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“Simpleness”: a qualitative description study exploring patient perspectives on the barriers and facilitators of using digital health tools to self-manage inflammatory bowel disease

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Abstract

Background: Inflammatory bowel disease (IBD) is a chronic condition requiring lifelong management and frequent interactions with healthcare providers. Digital health tools have the potential to enhance disease management by providing real-time data and improving care coordination. Despite their potential, there is limited evidence on patient perspectives regarding barriers and facilitators to the adoption of these tools.

Objectives: To explore patient perspectives on the barriers and facilitators associated with using digital health tools for IBD self-management, focusing on the adoption of a tool called MyIBDToolkit.

Design: This study employed a qualitative description approach to gather detailed insights into patient experiences.

Methods: Participants with a confirmed IBD diagnosis were recruited from clinics in Alberta, Canada. Data were collected via virtual semi-structured interviews conducted between June and July 2024. Thematic analysis was used to identify key themes, and member checking ensured the credibility of the findings.

Results: Eighteen interviews were conducted, reaching thematic saturation. Participants viewed MyIBDToolkit as beneficial for enhancing disease monitoring and care coordination. However, concerns about data entry burden, privacy, and engagement emerged as significant barriers. Variability in healthcare provider use of the tool was another critical concern.

Conclusion: While digital health tools such as MyIBDToolkit have the potential to improve IBD self-management, addressing barriers such as usability, privacy, and sustainability is crucial. Incorporating patient feedback during the design process can enhance the effectiveness and acceptability of these tools in chronic disease management.

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Plain language summary

Patient views on using digital tools to manage inflammatory bowel disease

This study looked at how people with Inflammatory Bowel Disease (IBD) feel about using digital health tools to help manage their condition. IBD is a long-term illness that affects the digestive system and requires constant monitoring. Researchers wanted to understand what helps or makes it harder for patients to use digital tools to manage their disease. Eighteen people with IBD from Alberta, Canada, were interviewed for the study. They were introduced to a digital health tool called “MyIBDToolkit,” designed to help patients track their symptoms and share information with their doctors. Many participants said

they liked the idea of using the tool, as it could make it easier to monitor their health and communicate with healthcare providers. They believed it could lead to better care and faster treatment.

However, some participants also mentioned concerns. They worried about the effort required to regularly enter data into the tool and whether healthcare providers would actually use the information. Privacy and security of personal health data were also important concerns for some users.

The study concluded that while digital tools like MyIBDToolkit have potential, their success depends on making them easy to use and addressing concerns about privacy. Including patient feedback in the design process can improve these tools, making them more effective for managing IBD.

Keywords: digital health, electronic health records, patient perspectives, qualitative research, self-management

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Introduction

Inflammatory bowel disease (IBD) is a chronic condition characterized by persistent inflammation of the gastrointestinal tract, primarily comprising Crohn's disease and ulcerative colitis. Effective management of IBD requires lifelong monitoring, complex medication regimens, and frequent interactions with healthcare providers (HCPs) to prevent disease flare-ups and complications.[1] The growing popularity of digital health tools offers a promising approach to enhance chronic condition management by providing patients and HCPs with real-time data and improving the coordination of care.[2]

Several high-quality reviews have demonstrated that digital health tools can improve patient outcomes by facilitating self-management, enhancing communication with HCPs, and providing educational resources tailored to patient needs.[3,4] For instance, a high-quality systematic review of 30 qualitative studies on patient perspectives regarding digital interventions for the self-management of chronic physical health conditions revealed that patients using these tools for diseases such as hypertension, diabetes, and chronic obstructive pulmonary disease felt more supported and actively engaged in their healthcare. This increased engagement not only enhanced patient empowerment but also enabled HCPs to manage these conditions more effectively.[5]

However, while numerous studies have concentrated on the technical and clinical aspects of digital health interventions, there remains a notable gap in evidence of how patients perceive these tools, including their usability and the barriers to their adoption. For example, de Jong et al.[6] conducted a randomized controlled trial across two academic and two nonacademic hospitals in the Netherlands involving patients aged 18–75 with IBD. Participants were randomized to receive either standard care or care facilitated by a digital health tool that monitored and recorded disease activity, with follow-up over a 12-month period.

The study found that the digital health tool was safe and effectively reduced outpatient visits and hospital admissions compared to standard care. However, the controlled nature of the trial may not fully reflect the challenges of implementing such tools in real-world settings, where patients do not benefit from constant supervision. In addition, a systematic review examining the patient and public involvement in digital health innovation identified significant gaps between the development and practical application of these tools.[7] The review highlighted that digital health tools are often developed without sufficient input from end-users, resulting in the recognition of barriers without corresponding solutions or actions. The authors emphasize the importance of "participatory design," a process that actively involves patients in codesigning digital health tools to better align with their needs and expectations.[7] Given that the success of digital health technologies relies on patient engagement, satisfaction, and sustained use, incorporating patient perspectives is essential.

Our study aims to address this gap by describing patient perspectives on the barriers to and facilitators of using and implementing MyIBDToolkit, a digital health tool designed to assist patients in self-managing their IBD.[8] Integrated into the electronic health record (EHR) system of the Canadian province of Alberta, MyIBDToolkit offers seamless communication and data sharing between patients and providers. By capturing the experiences and opinions of IBD patients, our research will provide valuable insights into the factors that influence the adoption of digital health tools in chronic disease management. The findings of this study have the potential to contribute to the existing body of knowledge and inform the development and implementation of patient-centered digital health interventions that are effective and acceptable to patients.

Methods

Ethical considerations

The Research Ethics Boards at all participating sites approved this study (University of Alberta: Pro00133852; University of Calgary: pSite-23-0059). We compensated participants with a $25 electronic gift card to show our appreciation for their contribution to the study.

Study design

We employed qualitative description (QD) to explore the research question: “What are the potential barriers and facilitators for using MyIBDToolkit for the management of IBD?” QD provides a comprehensive account of phenomena and is commonly used in healthcare and nursing research.[9] We opted to use QD because it allows researchers to capture straightforward descriptions of phenomena that are not easily measured by other means, such as human factors that influence the effectiveness of interventions.[9]

Before each stage of the research process—patient recruitment, data collection, and analysis—the primary author (L.A.), a 23-year-old cisgender male African Canadian medical student with a BSc (Hons) and experience in conducting semi-structured interviews, reflected on his positionality. While L.A. did not have IBD, his lived experiences with gastrointestinal issues heightened his sensitivity to the complexities of chronic disease management, potentially influencing his perspective. The second author (K.D.C.), a 24-year-old cisgender White Canadian woman with an MSc and serving as the study coordinator, brought years of experience in patient-centered research with individuals with IBD. Although she did not have IBD or a chronic condition, she acknowledged that her lack of lived experience might shape her interpretation of the data. Both authors committed to maintaining reflexivity throughout the study to ensure their perspectives constructively informed the analysis while prioritizing participants’ voices.

The study was designed by K.D.C. in collaboration with members of our Patient Advisory Council (PAC) to ensure its relevance and clarity for patients. L.A. conducted the interviews under K.D.C.’s guidance. To refine the interview guide, K.D.C. piloted it with two individuals with IBD: one with complex, active IBD who frequently used digital health tools and another in long-term remission who did not use such tools. We adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item checklist[10] to ensure comprehensive and transparent reporting.

Study population

L.A. recruited participants in person from IBD clinics and endoscopy units in tertiary academic and community hospitals across Alberta and online through university e-newsletters. Eligible participants were required to be 18 years or older with a confirmed diagnosis of IBD. L.A. invited eligible individuals to complete a 5-min anonymous online survey about digital health tools and IBD, which included an option to express interest in participating in a semi-structured interview. Those interested provided their contact information separately from their survey responses.

L.A. contacted all interested participants by telephone to discuss their potential enrollment in the study. To ensure a range of patient perspectives, we aimed to include participants with varying levels of prior experience with digital health tools. Participants were asked to disclose their experience with digital health tools when expressing interest, and we selected a balanced sample that included both experienced and inexperienced users. This approach ensured that the study captured opinions from those who were both familiar and unfamiliar with the types of tools under discussion.

Data collection

After obtaining informed consent and confirming participants' IBD diagnoses using their medical records, we scheduled one-on-one semi-structured interviews with participants via an online video conferencing platform between June 2024 and July 2024. A relationship between the researchers and participants was not established prior to the study's commencement. Participants were informed about the goals of the research, which focused on understanding patient experiences with digital health tools, and that the primary researcher, L.A., was a medical student conducting the study. No repeat interviews were carried out as the initial interviews were deemed sufficient for addressing the research objectives. In each interview, L.A. used the interview guide (see Supplemental Material 2) to ensure consistency while remaining flexible and encouraging respondents to elaborate on unexpected topics that emerged.

During the interviews, L.A. informed participants of existing features of Alberta's EHR system, EPIC (Version 2024; EPIC Systems Corporation, Verona, WI, USA),[11] which includes access to lab results, appointment schedules, communication with HCPs, and summaries of appointments, with links to resources. He then introduced participants to our bundled digital health tool, MyIBDToolkit, and demonstrated how elements of the tool, including symptom tracking, mental health resources, and dietary education, would integrate into their EHR, allowing them to share this information with their gastroenterologist.

Our study design required us to continue data collection until we reached thematic saturation, defined as the point when no new themes emerged from the data.[12] A systematic review by Hennink and Kaiser[13] demonstrated that thematic saturation can be achieved in qualitative studies with relatively small sample sizes, typically ranging from 9 to 17 participants.

Data management and analysis

Our protocol required transcribing the interview recordings verbatim and removing all identifying information. Transcripts were shared with participants to verify accuracy and ensure resonance with their intended meanings before proceeding to thematic analysis. Thematic analysis involves developing themes through coding, categorizing, and connecting data.[14] Two independent coders, L.A. and K.D.C., conducted line-by-line coding of the transcripts using NVivo 14[15] to identify recurrent concepts. During the coding process, they highlighted significant sections of the transcripts and made margin notes about salient data points. As new codes emerged, they revised earlier interviews and ensured no codes were missed. Once no additional codes emerged, both coders independently grouped similar codes into higher-order categories. L.A. and K.D.C. then compared and discussed emerging codes and themes. To improve the accuracy of our results, L.A. and K.D.C. reviewed all themes with the senior author (K.W.), a gastroenterologist with expertise in digital health tools for IBD, and with members of the PAC.

Establishing trustworthiness

We defined rigor in qualitative research through the concept of trustworthiness,[16] which is essential for ensuring the credibility and reliability of qualitative findings. Trustworthiness encompasses four key elements: credibility, transferability, dependability, and confirmability.[16] To enhance credibility, we employed two main strategies. First, during the interviews, we used member checking, a process where researchers share their interpretations or summaries of the data with participants to verify accuracy and resonance with the participants' intended meanings.[17] This approach ensured that our interpretations accurately reflected participants' perspectives and reduced the risk of misrepresentation. Second, during data analysis, the two coders engaged in peer debriefing, employing a critical friend approach to discuss and reach a consensus on coding and interpretation, thereby strengthening the analytical process.

Transferability was addressed by providing rich, detailed descriptions of the participants, the interview setting, and relevant contextual factors, allowing readers to assess the applicability of the findings to other settings or populations. To ensure dependability and confirmability, we implemented multiple strategies. After each interview, we documented detailed field notes to capture the research context, initial impressions, and potential influences on the data collection process. Both coders also maintained reflexive journals throughout the study, critically examining their personal experiences, assumptions, and emotional responses. This reflexive practice helped to identify and minimize the influence of preconceived notions and biases on the data analysis (see Supplemental Material 3, authors positionality statement).

Results

Sixty participants completed the online survey, with a median age of 33 years (IQR: 24.5–44; range: 18–76). Among the respondents, 60.0% (36/60) identified as female, 38.0% (23/60) as male, and 1 respondent identified as both gender fluid and nonbinary. Regarding their IBD diagnosis, 48.0% (29/61) reported having Crohn's disease, 31.0% (19/61) had ulcerative colitis, and 20.0% (12/61) were diagnosed with IBD-Unclassified.

In terms of experience with digital health tools, 47.0% (28/60) indicated they currently use or have previously used such tools to manage their IBD, while 53.0% (32/60) had never used them. Of the 60 survey participants eligible for interviews, 38 expressed interest in participating. All interested participants were contacted to obtain consent, and those who participated in the interviews were medically confirmed to have IBD.

We reached thematic saturation after conducting 18 interviews, with interview durations ranging from 7 to 50 min (median: 16 min). Among the 18 interview participants, 9 had Crohn's disease, 8 had ulcerative colitis, and 1/18 had IBD-Unclassified. Seventeen of the 18 interviewees were of European descent. The age range was 18–72 years, with 11 identifying as female and 8 as male. We classified urban, suburban, and rural status with groupings used by Statistics Canada for census data:[18] 10 lived in an urban location, 3 lived in a suburban location, and 5 lived in a rural location.

Participants had lived with IBD for a median of 12 years (range: 0–47 years). Five of the 18 had completed high school, 7 had a post-secondary certificate or diploma, 4/18 held a bachelor's degree, and 2 had completed a graduate degree. In addition, 11 of the 18 had previously accessed their medical information through an EHR (Table 1).

Self-management

Participants were asked about their experiences with self-managing their disease, defined as the aspects of disease management they felt they could control. All 18 participants reported engaging in self-management, with 16 identifying treatment adherence as a critical aspect they managed independently. In addition, 11 participants highlighted diet as another key area of self-management they handled on their own. Other areas of self-management included physical activity, symptom journaling, stress management, memory-based tracking, and seeking external information beyond what their gastroenterologist provided.

When asked whether they shared the information they collected while self-managing their IBD with their gastroenterologist, 14 participants reported that they did, most commonly during in-person appointments. The remaining four participants did not share this information, citing reasons such as not wanting to take up the physician's time and not being prompted by their gastroenterologist during appointments.

Digital disease management

When we described our bundled digital health tool, MyIBDToolkit, to each of the 18 participants, 15 of them expressed positive feelings about the tool, noting that it would likely be beneficial for their care.

> Yeah, I think it would be great. I mean, I obviously would only share things that I think would be important for her to see, but I think if that was available, I would definitely use it, and I could see how valuable it would be.—Participant 2

The remaining three participants expressed a mix of neutral and negative feelings about the tool, indicating that they may not use it or would not use it at all.

> Forget it, because I won't do it. If they want to send me the information. But I won't enter anything into it. I just don't do that. I'm not a computer guy. I never will be, and I just use it for recovering information from them. And I'm not very well, I'm

Table 1. Demographics of participants who participated in the semi-structured interviews.

Participant ID	Age	Gender	Location	Years with IBD	Highest level of education	Previously accessed their EHR?
1	30	Female	Urban	10	Graduate degree	Yes
2	28	Female	Suburban	12	Graduate degree	Yes
3	18	Female	Urban	9	High school	No
4	65	Female	Urban	19	Bachelor's degree	No
5	38	Female	Rural	28	Bachelor's degree	No
6	57	Male	Rural	32	Post-secondary certificate or diploma	Yes
7	33	Male	Rural	7	Bachelor's degree	Yes
8	41	Male	Urban	21	High school	Yes
9	54	Male	Urban	35	Post-secondary certificate or diploma	No
10	29	Female	Urban	12	Post-secondary certificate or diploma	Yes
11	46	Female	Rural	11	High school	Yes
12	43	Female	Urban	0	Post-secondary certificate or diploma	Yes
13	44	Female	Suburban	19	Post-secondary certificate or diploma	Yes
14	61	Male	Suburban	7	Post-secondary certificate or diploma	No
15	31	Male	Urban	8	Post-secondary certificate or diploma	No
16	22	Female	Urban	14	High school	No
17	33	Male	Rural	17	Bachelor's degree	Yes
18	72	Male	Urban	47	High school	Yes

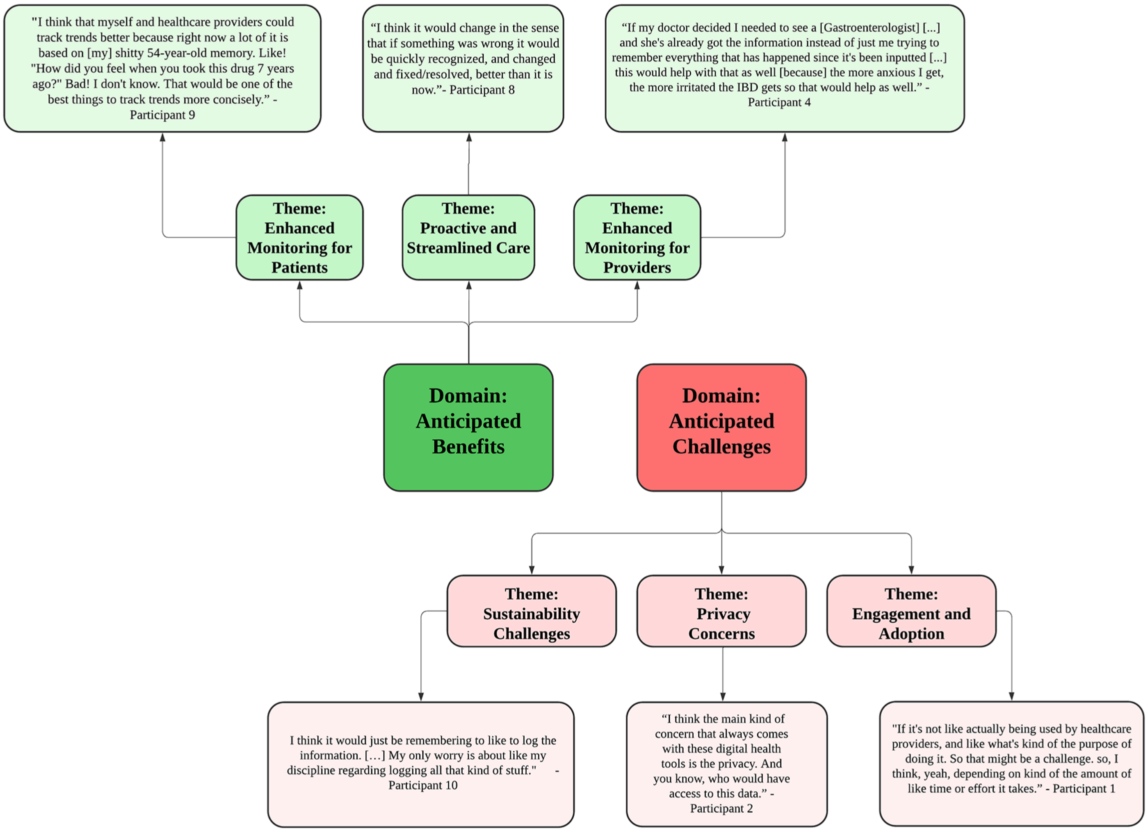
EHR, electronic health record; IBD, inflammatory bowel disease.

> not very good at that, either. Because I don't understand doctor talk.—Participant 18

Anticipated benefits and challenges with digital health tools

We identified several themes in responses to questions about how participants anticipated a tool such as MyIBDToolkit would alter their care. We sorted the themes into two domains: Anticipated Benefits (three themes) and Anticipated Challenges (three themes). A brief overview of each domain is presented below; the relationship between each theme and relevant quotes belonging to each theme is available in Figure 1.

Anticipated benefits. This domain includes themes focused on how the use of MyIBDToolkit would improve health care.



"I think that myself and healthcare providers could track trends better because right now a lot of it is based on [my] shitty 54-year-old memory. Like! "How did you feel when you took this drug 7 years ago?" Bad! I don't know. That would be one of the best things to track trends more concisely." - Participant 9

"I think it would change in the sense that if something was wrong it would be quickly recognized, and changed and fixed/resolved, better than it is now."- Participant 8

"If my doctor decided I needed to see a [Gastroenterologist] [...] and she's already got the information instead of just me trying to remember everything that has happened since it's been inputted [...] this would help with that as well [because] the more anxious I get, the more irritated the IBD gets so that would help as well." - Participant 4

I think it would just be remembering to like to log the information. […] My only worry is about like my discipline regarding logging all that kind of stuff." - Participant 10

"I think the main kind of concern that always comes with these digital health tools is the privacy. And you know, who would have access to this data." - Participant 2

"If it's not like actually being used by healthcare providers, and like what's kind of the purpose of doing it. So that might be a challenge. so, I think, yeah, depending on kind of the amount of like time or effort it takes." - Participant 1

Figure 1. Domains and themes that characterize participants' expectations of the value of using MyIBDToolkit.

Theme 1: Enhanced monitoring for patients. Ten participants stated that access to MyIBDToolkit would be beneficial for monitoring their own disease, allowing them to better understand their symptoms while providing tools for diet and medication tracking.

Theme 2: Enhanced monitoring for providers. Thirteen participants stated that MyIBDToolkit would facilitate their HCP's ability to monitor their disease enabling easier communication of tracked information and enhancing providers' understanding of their symptoms.

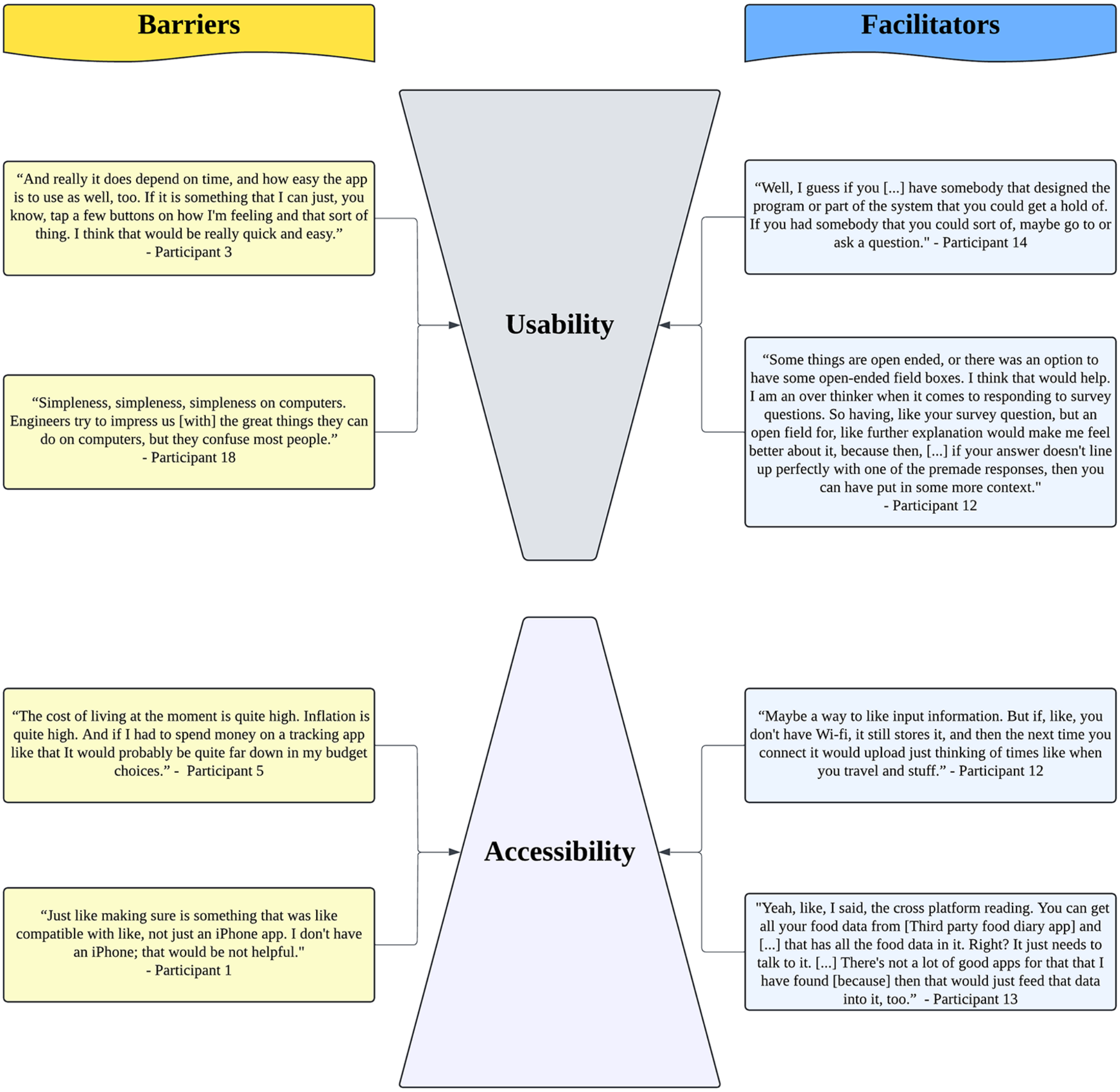
Theme 3: Proactive and streamlined care. Six participants mentioned that MyIBDToolkit could lead to more proactive and streamlined care, as it would promote better collaboration among HCPs, shifting care from reactive to proactive, and potentially increasing the speed at which they receive care.

Anticipated challenges. This domain includes themes focused on potential challenges and concerns pertaining to the use MyIBDToolkit.

Theme 1: Sustainability challenges. Seven participants mentioned concerns about the sustainability of using the tool, including the consistency of use and the burden of regularly entering data into the system.

Theme 2: Engagement and adoption. Five participants highlighted engagement and adoption of the tool as significant challenges, stating either that they lacked interest in using the tool or were concerned that HCPs might not utilize it effectively.

Theme 3: Privacy concerns. Privacy protection was a significant concern for six participants who expressed doubts about the security of their data and how effectively their information would be protected.



"And really it does depend on time, and how easy the app is to use as well, too. If it is something that I can just, you know, tap a few buttons on how I'm feeling and that sort of thing. I think that would be really quick and easy." - Participant 3

"Simpleness, simpleness, simpleness on computers. Engineers try to impress us [with] the great things they can do on computers, but they confuse most people." - Participant 18

"Well, I guess if you [...] have somebody that designed the program or part of the system that you could get a hold of. If you had somebody that you could sort of, maybe go to or ask a question." - Participant 14

"Some things are open ended, or there was an option to have some open-ended field boxes. I think that would help. I am an over thinker when it comes to responding to survey questions. So having, like your survey question, but an open field for, like further explanation would make me feel better about it, because then, [...] if your answer doesn't line up perfectly with one of the premade responses, then you can have put in some more context." - Participant 12

"The cost of living at the moment is quite high. Inflation is quite high. And if I had to spend money on a tracking app like that It would probably be quite far down in my budget choices." - Participant 5

"Just like making sure is something that was like compatible with like, not just an iPhone app. I don't have an iPhone; that would be not helpful." - Participant 1

"Maybe a way to like input information. But if, like, you don't have Wi-fi, it still stores it, and then the next time you connect it would upload just thinking of times like when you travel and stuff." - Participant 12

"Yeah, like, I said, the cross platform reading. You can get all your food data from [Third party food diary app] and [...] that has all the food data in it. Right? It just needs to talk to it. [...] There's not a lot of good apps for that that I have found [because] then that would just feed that data into it, too." - Participant 13

Figure 2. Participant-identified factors that would influence their use of MyIBDToolkit.

Additional features. In addition to the features of MyIBDToolkit that we described to participants, several participants suggested additional functionalities that they believed could be added to our bundled digital health tool to enhance their care. These included notifications and reminders for data input, an algorithmic and AI-based monitoring alert system, and digital stool sampling.

Implementation considerations

We identified two main themes when discussing potential barriers to and facilitators of using MyIBDToolkit with participants: usability and acceptability. Detailed quotes for each theme can be found in Figure 2.

Usability. We defined usability as the ease with which patients could envision effectively using the digital health tool to manage their disease. Participants emphasized the importance of a user-friendly interface to encourage consistent use, noting that a complex or unintuitive design could deter engagement. Two participants expressed concerns about feeling overwhelmed by excessive information, especially given their limited comfort with technology. To enhance usability, five participants suggested incorporating features that simplify data entry, such as premade selections, options for written responses, and accessible technical support.

Accessibility. We defined accessibility as how easily patients could access the tool. Mobile accessibility was a key topic, with seven participants stating that having the tool available on mobile devices and compatible with multiple operating systems (e.g., iPhone and Android) would increase usability. One participant mentioned that if the tool required payment to access, it would act as a financial barrier, making them less likely to use it. One participant pointed out that integration with other digital health tools, including those created by Alberta Health Services and third-party tools, would improve accessibility and overall usability. Another participant mentioned that having offline access to the tool would further enhance its accessibility.

Discussion

Summary of findings

This study characterized the perspectives of individuals with IBD regarding barriers and facilitators associated with using a digital health tool specifically designed for disease self-management. The 18 interview participants expressed a range of views on self-management and digital disease management, with most being receptive to using such a tool, citing perceived benefits, including enhanced disease monitoring and streamlined care. However, challenges such as sustainability, uptake, and privacy concerns were also noted. These findings provide valuable insights into patient perspectives on the potential implementation of digital health tools in IBD management.

Comparison with existing literature

Our study builds upon previous research on the importance of integrating patient-centered digital tools into existing EHR systems to enhance care coordination among individuals with chronic health conditions.[19] The feedback from participants in our study underscores the potential value of digital health tools such as MyIBDToolkit for facilitating better communication with HCPs while improving the patient's understanding of their disease symptoms and management. This is consistent with the broader literature on digital health tools for chronic disease management, where patients generally appreciate the convenience and empowerment offered by such technologies.[20,21]

A specific contribution of our study is its focus on the IBD population, for whom the use of digital tools presents unique challenges and opportunities. Previous research, such as the study by Nielsen et al.,[22] which examined patient perspectives on digital patient-reported outcomes in routine care for IBD, highlighted the potential of digital tools to enhance patient engagement and improve clinical outcomes. Their findings align with ours, showing that patients value the role of digital tools in self-management and fostering more informed interactions with HCPs. Our study adds a critical layer by characterizing not just the perceived benefits but also the barriers to uptake, such as concerns about data security, the need for personalized features, and integration with existing care workflows.

Similarly, the study by Gold et al.,[23] identified and evaluated mobile applications specifically designed for IBD self-management, revealing that while many apps are available, few are truly tailored to meet the comprehensive needs of IBD patients, such as diet and lifestyle management. This finding supports our observation that while digital tools hold promise, their effectiveness is contingent on how well they are tailored to the specific needs of IBD patients. Our study contributes to the literature by providing a detailed analysis of patient preferences, highlighting the need for customizable and integrative solutions that address the full spectrum of IBD management.

Practical implications

To successfully integrate digital health tools like MyIBDToolkit into IBD management, key considerations include prioritizing user-friendly designs with simplified data entry methods and customizable features to enhance usability. Robust privacy protocols and transparent communication about data security are essential for building trust. Seamless integration with existing EHR systems and mobile compatibility can facilitate real-time data sharing and improve accessibility. Engaging HCPs through training programs ensures effective use of these tools in care plans, fostering patient trust. Including patients in the design process ensures the tools address user needs, while embedded educational resources, technical support, and gamification elements can sustain engagement. Pilot testing with diverse patient groups allows for iterative improvements, increasing the likelihood of successful adoption. Addressing these factors can empower patients, enhance care delivery, and improve clinical outcomes.

Strengths and limitations

A key strength of this study is its emphasis on patient perspectives, offering direct insights into user expectations for digital health tools such as MyIBDToolkit. By employing a qualitative descriptive approach, we captured a nuanced understanding of the barriers and facilitators associated with adopting digital tools in chronic disease management. Our semi-structured interviews conducted face-to-face by a trained interviewer allowed us to establish rapport with respondents, so they felt at ease expressing their views on open-ended questions. Our recording of these interviews allowed us to capture participants' responses verbatim, minimizing missing or erroneously transcribed data. The diversity within our sample, including variations in age, gender, location, and experience with digital health tools, further strengthens the study. In addition, the involvement of a PAC in developing the interview guide and reviewing themes enhances the trustworthiness and relevance of our findings.

However, the study does have some limitations. The predominance of participants of European ancestry limits the generalizability of the findings to more diverse populations, including those of non-European ancestry. Therefore, the results cannot be assumed to apply broadly to all demographic groups. Moreover, the study did not include individuals with IBD who receive care at general gastroenterology clinics as opposed to IBD specialty clinics, thus, the findings may have less relevance for patients without access to care from IBD specialists at tertiary centers. While face-to-face interviews are a strength of our design, they have the potential for interviewer and responder bias, which we sought to mitigate through the use of trustworthiness practices.

Future directions

To further understand the barriers to and facilitators of patient uptake of digital health tools, future research should focus on characterizing individuals based on their level of involvement in managing their health. Identifying common traits among those who are highly engaged versus those who are less involved could provide valuable insights into tailoring digital health tools to better meet the needs of different patient groups and improve their uptake and sustained use. Such information could inform targeted interventions designed to encourage greater engagement in disease self-management among less-involved patients, ultimately improving their care outcomes. In addition, future studies should be designed to provide patients with opportunities to pilot digital health tools, allowing them to offer more specific and practical feedback. This approach would not only refine the tools themselves but also ensure they are better aligned with the needs and preferences of diverse patient populations.

Conclusion

This study underscores the potential benefits and challenges associated with implementing digital health tools for the management of IBD. Through a comprehensive qualitative analysis of semi-structured patient interviews, we identified key barriers and facilitators affecting the use of these tools. Patients generally perceived these tools as potentially valuable for enhancing self-management and communication with healthcare providers. However, issues related to usability, uptake, and privacy emerged as significant concerns. Addressing these challenges using iterative research and development cycles is crucial for ensuring the successful adoption of digital tools in IBD patient care. Future research should aim to develop targeted strategies to mitigate these barriers, with a particular focus on diverse patient populations and varying healthcare contexts. In addition, incorporating patients as codesigners in the development process of digital health tools will enhance their relevance and effectiveness, leading to improved patient engagement in self-management activities and, ultimately to improved health outcomes.

Declarations

Ethics approval and consent to participate

This study was approved by the University of Alberta Research Ethics Board (Pro00133852) and the University of Calgary Research Ethics

Board (pSite-23-0059). Written and verbal informed consent was obtained from all participants prior to their inclusion in the study.

Consent for publication

No identifiable patient data or images are presented in this manuscript.

Author contributions

Lekan Ajibulu: Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Validation; Visualization; Writing – original draft; Writing – review & editing.

Kaitlyn Delaney Chappell: Conceptualization; Formal analysis; Investigation; Methodology; Supervision; Writing – review & editing.

Cynthia H. Seow: Data curation; Investigation; Project administration; Writing – review & editing.

Karen J. Goodman: Conceptualization; Funding acquisition; Supervision; Writing – review & editing.

Karen Wong: Conceptualization; Data curation; Funding acquisition; Resources; Supervision; Visualization; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

All relevant data generated or analyzed during this study are included in this published article. Further inquiries can be directed to the corresponding author.

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Supplemental material

Supplemental material for this article is available online.

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