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ORIGINAL ARTICLE

Exploring Cancer Patients' Perceptions of Accessing and Experience with Using the Educational Material in the Opal Patient Portal

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Abstract

Purpose Opal is a new patient-centered mobile application that gives cancer patients access to their real time medical data in conjunction with disease- and treatment-specific patient education material. Few studies have focused on patients' experiences with such mobile applications. This study's objectives were to (1) explore cancer patients' perceptions of accessing the educational materials through Opal and (2) explore their experiences using these educational materials.

Methods A qualitative descriptive design was used. Patients were invited to participate in the study via Opal itself. Semi-structured individual interviews were done in person or over the phone, transcribed verbatim and analyzed using qualitative content analysis.

Results Nine women were interviewed. Three themes were identified as participants spoke about their perceptions of and experiences with Opal. First, *Opal makes me feel like I have more control*, conveying how learning more about their diagnosis and treatments allowed patients to advocate for themselves and plan their care. Second, *Opal tends to reassure me*, illustrating that having access to information was reassuring. Lastly, *Opal is just starting to have information which could help meet my needs*, reflecting patients' belief Opal is on the right track but could provide more of their medical record, treating team contact information and education material.

Conclusion Patients can feel more empowered when using patient-centered mobile applications, and mobile applications have potential for improving collaboration with healthcare professionals and care coordination. Healthcare professionals, including oncologists and nurses, should support patients' use of mobile applications and integrate them in their patient interactions.

Keywords Mobile applications · Patient education · Cancer · Patient centered care · Patient portal · Health services accessibility

Introduction

Cancer is a chronic illness that entails many psychosocial challenges related to anxiety and depression [1], as well as challenges related to symptoms, treatments and side effects. These can all negatively impact quality of life, employment and home activities [2]. Cancer patients report information needs related to diagnosis, prognosis, and treatment [3] as well as information needs relating to social and emotional well-being [4] Patients turn to many sources of information to meet their needs, including their healthcare provider, family, friends and the internet [5]. Electronic health (eHealth) tools are becoming commonly used to address the information and support needs of people living with cancer [6]. eHealth is defined as the use of information and communication technology to enhance health and healthcare services [7], such as interactive websites, patient portals and mobile applications. These tools have had positive outcomes on knowledge and social support [6]. Research has shown that cancer patients believe eHealth applications can be useful in meeting their information needs [8–10] and can facilitate communication with healthcare providers [9]. A function of eHealth applications patients

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identified as important is the ability to get tailored information about their treatment [10] and about specific problems, for instance cancer-related symptoms [11].

Opal, a new patient-centred mobile health application, co-designed by patients, healthcare professionals and healthcare informaticists, is currently used by cancer patients at the McGill University Health Centre (MUHC) [12]. The idea for Opal started with a breast cancer patient, Laurie Hendren, who believed that all patients should have access to their medical data in order to play an active and informed role in their healthcare [13]. The Opal patient portal offers patients real time access to both education material and medical data. The education material includes information found in the Education tab, which is specific to the patient's diagnosis and treatment phase. The three educational materials in Opal are html versions of printed materials developed with the support of MUHC Patient Education Committee and its Standards for Creating Patient Education Materials. Information specialists, clinicians and patient partners are an integral part of the development of patient educational materials at the MUHC. The educational content is based on best practice standards and all links to external information (such as labtestonline.com) have been vetted by information specialists and patients.

Other educational components of the application are provided in combination with medical data, for example, explanations of blood test results. The medical data are the same information found in patients' medical records and becomes available in Opal at the same time as in their electronic medical record. It includes laboratory test results, radiation oncology consultation notes and appointment schedules [12]. Given the sensitivity of medical information and desire to protect it from cyber-attack, the patients' information is stored on the hospital server and linked to the application and not stored on the patients' mobile devices. Prior to the launch of Opal, a vulnerability assessment was conducted, and recommendations were made to protect patients' information [12]. Patients are informed not to share their passwords and have to sign back-in if the app is left idle.

The literature has shown that cancer patients perceive eHealth tools to be useful [11, 14], have potential to better meet their information needs [9, 10, 15], and that eHealth could have a positive impact on health services delivery [16]. However, there is still a need to "capture what is important from the patients' perspective to improve [eHealth tools'] effectiveness" [17]. There is limited research focused on patients' experiences with disease and treatment specific educational material in mobile applications where education material is available in conjunction with real time medical data. The research questions for the study were: (1) what are cancer patients' perceptions of accessing educational materials through Opal? and (2) what are their experiences with using educational materials in Opal?

Methods

Design

A qualitative descriptive design was used, as this is suited to studies that aim to describe participants' experiences, learn from them [18] and apply findings towards improving practice [19]. The study was conducted at the MUHC and the institution's Research Ethics Board approved this study. The COREQ guidelines were used to ensure rigour in the study report [20].

Recruitment

The recruitment process and reasons for refusal are depicted in Fig. 1. The first part of recruitment was completed through two electronic self-report forms in Opal. Patients were sent a form that included a short description of the study, after which they indicated their interest. Those interested were sent a second form requesting their contact information and answers to three screening questions (see Fig. 1 for more detail). Then, the first author (KM) verified eligibility and scheduled interviews with those who were eligible. Patients were eligible if they were (1) 18 years or older, (2) currently followed at the MUHC for their cancer diagnosis and (3) had the Opal application downloaded on their smartphone. Patients were excluded if they (1) did not speak English or French, Opal is only available in these languages, (2) had been using Opal less than three weeks (3) had not opened the Education tab or the laboratory results tab in My Chart in Opal at the time of recruitment and (4) were not available for interviews between September and November of 2019. Convenience sampling was used and due to women being the large majority of respondents interested in the study and meeting the eligibility criteria, the research team decided to recruit only women. This was not unexpected as Opal was initially only available to breast cancer patients. The research team had set out to recruit 12 patients; however, redundancy in themes was identified within nine interviews putting an end to recruitment [21].

Data Collection

Participants took part in audio-recorded individual semi-structured interviews conducted by KM, a female, where only the interviewer and the participant were present. No prior relationship existed between the interviewer and participants. Participants were aware of the research objectives, and that the interviewer was a master's degree student researcher and nurse, AML and SL were researchers with experience in conducting qualitative research, and JK was part of the Opal development team. Interviews lasted on average 40 min (SD = 15.6, range 15 to 67 min). Seven interviews were

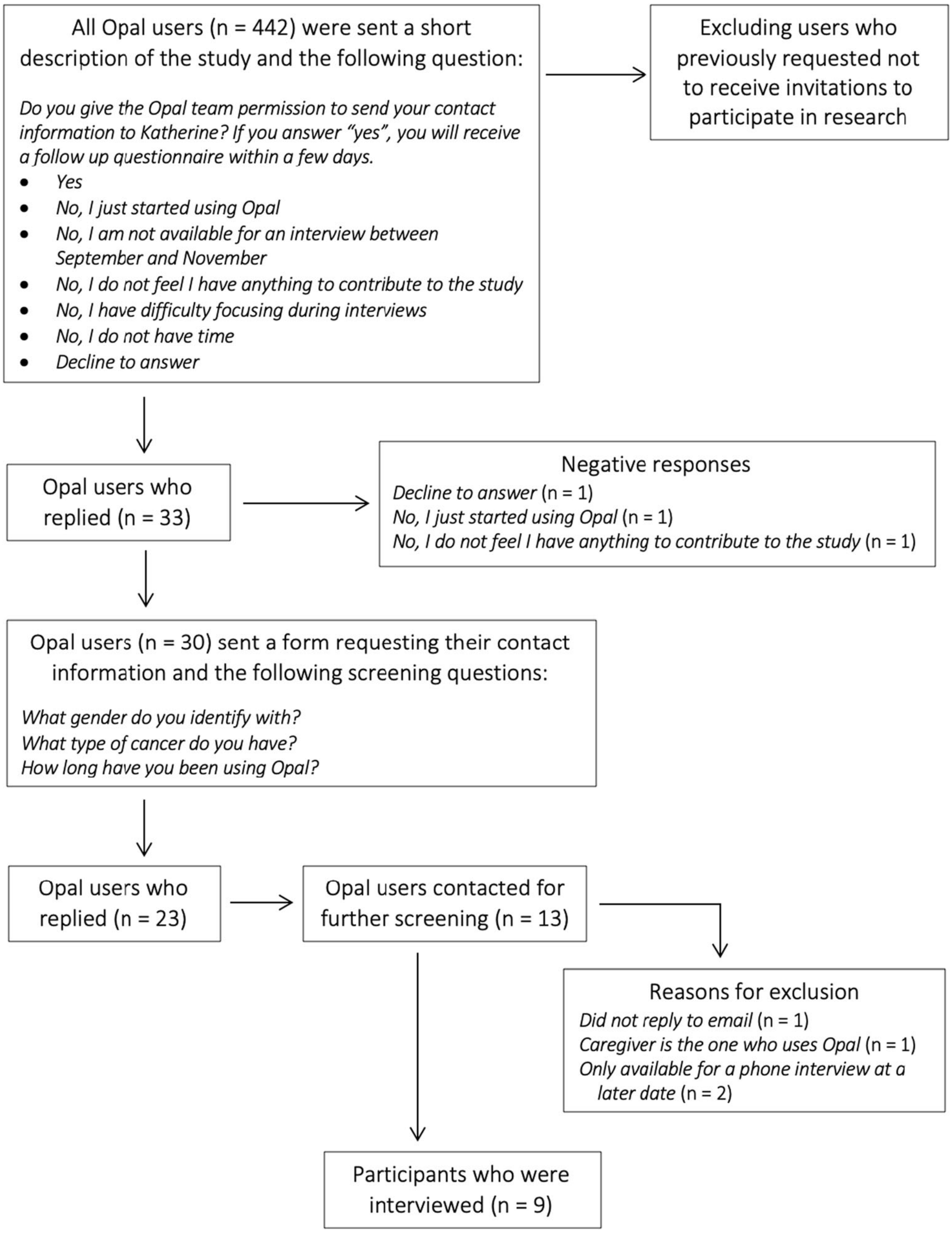


Fig 1 Recruitment process, reasons for refusal and for exclusion

conducted at the hospital and two over the phone. All participants opened Opal during the interview to comment on specific features and content.

The interview guide aimed to explore (1) how educational material is acquired through Opal, (2) how participants use the education material to manage challenges, such as treatment side effects and how they use the educational material during patient—healthcare professional interactions and (3) the perceptions of the educational material found in Opal. Table 1 describes how the interview guide was developed drawing on Gottlieb's Strengths-Based Nursing (SBN) values, *self-determination, collaborative partnership* and *learning, readiness & timing* [22] and from a Patient Engagement Framework with a focus on the sections *engage me*, *empower me* and *partner with me* [23]. The SBN values were used to emphasize individual patient characteristics, complementing organization-level implications of developing eHealth tools brought forward by the Patient Engagement Framework. Both the Patient Engagement Framework and the SBN approach align with Opal's objective of empowering patients [12]. An MUHC patient-partner was consulted during interview guide development for relevance of questions, flow and clarity.

Table 1 Excerpt of interview guide based on the Patient Engagement Framework [a] and Strength-Based Nursing values [b]

Patient Engagement Framework Concept	SBN Values	Questions Derived from Concepts
Engage Me		In general, how comfortable do you feel navigating Opal and finding the information you are looking for? - What helps you find information? - What makes it harder for you to find information?
Empower Me	Learning, Readiness & Timing	Have you ever received information through Opal that you felt did not apply to you? - *If yes*, can you tell me more about that time? - Was it the actual information? The timing of the information? Other?
	Self-Determination	Have you ever felt confused or unsure about information you were given in Opal? - *If yes*, can you tell me more about a time when this happened? - Did you take any measures to increase your understanding? *If yes,* can you describe what you did?
Partner with Me	Collaborative Partnership	Have you ever used Opal to discuss aspects of your care with healthcare professionals *outside of* the oncology department? - *If yes*, did using Opal make your appointment different than previous times? How? - *If no*, is this something you had considered doing?
Empower Me & Partner with Me	Self-Determination & Collaborative Partnership	Have you ever felt the need to contact someone from the clinic about something you read in Opal? - *If yes*, can you tell more about that time? What made you realize you had to speak with someone? Had someone spoken to you about this before? Who did you contact? - Can you give me an example of when you had to contact someone about something you read in the education tab

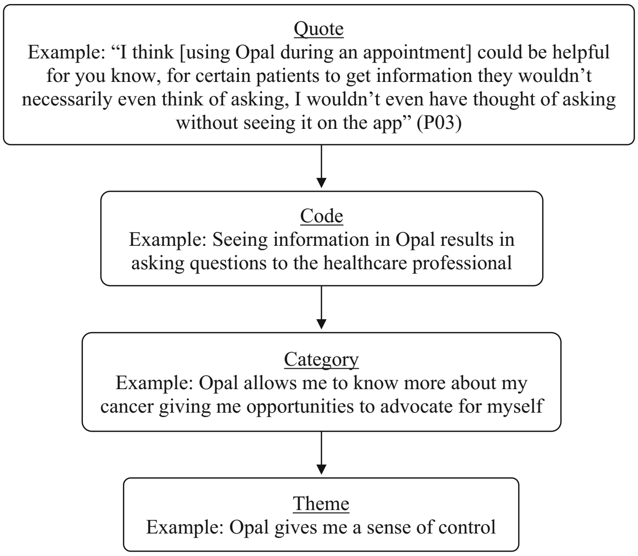
[a] Healthcare Information and Management Systems Society (2014)

[b] Gottlieb L (2013)

Data Analysis

Inductive qualitative content analysis was used to identify themes [24]. Figure 2 shows the coding tree, giving an example of how data were analyzed. While codes were all written in English, verbatim interview transcripts were analyzed in their original language as all members of the research team had good knowledge of English and French.

Interview transcription, reading the interview transcripts multiple times and open coding allowed for identification of codes while staying close to participants' words [24, 25]. KM, AML and SL separately coded the first interview transcript, while KM and AML coded the eight other transcripts. Weekly meetings took place amongst all authors to discuss interview data. Discussions also took place whenever there was a lack of consensus to avoid influencing the data in a way that would misconstrue participants' meaning [26]. The codes were then grouped into categories based on relatedness [25]. Finally, interpretation took place to identify themes representative of the underlying meaning of the participants' experiences [25]. All authors participated in category and theme development.



Example: "I think [using Opal during an appointment] could be helpful for you know, for certain patients to get information they wouldn't necessarily even think of asking, I wouldn't even have thought of asking without seeing it on the app" (P03)

Example: Seeing information in Opal results in asking questions to the healthcare professional

Example: Opal allows me to know more about my cancer giving me opportunities to advocate for myself

Example: Opal gives me a sense of control

Fig 2 Coding tree

Microsoft Office's Excel program was used to support data analysis. Credibility within the interviews was achieved by asking participants for verification of their responses during the interview and member checking across participants [26]. Credibility of the data and its interpretation was achieved through researcher triangulation during data coding and through discussion amongst the research team [26]. Transferability was achieved through in-depth description of both participant characteristics and of research findings [24]. Dependability and confirmability were achieved by maintaining an audit trail, including interview notes and documentation of data analysis strategies. No repeat interviews took place, transcripts were not reviewed by participants and participants were not sought to review study findings due to time constraints for study completion.

Results

Study Participants

Table 2 provides a description of the nine women who took part in the study. The time elapsed since their cancer diagnosis ranged from two months to 11 months. Opal is continuously being developed and content is progressively being added therefore participants had varying amounts of information available to them based on their diagnosis and treatment modality. Information about what content was available in Opal can be found in Table 3.

Perceptions of accessing and experiences using Opal

Three themes were identified: (1) *Opal makes me feel like I have more control*, (2) *Opal tends to reassure me* and (3) *Opal is just starting to have information that could help meet my needs*. These themes, in the shadowed boxes, and their categories are represented in Fig. 3. The top half of the figure illustrates what Opal was currently doing for participants. The lower half of the figure represents what participants felt was missing, with the dashed boxes indicating how participants believed Opal could improve their patient experience but was not there yet.

While the research team set out to explore perceptions and experiences specifically with the patient education material, it became clear from the first interviews that participants found the Opal application to be educational as a whole. Using and becoming familiar with all the aspects of Opal, including the appointments, the medical data and the educational material, was a learning experience in itself.

Table 2 Characteristics of participants and Opal use (n = 9)

Variable	Number of Participants (%)
Age	
30 – 39	3 (33.3)
40 – 49	2 (22.2)
50 – 59	1 (11.1)
60 – 69	1 (11.1)
70 – 79	2 (22.2)
Diagnosis	
Breast Ca	8 (88.9)
Colorectal Ca	1 (11.1)
Highest Level of Education Completed	
CEGEP or College	2 (22.2)
University	7 (77.8)
Level of Comfort with Smart Phone or Tablet	
Not comfortable or A little comfortable	0 (0)
Somewhat comfortable	3 (33.3)
Quite comfortable	1 (11.1)
Very comfortable	5 (55.6)
Length of Time using Opal	
4 months or more	3 (33.3)
3 months	2 (22.2)
1 – 2 months	4 (44.5)
Frequency of Use of Opal	
Once a day or more	2 (22.2)
1 – 6 times a week	5 (55.6)
Less than once a week	2 (22.2)
Less than once a month	0 (0)

Opal makes me feel like I have more control

This theme is shown in the top left corner of Fig. 3. The majority of participants (77.8%) reported feeling that Opal gave them a sense of control over their care, by *allowing them to plan their care* and *learn additional information*, as well as for some, to *care for themselves*, *make treatment decisions* and *anticipate treatment schedules*. In fact, all participants reported finding the appointment section useful, allowing them to *plan their care,* "I live alone, and I like to tell people you know 'I have treatment next Wednesday at 2 pm' or if it's at 9am it changes their day right […] it helps me organize my care" (P07).

The majority of participants appreciated having access to their radiation oncology consultation note, laboratory results and education material. These allowed patients to *learn additional information about their diagnosis and treatments*, often learning more in Opal than from their healthcare team. This resulted in participants asking questions during appointments and using other resources to find further information "I was wondering what I needed to do [about my low magnesium]. Like it's saying why it's getting tested but 'what do I need to do to rise it up?' [so] I searched the internet" (P02). In addition, participants advocated for themselves by calling their nurse and by having mistakes in their file corrected. "I was able to be more proactive, call [my nurse] and say 'you need to change an appointment', had I not had the app I wouldn't have known they had just booked me for chemo with a conflict" (P07).

Lastly, the information in Opal allowed a few participants to *care for themselves*, using the self-care information in the education tab and to *make treatment decisions.* It also allowed one participant to *anticipate her treatment schedule*, stating "being able to see that my blood cells are normal […] allows me to know that we are continuing in the treatment process" (P01). A few participants chose to delegate their use of Opal to a family member, either for information sharing, for support navigating the application, for help interpreting results or making treatment decisions. This theme illustrates that participants viewed Opal as a tool which fulfilled some of their information needs, allowing them to feel engaged in their care. As one participant put it, "at the end of the day, I am in charge of my file".

Opal tends to reassure me

Represented in the right upper corner of Fig. 3, the majority of participants (66.7%) felt that the information in

Table 3 Availability of content in Opal

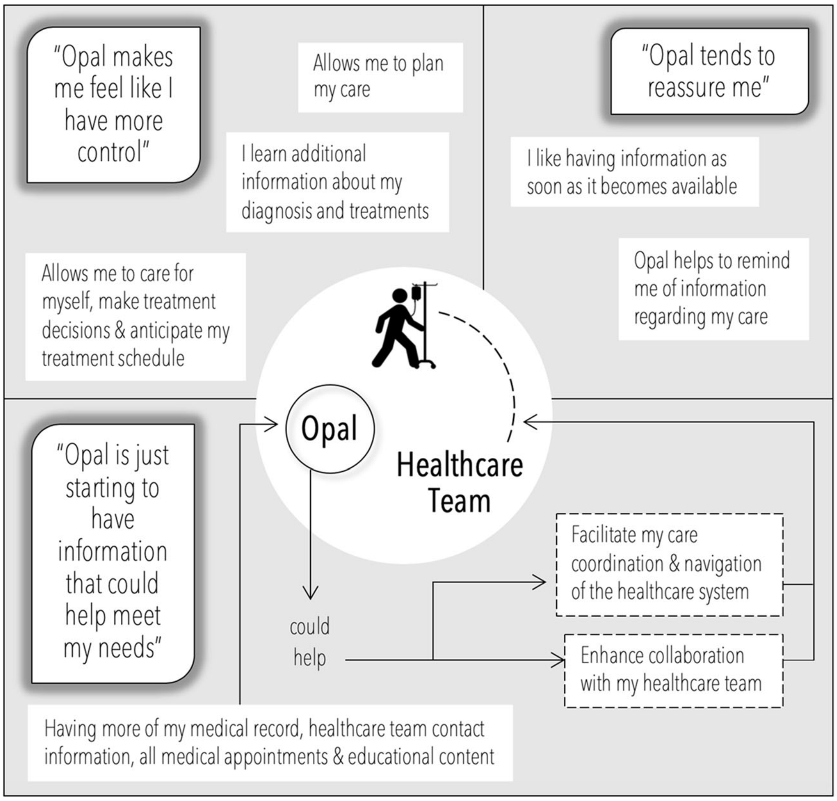
Content in Opal	Number of participants who had access n (%)
Information about appointments at the cancer centre	9 (100)
Laboratory results and explanatory online information page associated with them	9 (100)
Educational material about radiation therapy	7 (77.8)
Educational material about radiation therapy for breast cancer	6 (66.7)
Consultation note from their radiation oncologist	8 (88.9)
Educational material about the effects of cancer treatments on fertility and fertility preservation	1 (11.1)

Opal was reassuring, reporting that they *appreciated having access to information* and that the *information acted as a good reminder*. More than half of the participants *appreciated having access to information as soon as it became available* "I am a control freak as far as my results […] so it kind of made my life easier, a lot, because I have access right away" (P02). Other participants expressed the desire to know everything, despite not always fully understanding the information. "I found it really interesting to read my consultation […] it can sound a little bit scary […] but uh, I am one of those people who I'd rather know everything" (P03).

Additionally, half of the participants reported that *Opal acted as a good reminder of information*, especially in the stressful context of a new cancer diagnosis. Others wished Opal could clarify ambiguous information, "I was told I had a spot on my lung, but then I was told 'it's nothing finally' […] but those imaging reports weren't in Opal […] I would have liked to know why they said 'there is something' then said 'there isn't anything'" (P06). The few participants, who preferred not to know everything, appreciated that looking for more information was optional.

One participant did experience worry after reading her radiation oncology clinical note, which contained mistakes in her name and age. She was able to flag her concern, and have it corrected. Another participant expressed concern about the availability of certain educational material in Opal, having felt uncomfortable receiving information about the effects of chemotherapy on fertility.

Fig 3 Opal: A Tool that Places my Care in my Hands



Only one participant expressed concerns about information security relating to her medical data being available through a portal. This participant still wanted to have more access to her medical file but acknowledged that it is not risk free. While a very small number of participants questioned the availability of real time information, the majority of participants reported a strong desire for it and experienced reassurance.

Opal is just starting to have information that could help meet my needs

The third theme, located in the lower half of Fig. 3, illustrates areas of care participants believe could be improved by Opal. The dashed boxes and the dashed line in the circle, representing the patient-healthcare professional relationship, allude to the need to further develop Opal in a way that could positively affect interactions with healthcare professionals. Although many of the features of Opal were perceived as useful, all participants (100%) felt that more content could be made available. Most importantly, contact information for each member of their healthcare team and more of their medical record, including clinical notes, imaging reports and treatment plans. In addition, half of the participants wanted access to more educational content, in the application and through links to online cancer-related resources, as well as access to all medical appointments, not limited to the cancer centre.

Participants believed access to this additional information could help them in two ways. First, by *enhancing collaboration with healthcare professionals* and second by *facilitating care coordination and navigation of the healthcare system*. The majority of participants relied on multiple resources for information and support. The most common being healthcare professionals, including nurses, oncologists and radiation oncologists. Half of the participants believed adding a note section to Opal could support communication with their healthcare team, “I have a whole list of questions […] often times you start talking to the doctor and […] forget things you want to say […] you could potentially maybe put in a section for notes” (P03). Furthermore, a few participants believed that additional information would, as in the first theme, allow them to ask their doctor or nurse even more questions. The majority of participants indicated they would feel comfortable opening Opal during their appointment to clarify or confirm information. “[Opal] would be helpful [during the appointment] because then we could ask ‘here you wrote this, is there a reason why?’” (P05). In addition, a small number of participants indicated a desire for their doctor to help them find information in Opal, and to interpret medical jargon and laboratory results.

Participants felt that Opal could help them coordinate their care. One shared “expanding [Opal] to all medical appointments […] would be very helpful for us [so] we don’t have three ways to manage our appointments” (P02). Participants also reported that Opal could help by sending appointment notifications, “it would help to receive a notification when […] there is a change or an addition to the appointment schedule […] otherwise I don’t know when to look for it” (P09). A few participants also wanted their healthcare team’s phone numbers, email addresses and/or a messaging system in Opal, “I was on vacation and did not have my nurse’s phone number […] I had to call the hospital’s general phone number, [Opal] would be a good place to put those numbers” (P08). Participants expressed that calling the general hospital number often meant lengthy wait times before reaching the desired person.

Lastly, participants believed Opal could mitigate the arduous process of accessing their file through medical records, helping them coordinate care with other healthcare providers. “[The naturopath was] going through my medical history and everything, but I mean I physically brought with me all my path reports […] my MRI, my mammograms […] the only thing that I was able to provide to her through the app was the lab results” (P07). Ultimately, while this theme illustrates that participants are just starting to have content they want, they readily made suggestions about how having more information in Opal could improve their patient experience.

Discussion

Opal gave patients a sense of control over their care and a feeling of reassurance, by allowing them to learn additional information about their diagnosis and treatment. The majority wanted more information in Opal and believed the additional information had the potential to enhance healthcare collaboration and facilitate care coordination. Patients’ experiences reflect that using Opal was a learning process and that Opal was perceived as useful; however, some areas need further consideration and development.

Patients felt a sense of control over their care from having access to information. Similar results were found between this study and previous research on eHealth applications including the usefulness of having an appointment section [14]. Patients also desired more of their medical record and education material, such as online cancer information resources, which is congruent to others’ findings [9, 15]. This is consistent with cancer patients’ varied information needs and supports other research findings indicating patients learn from their electronic medical records, giving them a sense of control and making them feel prepared for their appointments [27]. This demonstrates that Opal contributed to patients' self-determination and allowed patients to feel engaged and begin to feel empowered, which is in the right direction based on the Patient Engagement Framework [23].

Patients also reported reassurance at having access to information and mainly access to their medical data. This is in accordance to another study demonstrating, contrary to healthcare professionals' beliefs, that patients rarely experience anxiety when receiving medical data outside the traditional in-person healthcare context [27]. Others have shown however, that discussions should take place between patients and healthcare professionals to evaluate specific information preferences in order to determine what type of access to medical data would best suit individual patients [28]. This reflects that, as in this study, some patients felt comfortable with access to less information. In line with SBN, prior to disclosing information or providing education, an assessment of patients' readiness and of the timing of the information should be undertaken [22].

Lastly, participants believed having more information in Opal and having Opal itself better integrated into their care could enhance patient-healthcare provider collaboration. This shows the importance patients place on care coordination and communication, which is in line with others' findings that patients believe eHealth applications could facilitate communication with the healthcare team [9, 11]. As in this study, patients desired more ways to communicate with their healthcare team, for instance through a messaging system and this is supported by others, who found that their patient-nurse messaging system was the highest rated feature of their eHealth application [11]. While Opal features are currently being developed, it is on track towards creating stronger patient-healthcare professional partnerships.

Implications for Practice and Future Research

Participants were forthcoming in how they felt their experience with Opal could be improved, from getting the healthcare team involved, to specific information they wanted in Opal. Doctors and nurses must be involved in patients' use of Opal, by informing them about different features and by using the content in Opal to provide clarification or further medical and educational information.

The idea of individualizing access to certain information and uses of eHealth [28], for example, only having appointments in Opal, could be explored in future research as a few patients expressed feeling worried when reading medical data and a few felt satisfied with the current amount of information. Lastly, other studies found that patients believe eHealth is an ideal platform to provide "tailored information" [10, 15]. The meaning of "tailored information" could be explored further, as some patients found the education material in Opal to be tailored, while others, who had the same diagnosis and treatment modality, found the educational information was too general, leading to a desire for more in-depth information. In addition to involving cancer care professionals, health information specialists could be further included in this process, as they have more knowledge about how patients acquire information through various platforms.

Opal is still in development and this study was the first exploring patients' experiences with this patient portal. Several research projects are ongoing and related to concerns of tailored information, as well as to the depth and complexity of medical and educational information available in Opal. Opal users' concerns relating to privacy and security should also be explored, given the overwhelming requests from patients in this study to have more of their medical data and given that information security is often perceived as a barrier to use of patient portals [29].

Limitations

The main limitation of this study is the lack of representation of all Opal users. This study only included women who all had a university or college degree; however, Opal users vary in gender and education level. Given that the recruitment strategy required patients to reply to recruitment questionnaires in Opal, it is also likely that study participants were comfortable with mobile applications, which is not the case for all patients who have access to Opal. As Opal is a new technology at the MUHC, it is probable that current Opal users are not representative of cancer patients in general. Future studies might include the experiences of patients with varying literacy levels, literacy having not been evaluated for this study, and of patients who are less in favour of using mobile applications as part of their healthcare experience.

Conclusion

The findings highlight that patients had an overall positive perception of Opal, identifying many features of the application as being useful. Patients also reported their experience with Opal gave them a sense of control over their care and a feeling of reassurance at having access to appointments, medical data and education materials. eHealth tools, which increase access to information and enhance collaboration with healthcare professionals, are more likely to meet patients' information and support needs. Healthcare professionals should support patients' uses of eHealth applications in a way that meets their unique needs, potentially leading to more patient-healthcare professional encounters and increasing patient satisfaction.

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Author contributions All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Katherine Mohsen, Andréa Maria Laizner, Sylvie Lambert and John Kildea. The first draft of the manuscript was written by Katherine Mohsen and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability In accordance with the McGill University Health Centre Research Ethics Board, interview data will not be available, as this is a qualitative study and participant confidentiality needs to be maintained.

Code availability Not applicable.

Compliance with ethical standards

Conflicts of interest/Competing interests Dr. John Kildea declares he is a shareholder in a company, Opal Med Apps Inc., created to hold the intellectual property of Opal and possible future commercialization of the software.

Katherine Mohsen, Dr. Andréa Maria Laizner, and Dr. Sylvie Lambert have no conflict to declare.

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