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Improving colorectal cancer in Alberta, Canada: a qualitative study of patients and close contacts' perceptions on diagnosis following an emergency department presentation



Anna Pujadas Botey^{1,2*}, Ashley J. Watson³ and Paula J. Robson^{2,4,5}

Abstract

Background Colorectal cancer (CRC) is globally the third most prevalent cancer and a leading cause of cancerrelated deaths. In Alberta, Canada, a significant portion of CRC diagnoses occur following emergency department (ED) presentations. Gaps remain in understanding patient's perspectives on CRC diagnosis after an ED visit. The aim of this study was to examine the experiences and perspectives of a group of patients diagnosed with CRC subsequent to an ED visit in Alberta and their close contacts.

Methods We conducted a qualitative study using in-depth, semi-structured interviews with patients diagnosed with CRC after an ED visit at the Rockyview General Hospital, Calgary, and their close contacts, from November 2022 to June 2023. Interviews focused on symptom recognition, healthcare interactions, and the decision-making process leading to an ED visit. They were conducted in-person or over the phone, and analysed using thematic analysis.

Results Eighteen participants (12 patients and 6 close contacts) were interviewed, revealing four main themes: (1) variability in symptom recognition and interpretation; (2) inconsistencies in primary care consultations; (3) factors influencing decision-making leading to an ED visit; and (4) recommendations for expedited diagnosis outside of EDs.

Conclusion The findings highlight the complexity of the diagnostic journey for CRC patients in Alberta, pointing to significant gaps in symptom recognition and response by patients and healthcare providers. Improved diagnostic protocols and targeted support for healthcare providers, as well as approaches to address systemic delays may help streamline the diagnostic journey. Future research should focus on exploring innovative interventions to address the identified barriers to timely CRC diagnosis.

Keywords Colorectal cancer, Emergency department, Patient perspectives, Cancer care, Diagnostic process, Diagnostic delays, Qualitative

*Correspondence: Anna Pujadas Botey anna.pujadasbotey@ahs.ca

Full list of author information is available at the end of the article



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Introduction

Colorectal cancer (CRC) ranks as the third most prevalent cancer and is the second leading cause of cancerrelated deaths globally [1]. Canada has observed a gradual decline in both CRC incidence and mortality from 1980 to 2016, partly attributed to the establishment of population-level screening programs across the country [2]. An example is the Alberta CRC Screening Program [3], established in 2007 in Alberta. Despite efforts to enhance uptake, screening rates remain low, with percentages of screened eligible individuals ranging from 50.0 to 55.5% between 2018 and 2022, and targets set for 54.5% in 2023-24, 55.5% in 2024-25, and 57% in 2025-26 [4]. CRC incidence in Canada is increasing among younger age groups [5], and following national trends, in Alberta, it is among the four most common cancers and is projected to remain a predominant cancer type over the next twenty years [6].

Administrative data show that 35% of patients diagnosed with CRC in Alberta in 2017 were diagnosed following an emergency department (ED) presentation [7]. An ED diagnosis of CRC is often regarded as an indicator of adverse outcomes; patients diagnosed this way often present with more advanced, aggressive cancer forms that are associated with higher mortality rates [8-13]. Studies in Canada and other jurisdictions with universal, publicly-funded health care systems have reported, although not always consistently [13, 14], on individual factors associated with CRC ED diagnosis. These include a higher risk among women [15-20], older individuals [8, 17], those with lower socio-economic status [17, 18, 21], and those with higher levels of comorbidity [8]. Additionally, an association has been suggested between CRC ED diagnosis and healthcare usage patterns, including decreased primary care and increased secondary care utilization [13, 16]. Despite this wealth of data, gaps remain in understanding how ED diagnosis might be prevented. Most studies rely on administrative data, which often overlooks the intricate experiences of individual patients. Furthermore, while existing literature has explored delayed CRC diagnosis from the patient's perspective [22-28], it lacks a focused examination of patient perspectives specifically related to factors connected to CRC ED diagnosis.

To bridge this knowledge gap, this study was designed to gain a comprehensive, nuanced, and patient-centered understanding of the path to an ED diagnosis of CRC. The objective was to examine the experiences and perspectives of a group of patients diagnosed with CRC in hospital after an ED visit in Alberta, Canada, along with their close contacts such as family members and friends. This exploration aimed to uncover the intricacies of the diagnostic period, from the onset of suspicious symptoms to a CRC diagnosis via ED. The findings are intended to provide valuable insights that could inform and enhance the diagnostic process for CRC, avoiding ED diagnoses, ultimately aiming to contribute to improved patient outcomes.

Methods

Design

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We conducted a qualitative study using interviews that followed an interpretive description approach [29]. This approach allowed us to generate an interpretive description of the diagnostic period, capturing the nuanced themes and patters within the subjective perceptions of patients and their close contacts.

Setting and participants

Participants in this study were patients diagnosed with a colorectal mass during their stay at the Rockyview General Hospital, Calgary, subsequently diagnosed with CRC, and their close contacts. Eligible participants were individuals of any gender, residing in Alberta, aged between 18 and 75, able to complete an interview in English, and possessing the capacity to consent to participate in this project and willing and interested to participate. Since participants were identified in the hospital, close contact participants were restricted to those accompanying patients to the hospital or visiting them there. The conduct of the study within the Rockyview General Hospital premises received full approval and support from the hospital's management, ensuring adherence to both ethical considerations and facility policies.

Recruitment

Purposive sampling [30] was employed to recruit participants. One author, who also served as a nurse partner in the project (AW), facilitated this process. AW identified potential participants from the Colorectal and Surgery Unit based on admitting information, approached them to confirm eligibility, and provided a verbal overview of the project along with study information and contact information. Interested individuals were invited to contact the research team.

Data collection

We conducted in-depth, semi-structured interviews. Two authors (APB and AW) developed the interview guides based on the literature, insights from previous studies examining perspectives of both patient and healthcare providers [31, 32], and feedback received from two patient advisors. The interview topics are presented in Table 1. We pilot-tested the interview guide with three individuals. Before commencing their interviews, participants verbally confirmed their informed consent.

The interviews were conducted by one author (AW), who has extensive experience supporting CRC patients

 Table 1
 Topics included in interview guide

Understanding and interpretation of symptoms by participants

Duration of symptoms prior to hospital visitation Reasons for choosing hospital care (for themselves or the related CRC patient)

Previous interactions with community healthcare providers Perceptions of available support for symptom explanation and management

Experiences during testing leading up to a definitive CRC diagnosis Suggestions for improvements in the diagnostic process based on personal experience

and their families, and who was involved in the study from its inception. AW's keen interest in the topic ensured a thoughtful and inquisitive approach to the interviews. To prevent potential conflicts of interest, AW did not interview any patients for whom she had provided nursing care. This clear delineation between her roles as a nurse and a researcher was strictly maintained throughout the study, as documented in our ethical approval from Health Research Ethics Board of Alberta– Cancer Committee (HREBA CC-22–0132). Participants were assured that their care would remain unaffected by their involvement in the study, a commitment rigorously upheld to ensure the integrity of both the research and clinical care.

Interviews were conducted either in-person in a private space at the hospital, or over the phone after the patient's discharge from the hospital. No non-participants were present during the interviews, and no repeat interviews were conducted. All participants completed the study without dropping out. During each interview, the researcher took field notes to capture contextual details. The interviews took place between November 2022 and June 2023. As a token of appreciation, participants were offered a gift card of their choice in the amount of \$25 per hour of participation, in accordance with accepted appreciation guidelines [33].

Data analysis

We recruited additional participants until data saturation was reached, meaning that no new themes emerged as we analyzed further interviews [34]. All interviews were audiotaped, transcribed verbatim, and imported into NVivo Version 12 (QSR International). We performed a thematic analysis [29] using an inductive, data-driven coding process to reflect on how participants made meaning of their experiences [35]. The analysis entailed reviewing each transcript, identifying initial themes, and iteratively developing and refining themes as data collection and analysis proceeded. One author (APB), in collaboration with the author who conducted the interviews (AW), organized themes into codes that were applied to text fragments in the transcripts. To ensure consistency and trustworthiness [35], a second researcher coded randomly-selected segments, with both researchers discussing their interpretations and codes until reaching consensus. See Additional file 1.

Results

We interviewed 18 participants, including 12 patients (P) and 6 close contacts (CC). 67% were women (n=12), their median age was 63 years (range 38–85 years), 83% identified as white (n=15) and 50% had post-secondary education (n=9). For patient participants, 83% had a family physician (n=-10), and 60% of those regularly visited their family physician (n=6). Interviews lasted 37 min on average (range 20–50 min).

Thematic analysis revealed four salient themes as being relevant to the experiences and perspectives of participants: (1) variability in symptom recognition and interpretation, (2) inconsistencies in primary care consultations, (3) factors influencing decision-making process leading to an ED visit, (4) recommendations for expedited diagnosis outside of EDs.

Variability in symptom recognition and interpretation

Participants reported experiencing a range of symptoms, including bloating, indigestion, alterations to bowel habits, the presence of blood in their stool, fatigue, and weight loss. These symptoms occurred at times inconsistently and were often described as severe and enduring over extended periods. As explained by some participants:

"It even was funny, because of the eggs, she [the patient] could eat a dozen, not a problem, and then, all of a sudden, they did not agree with her. [...] It was at least four years ago. And it got to a point where she would eat, and it wasn't 5 minutes, she would have to run. She was going 13–14 times a day." (CC-12).

"My bowels were acting up. Either couldn't go to the bathroom, or if I did, you couldn't control it. It was just... if I was trying to washroom right now..., I mean, I couldn't get to a washroom fast enough. And it would to be just pure hell. And I was getting just so fatigued and tired. And then, all of a sudden, I started losing muscle mass." (P-10).

"So, we can go back one year and a half... And the first thing, signs that I had, was, after a meal, like not every meal, but some meals, and usually a restaurant meal, I had the urge to go to the bathroom like right after the meal. And that and that's something that in my life, I've never really had...., that kind of urge. So, that was the first sign that my usual routine was different. And then that progressed to a little more difficulty in in pushing, and a tiny bit of pain...., like you start to notice that. Then, as time... These are all symptoms that take time to manifest. And the next thing I remember is just more frequency of bowel movements, and the appearance of your stool changed. And then that sometimes would be normal and flip back and forth. So, you didn't worry about it too much because, everything is the way it was and then goes on some more. So, that progressed and then stool started to darken. And they started to change in size. And again, the frequency was increasing. And then it just kept going like that, and then it became more and more difficult to go to the washroom." (P-7).

Most participants did not attribute their symptoms to cancer. Some felt that given the long duration of their symptoms, they would have experienced more severe outcomes if it was cancer, as one participant expressed, "if it was cancer, I'd be dead, because that had been there for a while" (P-7). Others dismissed the possibility of cancer due to their younger age, with one participant referring to CRC as "the kind of cancer that standard screens start at 50" (P-8). Several participants believed their symptoms resulted from factors like food intolerance, constipation, stress, anemia, or general fatigue. Very few participants considered the possibility of cancer or CRC. Their suspicions mainly stemmed from a family history of cancer, having a relative in the oncology field, or awareness of symptoms due to the aforementioned reasons or from "using Dr. Google" (P-9).

Inconsistencies in primary care consultations

Several participants consulted their family physician or another general practitioner at walk-in clinics concerning early symptoms. Some participants reported that practitioners did not investigate or contemplate the possibility of cancer. A few participants mentioned symptom investigation was not extensive: *"He [doctor at walk-in clinic] didn't even give her [patient] any exam, anything. Like, that ticked me off too, because if he had checked her. At least when you say you got something really wrong, you would think they would look into it"* (CC-12). Others mentioned other diagnoses were contemplated:

"And because it was on the right side, she [family physician] says: "oh yeah, that's digestion. [...] She suggested this prescription for [name of a drug], which is supposed to relax the muscle and the intestine. It was quite some time before I tried it, but it didn't really touch it as far as I'm concerned. And then she also suggested probiotics, which I started experimenting with. And then I tried another parabiotic just this past January. So, I had some success with that. And then we also talked about adjusting my thyroid medication because that can also wreak havoc with digestion as well. So, we were kind of, you know, approaching it in different ways, including probiotics, and adjusting thyroid medication. So, we never took her beyond that to a specialist." (P-4).

Other partitioners might have suspected cancer, but cancer was never diagnosed. As explained by some participants, CRC testing came back negative: "the fit test where they smear the poop, I've done that at home a few times, and it's always came back fine" (P-11) or "I had a scope done, but they never found anything" (P-6). As a result, some practitioners discarded the idea of cancer and recommended various treatment paths, such as "we did a laxative, increase my water intake [...], and we purged the system" (P-5). Other practitioners referred patients to a gastroenterologist and/or prescribed other tests to investigate further, but due to extended wait times to see a specialist or receive testing results, some practitioners advised patients to seek immediate medical attention at an ED if needed:

"[After being prescribed all tests] I just couldn't wait six weeks. So, we called the doctor, and I said, I can't wait for all these tests. And one of the people at his [family] clinic said, 'get yourself to emergency'" (P-12), or "he [family physician] was, like, 'don't even come to see me, go to urgent care, I know you, and if you're in that much pain, go straight to urgent care" (P-3).

Some participants chose not to follow up on their specialist referral or declined colorectal testing due to feelings of embarrassment or anxiety associated with the procedures. In a few cases, this was associated with prior abuse as explained by this participant:

"One of the issues I have is just being embarrassed and not wanting people down there... I did suffer from some childhood sexual abuse, and because of that, just having a male poking down there, it's like very uncomfortable for me. I get a lot of anxiety." (P-9).

Factors influencing decision-making leading to an ED visit All patient participants ultimately ended up visiting the ED. Many attributed their decision to go to the ED to dissatisfaction with primary care, reflecting a broader context of their healthcare experiences. One participant expressed: "I feel like a lot of my concerns were maybe not taken as seriously as I would like to be taken by my family doctor. So, I just kind of wanted to dock that truck, and *I knew I had to go to emergency*" (P-4). This dissatisfaction was not necessarily linked to the immediate decision to visit the ED, but rather a perceived pattern of unaddressed concerns and missed opportunities over weeks or even months. As the same participant elaborated:

"My family doctor requested a colonoscopy for me, which was done in July last year... So, seven or eight months ago. [...] So, then, when I had these little hiccups after my colonoscopy, that were kind of still on the right side, you know, my family doctor, she suggested this prescription for [name of a drug], which is supposed to relax the muscle and the intestine. [...]. And then she also suggested probiotics, which I started experimenting with. And then I tried another probiotic just this past January. So, I had some success with that. And then we also talked about adjusting my thyroid medication because that can also wreak havoc with digestion as well. So, we were kind of, you know, approaching it in different ways, including probiotics, and adjusting thyroid medication." (P-4).

Most participants explained that their visit to the ED was prompted by worsening, severe, and acute symptoms, regardless of prior primary care access. For example, participants described: "when I came and brought myself into the hospital this last time, I couldn't handle my stomach pain" (P-1), "I went in for a bowel movement, and I had that toilet full of blood. And then that was the line that was crossed. Then, I mean I was instantly in the queue to the Rockyview [ED]" (P-7), and "for the last six months, it wasn't quite too bad, and then all of a sudden it just went worse, you [patient] couldn't control anything; lined panties, stuffed toilet paper and then just projectile diarrhea" (CC-12).

Many participants acknowledged they delayed seeking for medical help. They attributed various reasons for it. Some did not recognize or were in denial about the severity of their symptoms, as noted by one participant, "I didn't really worry about it; you think everything's fine" (P-7). Others lacked awareness of symptom significance, "I just had just a like kind of a stain of blood in my stool. And so, you think, 'oh, well, you know, that should have been a red flag'" (P-10). Some believed their conditions were manageable without medical intervention, "it'll probably be fine" (P-9), "he just thought he was just going to get better some day" (CC-10). Others cited procrastination, "basically, I just kept on going, instead of looking at it from a standpoint of 'there's something wrong, well, let's fix it'" (P-7) or fear of medical procedures or hospitals, especially post-COVID-19, "being the kind of guy I am, I have a really big fear of hospitals and procedures. And basically, I'm not talking about it to anybody" (P-7). Additionally, busy lifestyles or prioritizing other commitments were common reasons for delaying seeking medical attention, "*it got to a point where I had to help her up and down the stairs* [...]. She was going to go to work that day. I stopped her and I said, 'no, you're not going. Enough is enough. We're going to go [to ED]" (CC-12). Lastly, the lack of a family doctor was also mentioned as a barrier to seeking timely help.

Recommendations for expedited diagnosis outside of EDs

Reflecting on their experiences, participants offered several recommendations for expedited diagnosis, outside EDs. These suggestions focused on changes at the patient level and at the societal and public health level, grounded in the challenges they encountered during their own diagnostic journeys.

At the patient-level, participants often emphasized the need for increased awareness of CRC and the importance of breaking the stigma surrounding it. One participant expressed: "colon cancer it's not something that people talk about a lot. People have no idea. Nobody wants to talk about the C-word or poop. [...] I wish there was more information in the community about colorectal cancer, and how bad it can actually get" (P-1). Additionally, participants underlined the importance of listening to one's body and trusting one's intuition. They advised, "if you have any suspicion at all, anything, go get checked" (P-10), and "just look after yourself a little bit better. If you suspect something, get help for it. Even if you don't think you got it, but if you suspect something, just do it" (P-6). Another participant reinforced the need for urgency, insisting, "you can't procrastinate; you gotta do it" (P-2). Participants also encouraged self-advocacy in healthcare interactions, urging others to "don't be afraid to speak up" (P-11). Furthermore, they highlighted the importance of undergoing necessary medical tests, acknowledging the discomfort, but emphasizing the crucial nature of these procedures. As one participant noted, "if you ever have blood in your stool, it's important to go and get a colonoscopy. Nobody likes doing it, but you need to do it. It is important" (P-9). Participants stressed the significance of having a proactive and attentive doctor, with one participant describing the ideal as a "proper family doctor, that could have gotten us in weeks sooner and listens, and was a little bit more proactive" (CC-12).

At the societal and public health level, the primary recommendation from participants was to enhance awareness of CRC and cancer in general. Participants suggested spreading the message through various channels, including schools, TV, radio, social media, and printed materials in public places. They also emphasized the need to improve cancer screening, proposing starting screenings at younger ages and finding ways to increase participation. Ideas included mailing out screening kits or linking screenings to routine activities:

"Like, quite often, you get these little things in the mail, little sample things. They'll say, try this for a week, or maybe pass it on to her friend. Maybe they could do something like that, to put these little things [FIT tests] in the mail. If they're free to the public anyway, why not have them sent out? More people may do the screening." (P-11).

"I am thinking they could mandate this. [For example,] if you've gotta renew your drivers' license, you go get your colon and all that checked, whatever. You know, that it's for you, and you have no choice. Because people can't live without that. And that is every five years. It's not that you've got to do it every year or something. That's one way. But it is a big one to doing things you don't want to do." (P-10).

In addition, participants emphasized the need for increased public awareness about the role and importance of family physicians. While recognizing the value of community initiatives like Health Link (telephone advice line) and Primary Care Networks, some participants pointed out that these resources can be effective when the public is both aware of and actively utilizes them. One participant highlighted this, saying, "We do have good things, like Health Link and Primary Care Networks. And there's a lot of stuff being done to help people access family physicians. But if you don't know you need to go to one, it doesn't matter" (CC-7). The issue of awareness was further illustrated by another participant who shared a prevalent misconception: "Well, [we thought] there was no need for a family doctor. Nothing had ever come up. We eat well, we don't... We just don't do drugs. They don't do whatever" (CC-10). This comment reflects a gap in understanding the broader role of family physicians, not only in addressing immediate health issues but also preventive care and ongoing health maintenance.

Discussion

This qualitative study contributed to the literature by focusing on patient perspectives of CRC ED diagnosis. Findings showed different experiences in symptom recognition and interpretation, often not immediately associated with cancer, and variations in primary care consultations. Participants' narratives also revealed the complex decision-making process leading to ED visits, alongside insightful recommendations for expedited diagnosis outside of EDs. These insights underscore significant gaps in CRC awareness among both the public and healthcare providers and emphasize the need for systemic improvements in healthcare practices and public health strategies to enhance early detection and improve patient outcomes.

Our study emphasizes the need to increase CRC screening rates in Alberta. Despite Alberta's populationlevel CRC screening program [36], previous research in the province has suggested suboptimal awareness and uptake [37, 38]. Studies have identified lower CRC screening uptake linked with sociodemographic factors such as older age, lower income, lower educational attainment, and living in rural or deprived area age [38-41]. Moreover, health system access factors such as not having a regular healthcare provider and lack of frequent visits with them have been found to be associated with reduced CRC screening rates [37, 38]. Our findings add to this by suggesting personal barriers to participation, including misconceptions about cancer risk and underestimation of the importance of regular screenings, even among those with perceived healthy lifestyles. These findings highlight the need for more robust public education campaigns to address misconceptions and highlight the importance of early detection.

Building on this, our study emphasizes the critical role of self-advocacy in healthcare. As previously reported [31], participants shared the desire for an active role in their care during the cancer diagnostic period. This need for self-advocacy aligns with the responsibility of healthcare providers to not only manage and coordinate care [42, 43] but also support and empower patients by establishing deep connections and ensuring enhanced communication with them [22, 24, 31, 44, 45]. It may be beneficial for physicians to engage in discussions with patients about individual CRC risks and the significance of screening or exploration of symptoms [45, 46], while also addressing any fears and concerns patients may have. This personalized and dual approach, involving both healthcare providers and patients, might be key in boosting screening participation and improving public health outcomes.

While promoting and enhancing screening programs is vital, our study underscores the need for improved recognition and response to symptomatic presentations of CRC among primary care providers, who typically are the first point of contact with health services and determine referral and symptom investigation. Given CRC's often subtle and non-specific symptom development, early diagnosis poses significant challenges [47, 48]. Our research aligns with findings of others reporting frequent symptom misinterpretation [22, 27, 45, 48-50] or inadequate investigations [25, 48]. It also highlights the variability in primary care responses, as detailed in the results, including diverse diagnosis approaches, inconsistent investigations, and misdiagnosis. These findings underscore the need for refining diagnostic protocols and providing taregted support for primary care physicans

to increase CRC suspicion and streamline referral processes. The introduction of CRC pathways in Alberta [51] and the creation of the Alberta Cancer Diagnosis Program by the Cancer Strategic Clinical Network (Alberta Health Services) [52, 53], as intentional efforts to streamline cancer diagnosis are commendable steps. However, as highlighted by Warren et al. [21], a critical challenge remains in correctly identifying patients with single or subtle symptoms who may not meet urgent referral criteria, leading to potential delays and ED diagnoses. Therefore, continued efforts to improve CRC symptom awareness and diagnostic processes in primary care are essential.

In addition to the aforementioned aspects, our study provides insight into participants' decision-making processes leading to ED visits and subsequent CRC diagnosis. Our findings support existing literature that highlights system-related delays in healthcare, including prolonged wait times for specialist consultations and testing [26, 32, 48]. This aspect of our results illustrates how such delays contribute to urgent ED visits before scheduled care is provided. These system-related delays are further compounded by patient-related factors that contribute to delayed action in seeking medical attention. In alignment with previous research, our findings highlight some participants' perceptions of unmet expectations associated with primary care [24, 27, 28, 45, 54], symptom misinterpretation or underestimation of seriousness [22, 23, 25-27], as well as other personal barriers like denial, time scarcity, fear, embarrassment or the belief that symptoms would resolve [23, 24, 26]. Our study uncovers the broader social and psychological influences impacting a patient's journey to diagnosis, which need further exploration. This includes stigma around discussing CRC symptoms and personal experiences such as sexual abuse, potentially affecting a patient's willingness to undergo diagnostic tests or seek prompt medical help. This perspective offers a novel understanding of diagnostic delays in CRC, emphasizing the importance of patient-centric and trauma-informed care approaches [55]. Addressing these psychosocial factors, alongside improving symptom awareness, managing expectations of visits with primary care practitioners, and addressing current system wait times for specialist referral and diagnostic tests, is crucial in reducing delays in CRC diagnosis and optimizing patient outcomes.

Limitations

While our study has brought to light important aspects of the CRC diagnostic journey, it is essential to acknowledge certain limitations. Firstly, the use of purposive sampling, while effective in capturing in-depth experiences, may not encompass the full diversity of patient experiences across different demographic and socioeconomic backgrounds. By using this approach, we may be overlooking other factors associated with variations in patient pathways to diagnosis. Secondly, the study's focus on English-speaking participants within a specific age range, and the confinement of our study to a single hospital setting might have constrained the breadth of perspectives we were able to capture. The exclusion of perspectives from non-English speaking individuals or those unable to participate due to the severity of condition or communication barriers may result in the omission of important aspects of the diagnostic journey. Third, the involvement of a nurse researcher (AW), particularly in facilitating the interviews, could introduce biases related to dual role as both a researcher and healthcare provider. This involvement may affect the dynamics of participant interactions, potentially influencing responses due to perceived authority or expectations. Although steps were taken to prevent direct conflicts of interest by not interviewing patients for whom she had provided care, her overall role in the study may still impact participant responses and interpretations. Lastly, due to time constraints, transcripts were not returned to participants for comment or correction, missing an opportunity to deepen the validation of our findings through participant feedback. Despite these limitations, results form the study make significant contributions to understating CRC ED diagnosis from the perspective of patients. They also suggest avenues for future research, emphasizing the need for a more diverse participant pool, including non-English speakers and individuals from a wider age spectrum, involving multiple EDs across Alberta.

Conclusion

This study offers valuable insights into the journey leading to a CRC diagnosis following an ED presentation in Alberta. Our findings highlight that patients often did not initially associate their symptoms with cancer and experienced varied responses when seeking medical help. Importantly, the study revealed a complex decisionmaking process leading to ED visits, underlining the importance of self-advocacy and acknowledging the psychosocial factors influencing patient behaviour, as well as the need for improved public awareness about CRC. Our results also underscore the importance of enhancing recognition and response to symptomatic presentations of CRC among primary care providers, suggesting the need for enhanced diagnostic protocols and targeted support for healthcare providers. Additionally, addressing systematic delays-such as gaps in screening coverage, limited access to primary care, and other barriers to timely healthcare services like prolonged wait times for diagnostics-is crucial for reducing delays in diagnosis and optimizing healthcare delivery. Future research should prioritize exploring innovative interventions aimed at overcoming the identified barriers to timely CRC diagnosis.

Abbreviations

- CRC Colorectal Cancer
- ED Emergency Department, P:Patient
- CC Close Contact (e.g., family member or friend)

Supplementary Information

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Supplementary Material 1

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Author contributions

Conception and design of the work, A.P.B., A.J.W. and P.J.R.; data collection, A.J.W; analysis and interpretation of data, A.P.B. and A.J.W; original draft preparation, A.P.B., substantial contributions, A.J.W. and P.J.R. All authors have approved the submitted version of the manuscript and have agreed both to be personally accountable for their own contributions and to ensure that questions related to the accuracy or integrity of any part of the work are appropriately investigated, resolved, and the resolution documented in the literature.

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Data availability

The datasets generated and/or analysed during the current study are not publicly available due confidentiality, but excerpts are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Health Research Ethics Board of Alberta, Cancer Committee (HREBA CC-22–0132). All participants received an information sheet and consented to participate in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

Author details

¹Cancer Strategic Clinical Network, Alberta Health Services, 1403 29 Street NW, Calgary, AB T2N 2T9, Canada

²School of Public Health, University of Alberta, 11405 87 Ave NW,

Edmonton, AB T6G 1C9, Canada

³Unit 83, Alberta Health Services, Rockyview General Hospital, 7007 14 St SW, Calgary, ABT2V 1P9, Canada

⁴Cancer Strategic Clinical Network, Alberta Health Services, 10030 107 St NW, Edmonton, AB T5J 3E4, Canada

⁵Cancer Research & Analytics, Cancer Care Alberta, Alberta Health Services, 10030 107 St NW, Edmonton, AB T5J 3E4, Canada

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References

- World Health Organization. Colorectal cancer: Global Health Observatory; 2020 [cited 2024, December 1]. https://gco.iarc.fr/today/data/factsheets/ cancers/10_8_9-Colorectum-fact-sheet.pdf
- Wong MCS, Huang J, Lok V, Wang J, Fung F, Ding H, et al. Differences in incidence and mortality trends of Colorectal Cancer Worldwide based on sex, Age, and anatomic location. Clin Gastroenterol Hepatol. 2021;19(5):955–e6661.
- Alberta Health Services. Alberta Colorectal Cancer Screening Program. n/d [cited 2024, January 22]. https://www.albertahealthservices.ca/info/ Page8343.aspx
- 4. Alberta Health Services. 2023-26 Health Plan & 2023-26 Business Plan. 2023.
- Brenner DR, Ruan Y, Shaw E, De P, Heitman SJ, Hilsden RJ. Increasing colorectal cancer incidence trends among younger adults in Canada. Prev Med. 2017;105:345–9.
- 6. Cancer Strategic Clinical Network. The future of Cancer Impact in Alberta (FOCI). Edmonton: Alberta Health Services; 2022.
- Surveillance and Reporting. Alberta Colorectal Cancer Patients: Cancer Care Alberta, Alberta Health Services. 2021 [cited 2022, January 10]. https://tableau.albertahealthservices.ca/#/views/AlbertaColorectalCancerPatients/Inhos pitalDiagnoses?iid=1
- Nilssen Y, Eriksen MT, Guren MG, Møller B. Factors associated with emergency-onset diagnosis, time to treatment and type of treatment in colorectal cancer patients in Norway. BMC Cancer. 2021;21(1):1–18.
- 9. Weithorn D, Arientyl V, Solsky I, Umadat G, Levine R, Rapkin B, et al. Diagnosis setting and Colorectal Cancer outcomes: the impact of Cancer diagnosis in the Emergency Department. J Surg Res. 2020;255:164–71.
- Hogan J, Samaha G, Burke J, Chang KH, Condon E, Waldron D, et al. Emergency presenting colon cancer is an independent predictor of adverse disease-free survival. Int Surg. 2015;100(1):77–86.
- Téllez T, García-Aranda M, Zarcos-Pedrinaci I, Rivas-Ruiz F, Pérez-Ruiz E, del Carmen Padilla-Ruiz M, et al. First hospital contact via the Emergency Department is an independent predictor of overall survival and disease-free survival in patients with colorectal cancer. Rev Esp Enferm Dig. 2019;111(10):750–6.
- McArdle CS, Hole DJ. Emergency presentation of colorectal cancer is associated with poor 5-year survival. Br J Surg. 2004;91(5):605–9.
- Mitchell ED, Pickwell-Smith B, Macleod U. Risk factors for emergency presentation with lung and colorectal cancers: a systematic review. BMJ Open. 2015;5(4):e006965–e.
- Renzi C, Lyratzopoulos G, Card T, Chu TPC, Macleod U, Rachet B. Do colorectal cancer patients diagnosed as an emergency differ from non-emergency patients in their consultation patterns and symptoms? A longitudinal datalinkage study in England. Br J Cancer. 2016;115(7):866–75.
- Abel GA, Shelton J, Johnson S, Elliss-Brookes L, Lyratzopoulos G. Cancer-specific variation in emergency presentation by sex, age and deprivation across 27 common and rarer cancers. Br J Cancer. 2015;112(1):S129–36.
- Esteva M, Ruiz-Dōaz M, Sanchez MA, Pertega S, Pita-Fernandez S, Macià F et al. Emergency presentation of colorectal patients in Spain. PLoS ONE. 2018;13(10).
- Wallace D, Walker K, Kuryba A, Finan P, Scott N, van der Meulen J. Identifying patients at risk of emergency admission for colorectal cancer. Br J Cancer. 2014;111(3):577–80.
- Rabeneck L, Paszat LF, Li C. Risk factors for obstruction, perforation, or emergency admission at presentation in patients with colorectal cancer: a population-based study. Am J Gastroenterol. 2006;101(5):1098–103.
- Abdel-Rahman O, Ghosh S, Scarfe A, Tang PA. Patterns of emergency department visits preceding colorectal cancer diagnosis: a population-based study. J Comp Eff Res. 2022;11(5):311–8.
- Esteva M, Ruiz-Doaz M, Sanchez MA, Pertega S, Pita-Fernandez S, Macià F, et al. Emergency presentation of colorectal patients in Spain. PLoS ONE. 2018;13(10):1–14.
- Warren M, Emery J, Krishnasamy M, O'Donnell A, Gough K. Pre-diagnostic routes to colorectal cancer in Central New Zealand: factors that lead to emergency presentation and longer diagnostic intervals at primary and secondary level care. J Prim Health Care. 2022;14(1):48–56.
- 22. Blackmore T, Norman K, Kidd J, Cassim S, Chepulis L, Keenan R, et al. Barriers and facilitators to colorectal cancer diagnosis in New Zealand: a qualitative study. BMC Fam Pract. 2020;21(1):1–10.
- Courtney RJ, Paul CL, Sanson-Fisher RW, Macrae F, Attia J, McEvoy M. Current state of medical-advice-seeking behaviour for symptoms of colorectal cancer: determinants of failure and delay in medical consultation. Colorectal Dis. 2012;14(5):e222–9.

- 24. Dobson C, Deane J, Macdonald S, Murchie P, Ellwood C, Angell L, et al. Barriers to early presentation amongst rural residents experiencing symptoms of Colorectal Cancer: a qualitative interview study. Cancers (Basel). 2022;15(1):274.
- Esteva M, Leiva A, Ramos M, Pita-Fernández S, González-Luján L, Casamitjana M, et al. Factors related with symptom duration until diagnosis and treatment of symptomatic colorectal cancer. BMC Cancer. 2013;13:87.
- Oberoi DV, Jiwa M, McManus A, Hodder R, de Nooijer J. Help-seeking experiences of men diagnosed with colorectal cancer: a qualitative study. Eur J Cancer Care. 2016;25(1):27–37.
- Parsonage RK, Hiscock J, Law RJ, Neal RD. Patient perspectives on delays in diagnosis and treatment of cancer: a qualitative analysis of free-text data. Br J Gen Pract. 2017;67(654):e49–56.
- Siminoff LA, Rogers HL, Thomson MD, Dumenci L, Harris-Haywood S. Doctor, what's wrong with me? Factors that delay the diagnosis of colorectal cancer. Patient Educ Couns. 2011;84(3):352–8.
- 29. Thorne S. Interpretive description qualitative research applied practice. New York, NY: Rootledge; 2016.
- 30. Patton MQ. Qualitative research & evaluation methods. Integrating theory and practice. Fourth ed. Saint Paul, MN: SAGE Publications, Inc; 2015.
- Pujadas Botey A, Robson PJ, Hardwicke-Brown AM, Rodehutskors DM, O'Neill BM, Stewart DA. From symptom to cancer diagnosis: perspectives of patients and family members in Alberta, Canada. PLoS ONE. 2020;15(9):e0239374.
- Pujadas Botey A, GermAnn K, Robson PJ, O'Neill BM, Stewart DA. Physician perspectives on delays in cancer diagnosis in Alberta: a qualitative study. CMAJ Open. 2021;9(4):E1120–7.
- Alberta SPORSUPPORT. Unit. Patient Partner Appreciation Guidelines: Compensation in Research. 2019.
- Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B et al. Saturation in qualitative research: exploring its conceptualization and operationalization. Qual Quantity: Int J Methodol. 2018(4):1893.
- 35. Miles MB, Huberman MA, Saldana J. Qualitative data analysis: a methods sourcebook. 3rd ed. Thousand Oaks, CA: SAGE Publications, Inc; 2014.
- Alberta Health Services. Standards and guidelines for Screening Colonoscopy services. Edmonton, Alberta: Alberta Colorectal Cancer Screening Program; 2014.
- 37. Adhikari K, Yang H, Teare GF. Patterns of up-to-date status for colorectal cancer screening in Alberta: a cross-sectional study using survey data. Can Med Association Open Access J. 2022;10(1):E203–12.
- Jessiman-Perreault G, Law J, Adhikari K, Machado AA, Moysey B, Xu L, et al. Geospatial analysis and participant characteristics associated with colorectal cancer screening participation in Alberta, Canada: a population-based crosssectional study. BMC Health Serv Res. 2023;23(1):1–16.
- Solbak NM, Xu J-Y, Vena JE, Al Rajabi A, Vaseghi S, Whelan HK, et al. Patterns and predictors of adherence to colorectal cancer screening recommendations in Alberta's Tomorrow Project participants stratified by risk. BMC Public Health. 2018;18(1):177.
- 40. McGregor SE, Bryant HE. Predictors of Colorectal Cancer Screening: a comparison of men and women. Can J Gastroenterol. 2005;19:359243.

- Mema SC, Yang H, Elnitsky S, Jiang Z, Vaska M, Xu L. Enhancing access to cervical and colorectal cancer screening for women in rural and remote northern Alberta: a pilot study. CMAJ open. 2017;5(4):E740–5.
- 42. Easley J, Miedema B, O'Brien MA, Carroll J, Manca D, Webster F, et al. The role of family physicians in cancer care: perspectives of primary and specialty care providers. Curr Oncol. 2017;24(2):75–80.
- McGregor SE, Hilsden RJ, Murray A, Bryant HE. Colorectal cancer screening: practices and opinions of primary care physicians. Prev Med. 2004;39(2):279–85.
- 44. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Milbank Q. 2005;83(3):457–502.
- 45. Blackmore T, Chepulis L, Keenan R, Kidd J, Stokes T, Weller D, et al. How do colorectal cancer patients rate their GP: a mixed methods study. BMC Fam Pract. 2021;22(1):1–10.
- Gilfoyle M, Chaurasia A, Garcia J, Oremus M. Perceived susceptibility to developing cancer and screening for colorectal and prostate cancer: a longitudinal analysis of Alberta's tomorrow project. J Med Screen. 2021;28(2):148–57.
- Sikdar KC, Dickinson J, Winget M. Factors associated with mode of colorectal cancer detection and time to diagnosis: a population level study. BMC Health Serv Res. 2017;17:1–11.
- Tomlinson C, Wong C, Au HJ, Schiller D. Factors associated with delays to medical assessment and diagnosis for patients with colorectal cancer. Can Fam Physician. 2012;58(9):e495–501.
- Yarden RI, Newcomer KL, Board NTYA, CancerAlliance C. Abstract 3347: young onset colorectal cancer patients are diagnosed with advanced disease after multiple misdiagnoses. Cancer Res. 2019;79(13Supplement):3347.
- Zarcos-Pedrinaci I, Téllez T, Rivas-Ruiz F, Del Carmen Padilla-Ruiz M, Alcaide J, Rueda A, et al. Factors associated with prolonged patient-attributable delay in the diagnosis of colorectal cancer. Cancer Res Treat. 2018;50(4):1270–80.
- Scott A, Liu G, Buckland TW, Stewart D. Colorectal Cancer diagnosis pathway datasets and associated modelling. Cancer Startegic Clinical Network, Alberta Health Services; 2022.
- Alberta Health Services. Alberta Cancer Diagnosis (ACD) Initiative. Cancer Strategic Clinical Network 2024 [cited 2024 March 12]. https://www.albertahealthservices.ca/scns/Page14125.aspx
- 53. Cancer Startegic Clinical Network. Alberta Cancer diagnosis program. Alberta Health Services; 2023.
- Pascoe SW, Veitch C, Crossland LJ, Beilby JJ, Spigelman A, Stubbs J, et al. Patients' experiences of referral for colorectal cancer. BMC Fam Pract. 2013;14:124.
- 55. Purkey E, Patel R, Phillips SP. Trauma-informed care: better care for everyone. Can Fam Physician. 2018;64(3):170–2.

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