everyone's in the loop and there's no gray area. HCP 2: I think its definitely helpful but at the same time, whoever is using it [the app] has to be diligent in updating it. So bringing the same list, this is my family doctor, this is what I'm taking and then once the doctor makes the change, they would update it. So wherever they bring this app and show it, that will be his current up to date med list. HCP 3: I know on the one app that I have . . . is that actually if there is changes, they can email your physician with it. So, if I had med changes or I can send my med list to them, I can send my blood pressure readings to them, and I just email and it automatically uploads all of that current information to the physician if they wanted it, or accepts it.

Note. Themes in green and blue correspond to Figures 1 and 2. HCP = healthcare providers.

professional responsibility if other medications were included in the app.

Self-management and accountability (recipients and HCP). Recipients and HCP both preferred that app development would facilitate recipients' self-management, specifically their accountability or responsibility for their own health. Recipients stated concerns about being monitored for medication adherence through the app and feared it would create overreliance on clinic staff. Similarly, HCP were hesitant about taking responsibility for entering medication information changes for recipients, stating concerns about the potential for confusion.

App Development to Improve Communication: 5 Essential Priorities

Clarity about scope of the app (HCP). One of the strongest priorities for HCP was clarification about the scope of the app. They raised a multitude of questions about the "boundaries" of the app. They wondered whether the app would include transplant care information or broader healthcare information. They questioned if the app would be limited to immunosuppression medication or all medications. Healthcare providers prioritized articulation of "who" would be responsible for updating information in the app for ongoing accuracy.

Legal, ethical, and professional obligations (HCP). Healthcare providers believed that for the app to improve communication, legal, ethical, and professional obligations needed to be addressed. Healthcare providers raised concerns about legal issues, and ethical principles such as confidentiality. Healthcare providers wanted assurance that the app would meet privacy regulatory requirements for recipient data. Interestingly, these concerns were rarely raised within the recipient focus groups. Healthcare providers highlighted the importance of explicitly stating the limits of legal and professional obligation in the app. Similar to their questions about scope of the app, they sought clarity about who would be responsible or liable for medication reconciliation, data accuracy, and so on.

Charting (HCP). Healthcare providers prioritized charting for app development to potentially improve communication. They expressed concerns about how communications via an app would be documented in the medical record. It was important to HCP that communications via an app would not require duplicate documentation but rather that app-based communications would be integrated automatically into the EMR. They also stated the importance of including charting safety features in the app (eg, soft and hard dose limits, flags for potential drug interactions, allergies, or drug tolerance issues).

HCP workload (recipients and HCP). A commonly expressed concern for both recipients and HCP was the potential for the

app to add to the workload of the HCP. Recipients and HCP shared the belief that the clinic staff were already working at capacity. They stated fears that the app would inadvertently decrease the quality of care by decreasing the amount of time available for communication with recipients. Both groups were unequivocal in their opinions that to improve care, the app's design must not increase HCP workload and be resourced appropriately.

Broader medication and health concerns (recipients and HCP). A top priority for both groups was HCP-recipient communication through the app about broader issues related to medications and health concerns. Healthcare providers were cautious, concerned that recipients would expect the app to be a vehicle of communication outside of clinic (and their work) hours. Recipients stated that broader communication with clinic staff was a top priority for app design, for the very reasons HCP anticipated—increased access to HCP. Recipients hoped the app would improve communication in general, and specifically for after-hours access for urgent healthcare concerns. Recipients shared their dilemmas when they were uncertain about the appropriate course of action for their symptoms, and their only option was to seek care from providers who lacked the clinic staff's expertise. Recipients perceived that communication with clinic staff at these times would facilitate good care decisions and be a cost savings to the healthcare system.

App Development to Improve Communication: Two Preferences

Tech support (HCP). When discussing future development of the app to improve HCP-patient communication, HCP preferred that recipients would have access to "outside" tech support for the app. They believed that tech support should not be provided through the transplant clinic.

App access for nontransplant HCP (recipients and HCP). Both recipients and HCP were interested but uncertain how other HCP outside of the transplant clinic would access the app. For example, recipients wished to share their medication lists through the app with other HCP within their broader circles of care. Although HCP similarly stated their interest in having HCP outside of the transplant clinic access the app, they also wanted clarification about roles and responsibilities for ensuring the accuracy of the information available in the app which would be shared outside of the transplant clinic, particularly updated medications.

Discussion

The overarching aim of this qualitative study was to explore the essential priorities and preferences of kidney transplant recipients and HCP to inform the development of a smartphone app to improve immunosuppression adherence and

communication. Interestingly, we found that HCP did not prioritize app development to improve immunosuppression adherence. Perhaps most importantly, recipients had reservations about an app for adherence since they felt transplantation provided freedom and potential app monitoring would infringe on their independence. Instead, HCP and recipients stressed improvement in communication. Communication was valued over adherence. Participants envisioned use of a comprehensive platform for broader communication between themselves, pharmacies, and nontransplant clinicians while upholding security requirements and streamlining HCP workload. In this discussion, we address not only the creation of an app to improve immunosuppression adherence and communication but also how these findings add to literature in the field and inform future technological interventions.

While one of our goals was to explore app development to improve immunosuppression adherence, it is instructive to learn that recipients prefer freedom and control over their medication usage, rather than using the app to monitor medication adherence. However, this opinion may be driven by the fact that most recipients who agreed to participate in this study were motivated individuals with high self-management, and perhaps were already adherent to taking their medications. Furthermore, recipients suggested that use of the app for medication management in the early posttransplant period would be very useful during that stressful and tumultuous time, a finding corroborated by Nielsen et al with recipients who received a telehealth solution after a kidney transplant.³² Through this study, we learned from recipients that they did not want to be monitored; they wanted control.

Although technology may broadly assist patients in beneficial health behaviors,³³ patients' input in design is critical for success.³⁴⁻³⁶ For technologies to be effective, they must meet users' needs, be easy to use, and be perceived as useful.³⁷⁻⁴¹ Involving end-users in the design of health technologies through "user-centered design," improves future usability and quality, and the likelihood of adoption.^{24,42} Both recipients and HCP end-users envisioned wider use of an app to improve communication pertaining to overall experiences within and outside of transplant care. Recipients saw the potential for greater access and control of their broader health information (including blood work), and improved communication with both their transplant and nontransplant HCP. However, there is inherent conflict here with HCP who expressed fears that greater access by recipients may increase their workload. Remarkably, patients were also concerned about HCP workload from the app, fearing it would decrease rather than increase communication with HCP. Yet it is important for HCP to know that recipients desire greater access, independence, and ownership; future research is needed to explore how such changes might impact HCP workloads. Healthcare providers prioritization of workload issues, charting, and need for clear articulation of scope, such as "who" would be responsible for data accuracy, address potential acceptability and use by HCP users.⁴³ While recipients did not highlight concerns about security,

details about liability, privacy, and integration with the EMR would need to be clearly outlined to support communication, and ultimately future adoption. These concerns are consistent with findings by Nguyen et al¹⁰ in the TAKE-IT TOO study.

While our intention was to inform the development of a smartphone app, recipients and HCP imagined a comprehensive platform for broader communication perhaps resembling an inclusive portal accessible by patients, HCP, pharmacies, nontransplant HCP, and health insurers. Future research is needed to enact their recommendations. While patient portals exist and are under development internationally,⁴⁴ including in kidney transplant care,⁴⁵ we cannot conclude a portal would improve communication, a finding supported by Lockwood et al.⁴⁶ However, others have identified that improved communication and relationships between recipients and HCP lead to better immunosuppression adherence.⁴⁷ Similarly, Reese et al⁴⁸ found that electronic pill-bottle monitoring, along with text reminders to kidney transplant recipients and notifications to HCP, resulted in 88% immunosuppression adherence compared with 55% with monitoring alone. Future research is needed to explore use of patient portals with transplant recipients, HCP-recipient communication, and impact on work processes. Given the global technological explosion and the COVID-19 pandemic-driven psychosocial distress on patients, consideration of electronic interventions specifically to improve communication is both required and timely.^{49,50} However, while this is an important area of further research, we acknowledge that there is a paucity of economic data to support broad implementation of mobile health interventions.^{51,52} Looking ahead to future research, while this study was carried out with kidney transplant recipients and HCP, after the prototype app is developed, we intend to pilot it, undertake several rounds of usability testing, and then scale-up to all organ transplant groups within our transplant center.

This is the first study to undertake a user-centered design to explore recipients and HCP priorities and preferences to inform development of an app to improve immunosuppression adherence and communication. However, there are some limitations. The transferability of some of the themes to other transplant settings is uncertain, particularly low-income countries. Our findings are potentially limited by underrepresentation of physicians who may have identified different priorities or preferences, and recipients with racial/ethnic diversity (which was not collected). Despite efforts to seek broad opinions for the app design, we acknowledge selection bias of transplant recipients who perceived themselves to be adhering to immunosuppression medications. Furthermore, the cause of end-stage kidney disease reflected in our recipient sample is atypical with higher representation of glomerulonephritis. Given that recipients with glomerulonephritis tend to have less comorbidities, this selection bias may have further influenced the findings about app priorities and preferences. Inherent in studies aimed at improving adherence, the most challenging part is to engage those who

struggle with adherence. Future research guided by integrated knowledge translation may purposefully engage in patient-oriented research with people who are at highest risk for nonadherence to tackle unanswered “thorny” questions in this field. However, as suggested by the recipient participants, an app may be most needed early in the transplant course or among younger generations, who we were able to consult through additional focus groups.

Conclusions

Before implementing technological solutions, it is imperative that such design is informed by and responsive to users’ perspectives. While we explored development of a smartphone app to improve immunosuppression adherence, we found this was not a priority to HCP. Healthcare provider-recipient communication to improve overall experience within transplant care was prioritized over immunosuppression adherence. Kidney transplant recipients favored choice, independence, and greater access to their health information over potential monitoring. Healthcare providers and recipients together imagined use of a comprehensive platform for broader communication between themselves, pharmacies, and nontransplant clinicians while upholding security requirements and streaming HCP workload.

Ethics Approval and Consent to Participate

This study was approved by the University of Alberta Health Research Ethics Board (Pro00082781) and Alberta Health Services.

Consent for Publication

Consent for publication of data was approved by all participants. All coauthors reviewed and approved the final manuscript for publication.

Availability of Data and Materials

No additional data or materials are available for sharing. Please contact corresponding author with any inquiries.

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Author Contributions

K.W. designed the study, collaborated with practice partners, and guided the manuscript. K.S.M. and L.L. analyzed the data and drafted the manuscript, and K.S.M. revised the manuscript. B.F., N.L., B.B., and A.B. substantially contributed to the design of the study and provided critical revision of the manuscript. All authors read and approved the final manuscript.

Declaration of Conflicting Interests

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Supplemental Material

Supplemental material for this article is available online.

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