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Artificial intelligence and e-health for inflammatory bowel diseases: the quest to enhance patient experiences, outcomes and costs

Zand, A.

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CHAPTER 8

Patient Experience and Satisfaction with an e-Health Care Management Application for Inflammatory Bowel Diseases

Submitted

A. Zand[1,2], A. Nguyen[1], C. Reynolds[1], A. Khandadash[1], E. Esrailian[1], D.W. Hommes[1,2]

[1] UCLA Center for Inflammatory Bowel Diseases, Vatche and Tamar Manoukian Division of Digestive Diseases, David Geffen School of Medicine, University of California at Los Angeles, CA, USA.
[2] Leiden University Medical Center, Department of Digestive Diseases, Leiden, the Netherlands.

Abstract

Rising healthcare expenditures have been partially attributed to suboptimal management of chronic illnesses including Inflammatory Bowel Diseases (IBD). Recognizing the need to increase efficiency of outpatient care and prevent hospitalizations, we developed a mobile app for IBD disease monitoring, UCLA eIBD, that includes disease activity monitoring and educational modules. We provide preliminary evaluation of patient satisfaction and experience with this mobile app. We surveyed IBD patients treated at the UCLA Center for Inflammatory Bowel Diseases. The Patient Experience Survey assessed patients' overall satisfaction with the app, perception of health outcomes after app participation, and open-ended feedback on educational modules and ways to improve the platform. 50 patients were included in this study. Responses indicated that users were greatly satisfied with the ease of patient-provider communication within the app and appointment scheduling features (68%). A majority of respondents (54%) also reported that program participation resulted in improved perception of disease control and quality of life. Lastly, a majority of participants (79%) would recommend this app to others. Mobile tools such as UCLA eIBD have promising implications in improving healthcare delivery and integrating into patients' daily lives. The findings of this patient satisfaction study of UCLA eIBD suggest the feasibility of using this tool by patients and providers. We further showed that UCLA eIBD and its holistic approach has led to improved patient experience and satisfaction, which can provide useful recommendations for future e-Health solutions.

Introduction

Value-based healthcare (VBHC) can be described as the systematic pursuit of the triple aim in healthcare: to improve the individual's experience, improve health outcomes, and reduce costs[1]. The concept of VBHC is particularly ready for application to long-term management of chronic illnesses, since rising healthcare expenditures have been partially attributed to suboptimal management of chronic illnesses including inflammatory bowel disease (IBD)[2]. The estimated annual disease-attributable cost of IBD is $6.3 billion[3]. Hospitalization represented over a third of costs and outpatient services one third. Reducing hospitalization and readmission therefore continues to be a challenge in chronic disease management. There is clearly an opportunity to reduce cost by increasing the efficiency of outpatient care and preventing hospitalizations.

Electronic health (e-Health) interventions are one solution for more effective IBD care management beyond the clinical setting, both in terms of patient outcomes and cost reduction. Smartphone applications are widely available for consumers, and the large population of smartphone users make apps useful tools to manage chronic illnesses like IBD[4]. In fact, smartphone devices with mobile applications and short message reminders have been used effectively by patients with IBD of mild to moderate severity[5].

Furthermore, mobile health technologies have been shown to improve patient outcomes and quality of life[6]. Patient satisfaction in mobile technologies has been found for many chronic diseases, including asthma[7], HIV[8], diabetes[9], atrial fibrillation[10], and IBD[11]. IBD patients generally have positive views on mobile apps, but there are desired improvements. A study from Con et al. surveying 86 IBD patients found that 98.8% of participants were willing to use communication technologies for IBD management, with mobile apps being one of the top two preferred forms[11]. These previous IBD mobile technologies were often created to assess a major single aspect such as quality of life[5], education curriculum[12], or diets[13]. Additional features that patients seek in their chronic disease management apps include easy user interface[14], tracking of disease symptoms[11], and easy access to medical data and services[11].

A systematic assessment of 26 IBD mobile applications found that apps offered a variety of features including diary functionalities, pain tracking, bowel movement tracking, and reminders, with app content playing a major role in driving patient behavior change[4]. The MyIBD Coach telemedicine tool, which monitors adherence, disease activity, quality of life,

and mental health among other measures through validated questionnaires, was shown to be successful with high rates of patient satisfaction and compliance[15]. It involves collaboration among healthcare providers but does not sync with electronic medical records and lacks educational app features on alternative medicine, behavioral health and physical activity.

To enhance VBHC in IBD, we developed UCLA eIBD to integrate various successful features of previous apps (i.e., appointment reminders, medication trackers) in addition to a healthcare provider portal. UCLA eIBD seeks to provide patients more agency in managing their IBD by increasing their access to healthcare professionals and providing self-help educational modules. Access to care providers through a messaging app provides patients with fast feedback on their conditions and streamlines patient care[16]. The application also contains disease activity, quality of life, and work productivity surveys that facilitate interactions between patients and providers. These tools allow healthcare providers to monitor patients' disease activity and give direct feedback. This comprehensive app therefore seeks to enhance patient outcomes by including direct connections to a healthcare team and extensive module options.

We previously conducted a pilot study of UCLA eIBD, which found significantly fewer endoscopies and decreases in healthcare utilization, long-term steroid use and IBD-related costs[17]. While it is important to evaluate the efficacy and outcomes of IBD self-management platforms, however, it is just as crucial to understand patients' satisfaction with these platforms to inform their feasibility. Gathering user feedback is necessary to develop the next generation of apps, improve product design, and reduce disconnect between app developers and consumers[18-20]. The present study therefore aims to provide an evaluation of perceived patient satisfaction and experience with the UCLA eIBD mobile app.

Methods

Objectives

The primary objective was to measure patient satisfaction and experience with the UCLA eIBD mobile application for care management. The secondary objective was to capture patient feedback on how to improve the mobile application.

Design and Population

We surveyed IBD patients treated at the UCLA Center for Inflammatory Bowel Diseases from October 2017 to October 2018. Included patients were 18 years old; diagnosed with

Crohn's disease (CD) or ulcerative colitis (UC) either by endoscopy, imaging or pathology; and had objectively logged into the app in the past year (assessed on platform). Patients with intestinal cancer, active chemotherapy, or a known intestinal infection were excluded. All eligible patients who had logged into the app in the past year were emailed and asked to complete a patient experience survey. Those who did not complete the survey in response to the initial email were followed up and interviewed via phone.

Description of UCLA eIBD

UCLA eIBD is a mobile app that administers a clinic-centered, care management program to its users (Figure 1). It was designed to be a comprehensive tool for patients' long-term disease management in the IBD outpatient setting. The features of this app include disease activity monitoring, messaging, educational modules, lifestyle modules, and electronic cognitive behavioral therapy (eCBT). The platform is also integrated with UCLA Health's electronic medical record, allowing patients to view their testing and lab results within the app.

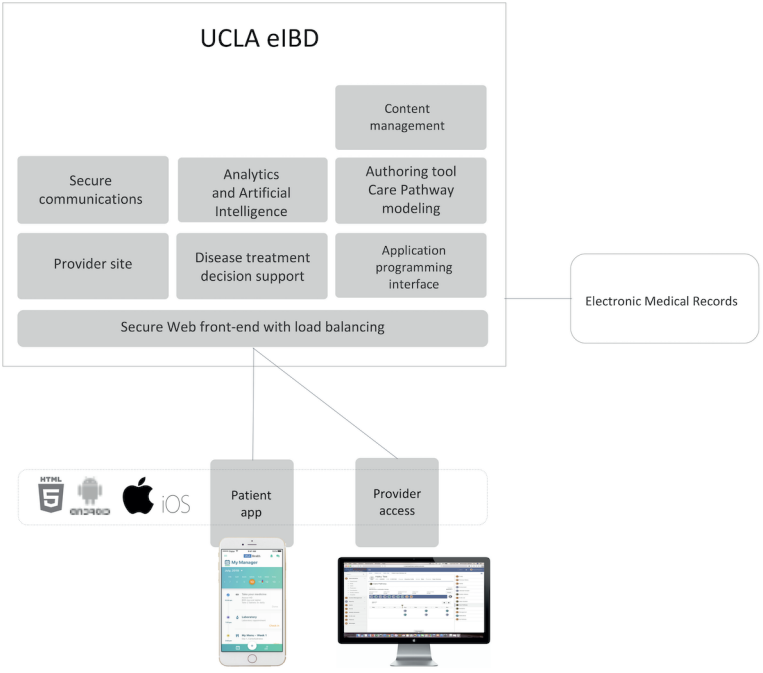

Figure 1. UCLA eIBD mobile app is an integrative care management platform for patients and providers.

For disease activity monitoring, a tool that was previously validated for use in mobile apps was integrated to assess patients' disease activity, quality of life and work productivity[21]. If the surveys indicated poor disease control or a significant change from prior surveys, a message was automatically generated through the app to clinic staff. Enrolled patients could also elect to take these surveys on their own time if they felt they were experiencing a sudden change in their health.

Lastly, the app provided education through several optional interactive modules designed to promote healthy lifestyle habits, including: nutrition (My Menu), exercise (My Yoga, My Fitness), relaxation (My Acupressure, My Meditation), and mental health (My Coach). My Menu teaches patients about specific foods to eat and avoid and includes recipes (Breakfast, Snack, Lunch and Dinner) designed for IBD patients. My Yoga provides a 6-week program promoting relaxation and flexibility for users. My Acupressure teaches patients about different pressure points focusing on elevating IBD pain via instructional videos and pictures. My Meditation is a self-guided mindfulness therapy that aims to reduce stress-related health issues. My Coach is a personalized mental life coach (6-week mental support program) aimed at improving mental wellbeing and stress management through a cognitive behavioral therapy method.

Data Collection & Outcomes

Patient demographic data was acquired via chart review. Data from the Patient Experience Survey was collected via REDCap[22]. The Patient Experience Survey (Table 1) consisted of 24 items aimed at assessing patients' overall satisfaction with the app and their perception of health outcomes after participation in the program. Responses were provided either via Likert scale or open text. Questionnaire items addressing the app's features and interface requested feedback on the ease of app use, ability to communicate with staff, and informativeness of modules. Questionnaire items pertaining to the patient's outcomes asked patients how effective they felt the app was at improving disease control, work productivity and quality of life.

Ethical Considerations

All patients gave informed consent to participate. This study was approved by the Institutional Review Board at UCLA with IRB protocol number 17-001208.

Statistical Analyses

Descriptive statistics were provided for the result of the questionnaires.

Table 1. Patient Experience Survey

#	Question	N=50
1	**How easy was it to communicate with program staff overall?**	26 (52%) Very Easy 8 (16%) Somewhat Easy 13 (26%) Neutral 3 (6%) Somewhat Difficult
2	How easy was it to schedule appointments?	26 (52%) Very Easy 8 (16%) Somewhat Easy 13 (26%) Neutral 3 (6%) Somewhat Difficult
3	How satisfied were you with program staff's response rate to messages and questions?	22 (44%) Very Satisfied 18 (36%) Satisfied 3 (6%) Somewhat Dissatisfied 7 (14%) Neutral
4	How did participating in the program affect your disease control?	15 (30%) Significant Improvement 12 (24%) Some Improvement 21 (42%) No Change 2 (4%) Somewhat Worse
5	How participating in the program affect your quality of life?	13 (26%) Significant Improvement 15 (30%) Some Improvement 20 (40%) No Change 2 (4%) Somewhat Worse
6	How did participating in the program affect your work productivity?	11 (22%) Significant Improvement 14 (28%) Some Improvement 24 (48%) No Change 1 (2%) Somewhat Worse
7	Did you participate in the cognitive behavioral therapy modules?	6 (12%) Yes 44 (88%) No
8	How did participating in the program affect your mental health?	8 (16%) Significant Improvement 6 (12%) Some Improvement 25 (50%) No Change 1 (2%) Somewhat Worse 10 (20%) Unknown
9	Were your clinic visits scheduled too often, just right or not often enough?	44 (88%) Just Right 6 (2%) Not Often Enough
10	Did you feel you were having lab tests done too often, just right or not often enough?	44 (88%) Just Right 1 (2%) Not Often Enough 5 (10%) Too Often
11	Did you feel you had to fill out surveys too often, just right or not often enough?	39 (78%) Just Right 4 (8%) Not Often Enough 7 (14%) Too Often
12	How accurately do you feel the survey results reflected your opinion of your disease activity and well-being?	17 (34%) Very Accurately 20 (40%) Somewhat Accurately 11 (22%) Neutral 2 (4%) Somewhat Inaccurate
13	How easy was it to navigate the mobile application?	18 (36%) Very Easy 19 (38%) Somewhat Easy 6 (12%) Neutral 4 (8%) Somewhat Difficult 3 (6%) Very Difficult

Table 1. Continued

#	Question	N=50
14	Did you find the graphics and overall 'look' of the application appealing?	40 (81.63%) Yes 9 (18.37%) No
15	Overall, how informative was the application, particularly My Academy?	12 (24%) Very Informative 11 (22%) Somewhat Informative 24 (48%) Neutral 3 (6%) Not Informative
16	Which of the following modules did you complete? (choice=My Fitness)	17/50 (34%)
17	Which of the following modules did you complete? (choice=My Meditation)	13/50 (26%)
18	Which of the following modules did you complete? (choice=My Menu)	17/50 (34%)
19	Which of the following modules did you complete? (choice=My Yoga)	10/50 (20%)
20	Which of the following modules did you complete? (choice=My Accupressure)	5/50 (10%)
21	Is there a topic you would like to see added to My Academy or My Wellness? If so, what topic?	Displayed in Supplementary Table 1.
22	Did you need to access technical support at any time during this study?	7 (14%) Yes 43 (86%) No
23	If so, how many times did you need to access technical support?*	4 (1 Time) 5 (2-5 Times)
24	How reliably were you able to reach technical support?*	3 (27%) Somewhat Reliable 7 (64%) Neutral 1 (9%) Very Unreliable

*Optional question

Results

Patient Demographics

In total, 151 patients had been active on the mobile application in the past year, of which 50 patients were included in this study (Table 2). Regarding the type of IBD, 44% were diagnosed with CD (n=22) and 56% with UC (n=28). Our inclusion cohort had a mean age of 43 years (SD 14 years) and an average BMI of 25.3 (SD 6.6). Of the patients, 44% was female and the majority were White (42%) and of Non-Hispanic ethnicity (90%). Most patients were non-smokers (78%) and 28% of the patients reported alcohol use. The patients stated use of the following medications: Anti-TNF (34%), ASA (16%), Combo-therapy (32%), IMM (10%) and Steroids (6%). Previous abdominal surgeries were reported in 36% of participants.

Table 2. Patient demographics

Variable	All (n=50)
Gender	22 (44%) Female
Disease Type	22 (44%) Crohn's disease 28 (56) Ulcerative colitis
Race	21 (42%) White 4 (8%) Black 3 (6%) Asian 1 (2%) Armenian 21 (42%) Unknown
Ethnicity	4 (8%) Hispanic 45 (90%) Non- Hispanic 1 (2%) Unknown
Current smoker	3 (6%) Current smoker 8 (16%) Former smoker 39 (78%) Never smoker
Age (mean SD)	42.58 SD 13.6
Alcohol use	14 (28%) Yes 36 (42%) No
BMI (mean SD)	25.3 SD 6.6
Disease duration (mean SD)	14.6 SD 11.2
Disease Activity	29 (58%) Clinical remission 11 (22%) Mild disease activity 6 (12%) Moderate disease activity 3 (6%) Severe disease activity 1 (2%) Unknown
Medications - Anti-TNF - ASA - Combo of any - IMM - Steroids - No Meds	 17 (34%) Anti-TNF 8 (16%) ASA 16 (32%) Combo 5 (10%) IMM 3 (6%) Steroids 1 (2%) No Meds
Abdominal Surgeries (%)	18 (36%)

Patient Satisfaction

50 participants completed the Patient Experience Survey to provide feedback on the mobile app (Table 1). Responses to Likert scale questions indicated that patients were overall satisfied with the patient-provider communication interface of the app. When asked how easy it was to communicate with program staff overall, 52% of participants responded with "Very Easy" and 16% responded with "Somewhat easy". A majority of participants also found it easy to schedule appointments through the app, with 52% and 16% responding with "Very Easy" and "Somewhat Easy", respectively. In addition, a large majority (88%) of

participants reported that the frequency of completing lab tests, surveys, and scheduling clinic visits was "just right" (Table 1). Regarding the ease of app use, 74% of participants expressed the app was either "Very easy" or "Somewhat easy" to navigate.

Additionally, a majority of participants reported an improved perception of disease control and QoL. 54% of participants indicated significant or some improvement in their disease control. When asked how program participation affected QoL, 26% expressed significant improvement and 30% expressed some improvement. Regarding work productivity, 44% expressed significant or some improvement.

When participants were asked whether they would recommend this app to their friends, family, or other patients on a ten-point scale, with 10 being most likely, the median score was 8 and 79% indicated a score of greater than 5. When asked about how informative the app was, 46% of patients felt that application was "somewhat" or "very" informative.

Patient Usage of Educational Modules

A majority of patients completed modules as part of their participation in the program. The most-used modules were "My Fitness" and "My Menu" (Table 1). Among the patients that participated in the CBT modules (12%), 28% indicated significant or some improvement in their mental health.

When asked about what they liked and disliked about the modules, patients identified positive aspects to be the modules' informative content, ease of use, and support of overall well-being (Table 3). For example, one patient said, "They're easy and I feel great afterwards." Another patient expressed liking the modules because they "encourage me to take care of my whole self instead of the focus just being on taking my meds".
The most common reason for not liking the modules was being unsure of the purpose or need for them (8%), particularly for modules where patients already had their own interventions in place. For example, one patient said they "didn't feel [the modules] applied to me" while another expressed that they "thought [the module] was good but [I have my] own routine for working out [with regards to My Fitness]."

Patient Feedback

In the Patient Experience Survey, patients could provide optional suggestions about additional topics and functionalities they would like the app to cover, which were not presently included (Table 4). One participant for instance suggested adding a subsection

Table 3. Patient Optional Feedback on Modules (n=50).
Patients provided open-ended feedback about the educational modules. Their responses were grouped into categories based on common themes identified across responses.

What patients liked about modules	Count	Examples of patient feedback
Informative content	7	"Modules contained useful information." "My Meditation provided helpful tips."
Ease of use	3	"Very user friendly"
Ease of communication with provider	1	"Liked the VQ visual display. The app gave me comfort because it gave me access to the doctors especially when you have this disease."
Supports overall well-being	2	"I like that the modules encourage me to take care of my whole self instead of the focus just being on taking my meds."
Reminders to complete the modules	1	"I like to get reminded to complete the modules, they're easy and I feel great afterwards."
Yoga module was simple and effective	1	"I liked the yoga app because it was simple and effective.."
Total	15	
What patients disliked about modules	**Count**	**Examples of patient feedback**
Not informative	1	"Modules need to contain information that is more specialized."
Difficult to use	2	"Hard to navigate."
Unresponsiveness from staff	1	"Not responsive from staff."
Didn't know about modules	2	"I did not know about the modules."
Takes too long to complete	1	"Liked overall content and goal that IBD trying to aim for. Time issue for completing the module."
Problem with a specific module (My Yoga, My Acupuncture, etc.)	1	"Yoga portion could contain an audio aspect... stopping and reading about doing the yoga was counter-productive to my relaxation."
Unsure of purpose or need for them	4	"Didn't feel like they applied to me, personally."
Total	12	

about nutritional advice related to "Veganism" within the My Menu module. Other recommendations included adding a "symptoms tracker", allowing patients to indicate what symptoms or lack thereof that they were experiencing, and generating in-app reminders for blood draws or lab orders. Other patient-recommended categories to add were the ability to chart lab results, side effects of their consequent medications, and health topics specific to gender (Table 4).

Table 4. Patient Optional Feedback on UCLA eIBD
Patients provided open-text suggestions to improve the app in general. These suggestions were grouped into categories of comment types, including improvements in app content such as possible additional topics and features, as well as miscellaneous critiques.

Comment Types	Total Count	Examples of patient feedback (count)
Suggestions for new app articles and topics	8	Module on acupuncture (1) Module on veganism (1) Medication side effects (1) Female health topics (1) Blood draw instructions (1) Resources for recommended pathways (i.e., local places to get nutritional advice, do yoga, fitness) (1) FAQ for family and friends (1)
Suggestions for new app features and tools	3	Ability to chart lab results (1) Symptom tracker (2)
Suggestions for better app technical aspects	3	Touch ID for sign in (1) No automatic logoff (1) Different languages (1)
Miscellaneous improvement suggestions	4	Staff response rate faster at beginning of program (1) Poor wording of some in-app questionnaires (2) - i.e., "I don't like the wording of the questionnaires. i felt they lacked nuance. none asked if i felt overwhelmed, anxious, or preoccupied by disease things. just 'angry' or 'depressed' which i think are really different experiences." - i.e., "Sometimes I feel just saying on a scale from 1 to 10, how my disease affects my work or social life is too broad a question" Lacks in-depth, longer-term info about IBD (1) - i.e., "app is good for people new to ibd but doesnt offer as much for people who have had ibd for a while and want more in depth information."

Patients' feedback regarding general comments about the app are also shown in Table 4 ("Miscellaneous Improvement Suggestions"). One patient stated, "I think this is a great idea and will be very helpful to future patients. I really like being able to communicate with the office without always having to call." Most patients who provided comments also highlighted aspects that could be improved, such as the app interface (i.e., adding a touch ID option to login; prevent automatic logoff from the app). Other participants reported critical feedback on app content. For instance, one patient stated that the app "this is good for people new to IBD, but doesn't offer as much for people who have had IBD for a while and want more in depth information."

Discussion

Principal Findings

Our study collected feedback on patient experiences with the UCLA eIBD app after one year of use. Our results could provide guidance for further app development and provide critical feedback for other e-Health apps like it. The outcomes suggest that patients strongly favored the ease of patient-provider communication, with 78% being satisfied. Beneficial outcomes were also seen in patient-reported measures, with 54% reporting a perceived improvement in disease control and 56% reporting a perceived improvement in QoL, indicating that a majority of patients felt the platform positively impacted their health. Patients having access to home telemonitoring in the palm of their hand may give them a greater sense of autonomy of their chronic condition management.

Additionally, participants rated this app with median score of 8 on a ten-point scale (10 being most likely) to recommend this app to friends, family or other patients. This rating suggests that while patients would strongly recommend the app to others, there is still room for improvement. Their suggestions to improve the app were centered on specific content interests and the need for additional educational categories (i.e. female health topics) rather than technical problems or lack of need for an app. The fact that suggestions were less focused on the design features could be explained by the overall satisfaction rate of 74% of participants finding the app easy to navigate. "My Fitness" and "My Menu" were the two most-used optional wellness modules, with each receiving 34% completed status. Our findings suggest that a platform with interactive modules promoting healthy lifestyle habits along with increased access to communication with healthcare providers is well-received by IBD patients and may potentially result in enhanced satisfaction with outpatient care delivery.

Comparisons

Mobile tools such as UCLA eIBD have been shown to have promising implications in improving healthcare delivery and integrating into patients' daily lives. Earlier comparison studies of UCLA eIBD have found impacts on cost and healthcare utilization and identified its unique features, such as automated messaging to care coordinators[17,23-25]. To complement previous outcome studies, this study aimed to understand patients' satisfaction and feedback to help elucidate gaps in current e-Health technologies and inform future designs.

For instance, GI Buddy is a mobile app developed by the Crohn's Colitis Foundation which enables patients to self-monitor their disease and receive reminders about clinical appointments; however, users cannot directly interact with their providers[26]. Similarly, while current apps for IBD may be useful for patient monitoring and self-management, many lack professional medical involvement and adherence to clinical guidelines[4]. UCLA eIBD addressed this gap by allowing users to make appointments and message their providers via the platform, in which a majority of users found it "easy" or "very easy" to communicate with their providers. Another self-management tool, myIBD Coach, showed feasibility among patients and providers[15]. 79% of UCLA eIBD users would recommend this app to others (indicated by a score of greater than 5 on the recommendation score item), compared to the 93% found from myIBD Coach's feasibility study[15].

The findings of this patient satisfaction study demonstrate the feasibility of UCLA eIBD as a remote monitoring tool and some advantages it can provide for both patients and providers. In addition to patient-provider communication features, the platform's educational modules are more diverse than previous tools and provide patients with more alternatives to aid traditional medicine, such as acupuncture, cognitive behavioral therapy, and meditation. These optional modules may improve IBD patients' wellbeing and productivity beyond the scope of their disease. Tracking the various modules that patients use can also provide care teams with broader information to create more personalized treatments.

Limitations

Some study limitations should be noted. As selected patients were individuals who use smartphones, they may be more adept to the usage of apps. Participants were also actively recruited and agreed to participate in this study; thus a selection bias may have impacted study results due to participants being predisposed to wanting to improve their health via e-Health solutions. We further acknowledge the sample size was small and relatively homogenous; however, we feel it was adequate for the purpose of directing the future development of this UCLA app and other healthcare apps.

Additionally, the fact that we invited participants to evaluate the app's feasibility, rather than making it mandatory during app usage, may explain the response rate of 33%. The response rate should further be considered in the context of challenges associated with adopting e-Health technologies into the healthcare space. The obstacles to widespread, long-term integration of e-Health technologies (i.e., loss of interest, data entry burdens)

are still being investigated[27,28]. Despite the growing population of individuals who use mobile health apps, many stop using them over time[29]. Our findings help provide insight to consumer perspectives on app usability and possible explanations to circumvent these challenges.

Future Outlook

In an era where the use of mobile technology has become irreplaceable in daily life, there is undoubted benefit of incorporating e-Health applications in the management of chronic conditions. Studies have shown proven effect of mobile applications but also that patients still desire improvements to existing solutions. We showed that UCLA eIBD and its holistic approach has led to greater patient experience and satisfaction, which can provide useful recommendations for healthcare providers and app developers. However, larger and controlled studies are recommended to assess its efficacy at a larger scale and its impact on costs.

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