

Patients' Perspectives on Health Information Seeking Throughout the Colorectal Cancer Experience: A Qualitative Study

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Abstract

BACKGROUND: With limited research on how patients with colorectal cancer (CRC) access and apply health information, our objective was to explore patients' perspectives on health information seeking.

METHODS: We invited participants from Canada, 18 years of age or over, to participate. Semi-structured, open-ended interviews were conducted over the telephone and transcribed verbatim. Transcripts were analyzed using an interpretive description approach.

RESULTS: Among 34 participants with CRC, 18 were females (52.9%). Twenty (58.8%) were diagnosed with CRC on or after the age of 50 years and 14 (41.2%) before the age of 50 years. Sixteen (47.1%) were diagnosed with colon cancer, 12 (35.3%) with rectal cancer and 6 (17.7%) with cancer at both sites. We identified three themes that reflect participants' health information seeking in terms of perspectives on sources primarily sought. These themes and specific sub-themes that suggest areas for improvement are: 1) perceived expectations of physicians – which included sub-themes of varied interactions and relationships with physicians and feeling abandoned after active treatment; 2) importance of personal and social connections – which included the sub-theme of experiencing gaps with current in-person cancer support groups; and 3) use of the Internet for information – which included the sub-theme of using credible Internet sources.

CONCLUSION: Our study identified gaps with respect to availability, access to, or knowledge of resources for CRC. Understanding how individuals with CRC seek health information have implications for informing interactions with patients and developing resources across the continuum of CRC care.

Introduction

Colorectal cancer (CRC) is the third most commonly diagnosed cancer in Canada. It is estimated that there will be 26,300 new cases in 2019.[1] Since 2011, the annual percent change in incidence (APCi) rates of CRC in Canada has declined 2.2% in males and 1.9% in females over the age of 50 years, which has largely been attributed to the increase in screening for CRC.[1] Even with increased screening, 50% of all newly diagnosed CRC cases in Canada are Stage III and IV[1] and the five year survival rate overall is 65%. [1] Also a recent trend is the increased risk of CRC among individuals less than 50 years, with an APCi of 4.45% for women less than 50 years since 2010 and APCi of 3.74% for men less than 50 years from 2006 through 2015.[2]

The physical (e.g. pain, disability)[3, 4] and psycho-social (e.g. diminished quality of life)[5, 6] impacts of CRC calls for expansion of limited psycho-oncology research on psychological, social, behavioural, or ethical aspects of living and dealing with CRC.[7] Of relevance is how CRC patients access and seek health information, as it has become recognized that looking for information about one's health serves as a coping and adjustment strategy in response to illness.[8] Furthermore, in this digital age when individuals can readily turn to the Internet to learn about health concerns and conditions, it begs the question of whether this is actually closing or widening disparities in access and use of health

information.[9] A widely studied but inconsistently defined construct,[8] for our purposes we applied Ormandy's definition of health information seeking as the active and intentional behaviour of individuals to fulfill information needs or perceived gaps in their knowledge regarding a specific health topic.[10] Qualitative research that seeks to understand the perspectives on health information seeking as individuals deal with diagnosis and treatment of CRC and beyond is scarce. A related, but different construct of "help-seeking" was explored in a qualitative study involving interviews with 40 participants diagnosed with and without CRC on experiences and perspectives with appraising symptoms and seeking help,[11] and thus limited to the period before and during CRC diagnosis. To this end, we conducted qualitative research applying a patient-oriented research approach[12] of collaborating with patients through the research process, to explore patients' perspectives on health information seeking across the continuum of CRC.

Methods

Study Setting and Participants

We conducted a qualitative research study in Vancouver, Canada where we have established our Colorectal Cancer Outcomes Research program. In brief, we conduct epidemiologic and psycho-social research with CRC patients to better understand experiences and inform future research and healthcare priorities. From prior research studies, we have identified individuals with CRC who indicated their continued interest in research participation, including receiving invitations to on-going research studies. We recruited those who met the following eligibility criteria: 1) 18 years of age or older; 2) have received a diagnosis of CRC; 3) reside in Canada; and 4) able to complete the one-on-one interview in English or French. We purposively sampled participants, that is, invited them according to age at diagnosis, sex, and residence (e.g., province), as we collected and analyzed the data.[13] Ethical approval was obtained from the authors' Institutional Research Board. Informed consent was obtained from all participants prior to participating in the interviews.

Data Gathering

We conducted semi-structured, open-ended telephone interviews. An interview guide was developed to support interviews with questions to facilitate participants to share their experiences and perspectives on seeking CRC information, including how they sought information as well as who and what sources and resources they relied on. For context, we also asked questions on participants' CRC history, experiences with CRC diagnosis and treatment, impacts of CRC, and any corresponding information needs. Prior to data gathering, we conducted pilot interviews with four individuals identified by a CRC partner patient organization. Notes from these pilot interviews along with feedback from patient research partners informed revisions to the interview guide. These interviews were not included in our qualitative analyses. Following the pilot, all data gathering interviews were audio recorded and transcribed by a professional

transcriptionist. Prior to each interview we asked participants to complete a brief, self-administered questionnaire on demographic information, CRC characteristics (e.g., stage, type), and history of cancer.

Qualitative analysis

We analyzed transcripts using an interpretive description,[14] applying this inductive approach for its relevance to our research question on understanding experience of a disease that have clinical implications as well its flexibility of epistemological beliefs. Initially, two researchers (HD and GB) read transcripts and coded specific text segments related to the study objective to establish a coding framework, consulting with each other throughout this process to ensure consistency and resolve discrepancies. Following, one researcher (HD) condensed and organized codes—grouping similar ones together and exploring and mapping relationships between to generate sub-themes and higher-level themes. These themes were reviewed, discussed, and finalized with the research team. Data gathering and analysis were iterative and although we noted saturation—that is, no new information or insight with additional data—approximately halfway, participants continued to be interviewed because of their high interest in the study. We used QSR International’s NVivo 12 software to support the analysis.

Results

Participants

A total of 34 individuals with CRC participated in semi-structured interviews, all in English, which lasted between 30 to 60 minutes. Demographic information is given in **Table 1**, including the sex distribution which was nearly equal with 18 (52.9%) female. Twenty (58.8%) were diagnosed with CRC on or after the age of 50 years (aCRC) and 14 (41.2%) before the age of 50 years (yCRC). **Table 2** summarizes CRC characteristics. Altogether, 47.1% of participants had colon cancer (n = 16), 35.3% had rectal cancer (n = 12), and 17.7% had cancer from both sites (n = 6). The majority of participants with had Stage II (n = 10, 29.4%) and III (n = 11, 32.4%).

Characteristic	Total (n=34)
Age at diagnosis	
20-29	5 (14.7)
30-39	4 (11.8)
40-49	5 (14.7)
50-59	6 (17.7)
60-69	8 (23.5)
70-79	5 (14.7)
≥80	1 (2.9)
Current age	
20-29	3 (8.8)
30-39	4 (11.8)
40-49	4 (11.8)
50-59	4 (11.8)
60-69	10 (29.4)
70-79	8 (23.5)
≥80	1 (2.9)
Sex	
Female	18 (52.9)
Male	16 (47.1)
Province¹	
British Columbia	23 (66.7)
Ontario	9 (27.2)
Alberta	1 (3.0)
Nova Scotia	1 (3.0)
Residence¹	
Urban	23 (69.7)
Rural	10 (30.3)

Education level	
Postsecondary	28 (82.4)
Secondary	6 (17.7)
¹ Missing one response	

Table 1
Participant characteristics

Characteristic	Total (n=34)
CRC type	
Colon	16 (47.1)
Rectal	12 (35.3)
Both Sites	6 (17.7)
CRC stage	
Stage 0	3 (8.8)
Stage I	2 (5.9)
Stage II	10 (29.4)
Stage III	11 (32.4)
Stage IV	6 (17.7)
Do not know	2 (5.9)
Time since diagnosis	
≤ 2 years	11 (32.4)
3-5 years	12 (35.3)
6-9 years	7 (20.6)
≥ 10 years	4 (11.8)
Doctor at diagnosis	
Surgeon	21 (61.8)
Gastroenterologist	9 (26.5)
Family doctor	3 (8.8)
Oncologist	1 (2.9)
Treatment type²	
Surgery	32 (94.1)
Chemotherapy	22 (64.7)
Radiation	12 (34.3)
None	1 (2.9)
Number of treatments	

Single	9 (26.5)
Multiple	24 (70.6)
None	1 (2.9)
Past cancer history¹	
Yes	7 (21.2)
No	26 (78.8)
¹ Missing one response	
² Multiple response answer	

Table 2
CRC characteristics

Health information seeking

We identified three themes that reflect participants' health seeking in terms of perspectives on sources primarily sought for health information on CRC. Accordingly, these themes were: 1) perceived expectations of physicians; 2) importance of make personal and social connections; and 3) use of the Internet for information. These themes and sub-themes are described as follows.

Theme 1: Perceived expectations of physicians

Physicians were one of the main sources that participants sought for information about CRC. Sub-themes describe the reliance on physicians for information on CRC, the complexity of patient-physician interactions and the role of printed information materials provided by physicians, and feelings towards physicians after completing treatment for CRC.

Sub-theme 1: Relying on physicians for information on diagnosis and treatment of CRC

Physicians are typically the first point of contact for individuals after being diagnosed with CRC. Many participants found physicians helpful regarding answering questions about diagnosis and treatment. Participants largely shared that their physicians often eased their concerns, explained treatments, and addressed questions: "[... and] got all the time in the world to talk to you about your questions." (age 70–79). We observed this reliance on physicians for information on CRC, particularly its treatment, regardless of age diagnosed as reflected by this quote from a younger participant:

“My medical oncologist went through possible treatments with me, went through every single page and read it to me to make sure I understood” (age 20–29)

Altogether our interviews revealed that physicians are critical sources of information for individuals with CRC, particularly as often being the first to speak to patients about their diagnosis and subsequent treatment.

Sub-theme 2: Varied interactions and relationships with physicians

Interviews suggested that that interactions and relationships participants had with their physicians largely varied—with some sharing both negative interactions while others shared positive interactions. Perceptions of negative interactions included feeling rushed or dismissed, for example, one participant shared:

“I didn’t feel comfortable. [My physician] didn’t talk to me before or much after. [They] was dismissive of my condition and I, I just didn’t feel happy about it.” (age 60–69)

We identified nuances with negative experiences shared. For example, as a consequence of feeling dismissed by physicians, participants shared that they often sought health information on their own, typically on the Internet (as further described in Theme 3). Notably, we also found that those diagnosed with CRC at younger ages, that is below the age of 50 years, more frequently shared that dismissal of their symptoms by physicians led to negative experiences, particularly around the time of diagnosis. One participant recounted:

“Sure it may have only been a hemorrhoid but it wasn’t. So I don’t know if they were just lazy or ... [their] story was I’m a new patient to [them] and [they] didn’t have all my history. There’s bleeding, there’s irregular bowel habits, you’re the frickin’ doctor, I know this and I’m not even a doctor.” (age 40–49)

On the other hand, it was clear when participants had a positive relationship with their physicians. Those with positive experiences reported that their physician took the time to explain their diagnosis and treatment as captured by this quote:

“I had a, really an awesome surgeon and, and [they] and I discussed ... colon cancer at length and, and statistics and so on...” (age 20–29)

We also found that those sharing positive experiences are those who felt supported by their physicians not only with regards to information about CRC, but also emotionally as well:

“I was more than satisfied with not only the information but with the support. I actually wasn’t expecting to have such emotional support from the doctors to be honest.” (age 30–39)

In identifying varied experiences with physicians by participants, interviews uncovered insights, for example, seeking information from other sources as a reaction to negative interactions with physicians.

However, with positive relationships, participants felt that physicians provided exceptional care and support.

Sub-theme 3: Receiving printed information from physicians

The topic of printed information on CRC, particularly from physicians was also discussed by a number of participants. As with interactions with physicians, experiences were quite varied. Some participants indicated that they did specifically seek out information on CRC in print, but were provided these by their physicians who went through content with them:

"I got a lot of pamphlets. It was a lot of paper and my medical oncologist ...went through every single page and read it to me to make sure I understood..." (age 20–29)

However, not all participants were provided with print materials by their physicians. Some participants shared that they were given printed materials after requesting, in some cases without explanation of the content:

"I had my pages of questions that I basically went through with them. And [they] reached up ... pulled out a, a little blue book that was published by Colorectal Cancer... [they] never mentioned that to me ...[they] never brought it up." (age 70–79)

This final sub-theme captures experiences with receiving printed material on CRC from physicians. As with interactions, experiences among participants varied with respect to whether these were provided directly or provided after requested by patients. There were also differences with respect to whether participants indicated that their physicians discussed content of these materials with them or not.

Sub-theme 4: Feeling abandoned after completing active treatment for CRC

The fourth sub-theme describes the experience that participants had once they completed treatment for CRC, they are often no longer regularly connected with their physicians. A few participants reported feeling abandoned by their physicians after they finished their treatment. One participant expressed wanting an expanded program because they did not experience adequate continuity of care.

"I worry that people get forgotten once they're at the point where active treatment is over or people, even if they aren't forgotten they feel forgotten." (age 70–79)

Participants indicated not knowing about how to or where to access information and resources for managing long-term side-effects of CRC treatment such as neuropathy and bowel irregularity. One participant said,

“they tell you a bit but I don’t think they tell you very much. And cause several of the things that I felt were really lacking had to do with diet and cooking” (age 60–69)

As a consequence, this hindered their ability to fully function in their daily lives. Altogether, participants who had completed treatment felt that they have been left on their own to navigate their future care. This sub-theme reflects a potential gap as often these individuals continue to have health-seeking needs after treatment for CRC.

Theme 2: Importance of personal and social connections

The second theme describes how participants sought information on CRC from personal connections made with other individuals with cancer, particularly in-person. This theme includes sub-themes of: knowing someone else with cancer, seeking out connections with other individuals with CRC, and identifying gaps in support groups for CRC.

Sub-theme 1: Knowing someone else with cancer

A number of participants indicated that they knew someone else with cancer, although not necessarily CRC. These individuals were often friends, families, and colleagues. Participants often connected with these individuals right after diagnosis to seek out information. We found that those diagnosed with CRC at a younger age particularly sought other individuals who had been diagnosed with young-onset cancer:

“I spoke to a colleague of mine who was actually also ... around my age, young kids, and went through breast cancer treatment a couple of years ago and ... I connected with [them].” (age 30–39)

These younger participants shared a reason for seeking these personal connections was to gain insights and advice on issues not often discussed at healthcare visits, such as working and parenting with cancer. As these issues are not specific to CRC that may explain why younger participants sought connections with other individuals diagnosed with cancer at similar ages.

Sub-theme 2: Belonging to cancer communities

Frequently after being diagnosed, many participants reported seeking support groups and communities, including those with individuals also diagnosed with CRC but as well as other cancer patient communities. With respect to CRC-specific groups, connecting with others individuals diagnosed with CRC allows participants to seek out CRC specific information, guidance, and support. This was particularly important as participants shared embarrassment and stigma associated with CRC due to the location of the cancer and unique challenges with treatment such as requiring an ostomy. Connections are made both through in-person support groups (offline) and online, through Internet-based forums and communities (related to *Theme 3*).. The value of group membership includes learning from others’

experiences as well as reassurance of their feelings and thoughts as they deal with CRC as shared from a participant who attended an in-person support group:

"I talked to [someone] who ... was recently diagnosed and finished 12 rounds of chemo, ... and [they] knew about my CT scan...So that kind of thing and it was so nice to hear that okay, I'm not the only one feeling that way, right?" (age 70–79)

Indeed, whether offline or online, being part of these communities allowed participants to connect with others who can relate with their experiences:

"Within the first month of being on YACC [Young Adult Cancer Canada], I met somebody who is my age with the same diagnosis in my city...like somebody else who understands what I'm going through." (age 20–29)

Altogether, this sub-theme captures the importance of cancer support groups as they allowed participants to not only gain information, but also connect with others experiencing similar experiences or who are in similar situations. These connections gave participants a sense of community.

Sub-theme 3: Experiencing gaps with current in-person cancer support groups

Related to prior sub-theme, a third sub-theme describes gaps identified with respect to support groups, particularly those held in-person. While some participants reported attending in person support groups offered by cancer organizations or medical centers, several participants reported a feeling of disconnect within the meetings. Participants spoke about not feeling like they belonged as reflected with this quote:

"I thought how will it be for me to turn up at these things where someone is without their hair because they're having chemo ... or someone is dealing with all of the possible outcomes of colon cancer and I say, "Well gosh guys I was so lucky. They took mine out. There was nothing in the lymph nodes. ... Do you think I could do that to people? I just, I just felt I couldn't. Not at a support group where ... most people might be really dealing with serious ongoing implications of cancer." (age 60–69)

Participants who were diagnosed with CRC at a younger age "found [it] challenging [to find support groups specifically aimed at young-onset CRC because] a lot of the support that was out there was for young women that had had women's cancers like breast cancer or ovarian. I felt like there was a gap ... because my cancer is associated with like an old person." (age 30–39)

Participants residing in rural communities also reported wanting to join a group, but not being able to due to geographic and time constraints. One participant residing in a rural community reported,

"There really wasn't anything like that here in our community and when I was dealing with it most was through the winter months and just driving into [city] I had to go there often enough for different things, I, I

didn't want to have to go in for any group things in [city].” (age 50–59)

Finally, some participants also shared experiences with lack of CRC specific support groups. Many participants felt there could be more sessions that address unique CRC issues, such as ostomy care. One participant spoke about searching for a CRC group in their city,

“I’ve never actually found one, and in fact..., I’d be really interested.” (age 50–59)

Altogether participants indicated that they sought in-person support groups for people with cancer. However, we noted challenges including accessing these groups, particularly for participants living in rural areas. We also noted a lack of availability of CRC-specific support groups, suggesting a gap given unique characteristics of CRC and potential associated stigmas that individuals may not feel comfortable sharing with others who do not experience the same type of cancer.

Theme 3: Use of the Internet for information

The third theme describes a key study finding that almost all of the participants spoke about using the Internet to seek not just health-information for CRC but also support, with two sub-themes of: using credible sources and the role of the Internet in supporting connections with other individuals with CRC and cancer. After receiving their initial diagnosis, many participants shared often returned home and immediately searching for information on the Internet about CRC: *“After my colon cancer diagnosis, I was like on Google like crazy.” (age 20–29)*. Participants sought out information regarding treatment options, side effects, recurrence, and prognosis, indicating that they wanted to know what to expect with a CRC diagnosis and the Internet providing an accessible resource to search for information.

Sub-theme 1: Using credible Internet sources

Participants shared that when seeking out more information on CRC, they turned to websites such as PubMed, cancer centres and hospitals, universities, and registered cancer organizations, indicating that they chose these websites because of their reputation. We found that participants are aware that there is a lot of misinformation about CRC on the Internet as captured by this quote:

“The Internet has been a good thing because you know there’s legitimate research on there but you have to be very careful.” (age 50–59)

With the majority of participants having post-secondary education (n = 28, 82.4%), many shared being in professions (e.g., lawyer, nurse) that provided them with skills to identify reliable information on the Internet. One participant with a background in science attempted *“to get reputable resources for info and some scientific papers too” (age 20–29)*. It is not surprising that all participants indicated seeking health information on CRC using the Internet. However, this sub-theme revealed participants’ perspectives on the

importance of finding credible information online and were wary to misinformation being spread on the Internet.

Sub-theme 2: The role of the Internet in supporting connections with other individuals with CRC and cancer

In addition to information on CRC, many participants shared that the Internet also played a role in supporting their connections with other individuals with CRC and cancer through channels such as online forums, Facebook groups, and YouTube. This sub-theme is related to prior sub-themes in *Theme 2* on the importance of joining cancer support groups and communities and identifying gaps in support groups for CRC in that through these Internet-based channels, participants are able to discuss diagnosis, treatment options, side-effects, along with other aspects of life that CRC and cancer has impacted. One participant spoke regarding their online CRC community,

“Oh my god. They [COLONTOWN] were [...] my total absolute salvation. I learned so much there. I didn’t really clue into it until somewhere in the middle of my second round of treatment, the chemotherapy, and I wish I’d known it from the very beginning ‘cause it was just so, so helpful.” (age 70–79)

Participants diagnosed with CRC at a younger age also told us about online communities which allowed them to connect with individuals that shared the same young-onset related concerns and questions. Frequently, these younger participants joined general young-onset cancer online communities because they felt that these were more relevant to their situation:

“The biggest problem for me when I was first diagnosed was that there was a lot of support groups ... but it was 50 or 60-year-old people that had totally different concerns going into it than what I had so it was... hard to get support going to those groups, like any of the local groups and that type of thing because they just, they couldn’t offer the support that I needed but whenever I found that Young Adult Cancer Canada group, it was like it was a huge relief to be able to have people to talk to about it that actually understood my situation and my concerns.” (age 20–29)

Although many participants reported that they connected with others on the Internet, a few participants also indicated that they were unaware that they could connect with individuals diagnosed with CRC online. This was particularly true for older participants as reflected with this quote:

“And I didn’t know that, that there were any. So that, that is interesting and... how would you get that information?” (age 80+)

Overall, this sub-theme highlighted the important role of the Internet in facilitating connections for participants with other individuals with CRC and cancer through various channels. Nonetheless, despite being a highly utilized resource, interviews also suggested some disparities with respect to knowledge of online communities for CRC, particularly with older participants.

Discussion

We conducted interviews with a large sample of participants with CRC and applied interpretive description, which allowed for an in-depth exploration of participants' experiences. We identified three themes that reflect participants' health seeking in terms of perspectives on sources primarily sought for health information on CRC, drawing insights from corresponding sub-themes. Specifically, implications identified from Theme 1, perceived expectations of physicians, were the quality of interactions and relationships between patients and physicians as well as the importance of having information and resources available after completing treatment for CRC. With respect to Theme 2's desire to make personal connections, findings suggest a gap with in-person support groups for with respect to availability, topics discussed, and age-specificity, particularly for individuals with CRC at younger ages. Finally, with Theme 3, use of the Internet for information, though online CRC and cancer communities potentially address limitations with in-person support groups, the sub-theme of using credible Internet sources highlights the importance of ensuring the reliability of information accessed by patients.

The finding that physicians played key roles in supporting health information seeking for individuals diagnosed with CRC was not surprising and consistent with findings from Law et al.'s 2018 qualitative study of 20 individuals with CRC and their caregivers that physicians are a highly valued form of support in CRC care.[15] Arguably more insightful were our sub-theme findings that suggested areas for improvement, which included the quality of interactions and relationships between physicians and patients and supporting health seeking after patients have completed treatment for CRC. As suggested by our study participants, patients' health seeking behaviors are often an outcome of the patient-physician interaction and relationship. While some participants described the support received from their physician, other participants described being unsupported during their diagnosis and treatment. Individuals with negative interactions sought out health information on their own accord, most frequently utilizing the Internet.

Another key finding that has implications for improving CRC patient support particularly continuity of care, is that many participants who had completed active treatment for CRC reported feeling abandoned after treatment. As a result, they found themselves left to navigate CRC issues and long-term side effects without the continued support of the medical system. This is a problem identified in multiple types of cancer. [16–19] For example, in a 2012 survey of 1,516 individuals who have completed any cancer treatment in the United States, Tish Knobf et al. reported that 12.0% of respondents were not told about available post-treatment services for cancer.[17] In our study, although this sub-theme of feeling abandoned after active CRC treatment was captured within the theme on perceived expectations of physicians as most participants alluded to their healthcare providers, we note that this arguably also applies to healthcare systems, institutions, and centres. Our study highlights that it is just as important to support health information seeking after CRC treatment as it is during treatment and discussions are warranted on how to improve the continuity of care beyond cancer and during survivorship.

Interviews revealed the importance of personal and social connections made with other individuals with CRC as well as other cancers and the role of the Internet in supporting these. However, findings suggest gaps including lack of CRC-specific in-person groups and need for greater awareness of online communities. Those that attended in person support groups reported challenges including not feeling that they belonged to the group, receiving information that was not relevant to their situation; or not being able to attend due to inconvenience. Many participants indicated that the in-person support groups that they accessed were not CRC-specific but rather general cancer support groups. CRC-specific support groups are warranted as due to its nature and location, there is often a stigma or embarrassment when discussing CRC. Interestingly, we found an interrelation with this sub-theme of gaps in support groups for CRC in Theme 2, with the sub-theme of using the Internet to connect with other individuals with CRC in Theme 3. Specifically, many participants shared experiences with online CRC communities, which may be easier and more convenient to access as compared to in-person support groups. Online communities that were frequently described were COLONTOWN and for participants diagnosed at younger ages, Young Adult Cancer Canada. Although most participants indicated being familiar with online support groups, we also found that some participants were unaware of these, suggesting an information disparity, particular with older participants. Furthermore, it should be noted that none of the participants reported learning about online groups from their physicians or healthcare providers and that these only communities were largely discovered through their own health information seeking behaviors.

Strengths and limitations of our study warrant discussion. We conducted interviews with a large sample (n = 34) of individuals with CRC. Pilot testing interviews and asking feedback from patient research partners were also strengths. A potential limitation was the convenience sampling strategy as we invited individuals who have previously participated in prior studies within our Colorectal Cancer Outcomes Research program via email. Thus, most participants are Internet users and findings may not be transferrable to patients with CRC who do not have access to or use the Internet. Although we purposively sampled on age at CRC diagnosis, sex, and residence (e.g. province) from a large pool (>350 potential participants in Canada) to obtain diverse experiences and perspectives, we note that the majority of participants reported having post-secondary education (82.4%) and lived in urban areas (69.7%). This may suggest potentially bigger gaps and greater need for supporting health information seeking for individuals with CRC with lower education status and living in rural areas. Although we gathered information on time since diagnosis, we did not collect information on whether participants were in active treatment for CRC or have completed treatment.

Understanding how individuals with CRC seek health information have implications for informing interactions with patients and the development of resources across the continuum of CRC experience. Our study identified gaps with respect to availability, access to, or knowledge of resources for CRC, highlighting these as areas for future work.

Declarations

Ethics approval and consent to participate:

This study was approved by the University of British Columbia Behavioural Research Ethics Board. Ethics number H18-03679

Consent for publication:

All study data has been anonymized

Availability of data and materials:

All data generated or analysed during this study are included in this published article and its supplementary information files.

Competing interests:

The authors have nothing to declare.

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Authors contributions:

Hallie Dau: Conceptualization, data collection, qualitative analysis, interpretation, writing – original draft, and writing – review and editing; Genevieve Breau: Data collection, qualitative analysis, interpretation, and writing – review and editing; Helen McTaggart-Cowan: Interpretation, writing – review and editing; Jonathan M. Loree: Interpretation, writing – review and editing; Sharlene Gill: Interpretation, writing – review and editing; Mary A. De Vera: Obtained funding, conceptualization, interpretation, writing – original draft, and writing – review and editing.

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