

Patient-Centered Access to IBD Care: A Qualitative Study

Courtney Heisler, MSc,^{*,} Noelle Rohatinsky, RN, MN, PhD, CMSN(C),^{*},
Raza M. Mirza, PhD,[†] Olga Kits, MA,[‡] Sandra Zelinsky,[§], Sander Veldhuyzen van Zanten, MD,
PhD, FRCPC,[¶] Geoffrey Nguyen, MD, PhD, FRCPC,^{**,} Jeffrey McCurdy, MD, PhD, FRCPC,^{††},
Mark MacMillan, MD, FRCPC,^{‡‡}, Peter L. Lakatos, MD, PhD, DsC, FEBG, AGAF,^{§§},
Laura Targownik, MD, MSc, FRCPC,^{**}, Sharyle Fowler, MD, FRCPC,^{¶¶}, Kevin Rioux MD, FRCPC,^{***},
and , Jennifer Jones, MD, MSc, FRCPC,^{‡‡,†††,}

^{*}QEII Health Sciences Centre, Division of Digestive Care & Endoscopy, Halifax, Canada

[†]University of Saskatchewan, College of Nursing, Saskatoon, Canada

[‡]University of Toronto, Institute for Life Course and Aging, Toronto, Canada

[§]Dalhousie University, Research Methods Unit, Halifax, Canada

[¶]University of Calgary, Patient and Community Engagement Research Program, Calgary, Canada

^{**}University of Alberta, Faculty of Medicine and Dentistry, Edmonton, Canada

^{††}University of Toronto, Toronto, Canada

^{‡‡}University of Ottawa, Ottawa, Canada

^{§§}Dalhousie University, Faculty of Medicine, Halifax, Canada

^{¶¶}McGill University, Montreal, Canada

^{***}University of Saskatchewan, Saskatoon, Canada

^{†††}University of British Columbia, Vancouver, Canada

Address correspondence to: Jennifer Jones, MD, MSc, FRCPC, Room 932 Victoria Building, QEII Health Sciences Center, 1276 South Park Street, Halifax, Nova Scotia, B3H 2Y5 (jjones@dal.ca).

Background: Canada has the highest global age-adjusted incidence and prevalence rates of inflammatory bowel disease (IBD). Due to IBD patient volumes and limited resources, challenges to timely access to specialty care have emerged. To address this gap, the aim of this paper was to understand the experiences and perspectives of persons living with IBD with a focus on accessing health care.

Methods: Using a qualitative descriptive approach, patients diagnosed with IBD (≥ 18 years of age) were purposively sampled from rural and urban gastroenterology clinics and communities across Canada. Co-facilitated by a researcher and patient research partner, 14 focus groups were recorded, transcribed, and coded for themes. Thematic analysis was used to ascertain the congruence or discordance of IBD specialty care access experiences.

Results: A total of 63 individuals participated in the study. The majority of participants were female (41/63, 65%) and from urban/suburban regions (33/63, 52%), with a mean age of 48.39 (range 16–77 years). The analysis generated three main themes: (1) need for patient to be partner, (2) adapting IBD care access to individual context, and (3) patient-defined care priorities should guide access to IBD care.

Conclusions: The complexity of specialty care access for IBD patients cannot be underestimated. It is vital to possess a robust understanding of healthcare system structures, processes, and the impact of these factors on accessing care. Using a patient-centered exploration of barriers and facilitators, IBD specialty care access in Canada can be better understood and improved on provincial and national levels.

Lay Summary

Canada has more people living with inflammatory bowel disease (IBD) than anywhere in the world. Patients feel that their journey is harder when first diagnosed. Timely, appropriate, shared, “whole person” care with a team that provides quality education is most valued by patients.

Key Words: inflammatory bowel disease, access to care, patient-oriented research, patient engagement, barriers

Abbreviations: CCC, Crohns & Colitis Canada; CD, Crohns disease; IBD, inflammatory bowel disease; NS, Nova Scotia; UC, ulcerative colitis

Introduction

The complexity of treating and managing chronic medical conditions like inflammatory bowel disease (IBD) is an area of concern for patients and healthcare providers.^{1–4} Despite the rise in the need for specialty care services, limited resources, and system-level challenges persist. Given the chronic nature of IBD, many individuals face a lifetime of health system

interactions leading to a high patient, familial, and societal burden.^{5–10}

Canada has the highest observed IBD prevalence rates in the world.⁸ Due to compounding prevalence, the rates of IBD are expected to increase by 2.39% per year over the next decade. By 2025, close to 1 in 100 Canadians of all ages will have IBD with direct healthcare costs expected to increase

exponentially. Rising prevalence rates and costs will continue to strain an overburdened system, further exacerbating health system access barriers.

Delays in accessing IBD care can have profound effects on quality of life, disease prognosis, and psychosocial wellbeing.^{11,12} Both patient-centered, as well as health system factors, must be considered when conceptualizing access to care.¹³ Prompt access to care has been associated with reductions in diagnostic delays, fewer disease-related complications, and expedited access to therapies and IBD monitoring.^{11,12,14–18} Providing timely, coordinated access to care has the potential to improve health outcomes and may yield cost savings.^{18–21}

Disjointed healthcare delivery systems can lead to deficiencies in care quality for chronic diseases like IBD.²² There is limited research on IBD healthcare access using a person-centered framework that acknowledges the complex nature of access.²³ Previous publications in this area have demonstrated significant gaps in care for IBD patients in Canada.²⁴ A recent study reported that 70% of patients reported relying on emergency department services and walk-in clinics for treatment and management of their IBD. Wait times and limited resources were identified as the largest access barriers to receiving IBD care.²⁵ To gain a comprehensive perspective of the patient experience of accessing IBD specialty care in Canada, the aim of this paper was to use a patient-centered framework for access to care to better understand the experiences and perceptions of persons living with IBD, and their caregivers, relating to accessing specialist healthcare for IBD. The objectives of this study were to (1) gain an in-depth understanding of the patient perceived IBD care access barriers and (2) assess the impact that access barriers have on the physical and emotional wellbeing of persons living with IBD.

Methods

An exploratory, qualitative descriptive design was used.^{26,27} Given limited research in this area, an exploratory design was most appropriate to gather insights from participants.^{26–28}

Setting, Sample and Recruitment

Research ethics approval was obtained prior to recruitment and data collection. Participants were recruited using purposive sampling between September 2018 to December 2018. Adults Canadians with IBD (aged 18 years or older) were recruited from gastroenterology clinics during routine clinical care and communities, through advertising in collaboration with Crohn's and Colitis Canada (CCC), and through national social media campaigns directed at CCC national membership. Patient participants received support (logistical and financial support for travel) to participate in planning activities and meetings. Patient participants were encouraged to have caregivers attend during data collection, as they were often present during clinical visits. This method was responsive to the experiences of IBD patients who may have been diagnosed in the pediatric system and was as a result not fully autonomous in their care and access journey before transitioning to the adult healthcare system.

Data Collection

Participant data were generated via focus groups to encourage interaction between participants in order to explore in depth their thoughts, attitudes, and experiences in relation to accessing healthcare for IBD.^{29,30} All study materials were co-designed with patient research partners, physicians, and academic researchers. The development of the focus group script was guided by existing literature on IBD access and was an iterative process. Grounded in the research objectives, the focus group questions and prompts were guided by the Levesque framework ([Appendix C](#)). Focus groups were conducted and co-facilitated by a researcher (*initials redacted for blinded manuscript review*) and patient research partner (*initials redacted for blinded manuscript review*). Five to seven participants attended each focus group that allowed for a range of perspectives to be heard and for participants to respond to other group members' thoughts and experiences.³¹ To ensure geographic representation, focus groups were held in both rural and urban regions in Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, and British Columbia.

Data Analysis

All focus groups were audio recorded and transcribed verbatim, deidentified and transcripts double-checked for accuracy and completeness. Coding and analysis were completed using Quirkos software (Version 2.3.1, 2020). The data were examined using inductive thematic analysis.²⁹ Transcripts were re-read leading to the development of codes, categories, and themes creating a coding framework. A complete list of themes reflecting the experiences of focus group participants was developed.³² Data analysis was reviewed by two other members of the research team (*initials redacted for blinded manuscript review*), and patterns and themes were discussed collaboratively. The Levesque framework of patient-centered access to care¹³ was applied after themes were identified. The Levesque framework helps to reconceptualize access through both a patient-centered and health system lens by examining access from five patient-centered domains: Approachability, Acceptability, Availability and Accommodation, Affordability, and Appropriateness (see [Figure 1](#)) ([Appendix A](#)). The framework also presents corresponding patient and community “abilities” for each domain of access. The patient and community domain suggests that these abilities should be present when each of the domains of access has been addressed. We do not focus on the patient and community abilities in this article; however, they may be a useful reference for service providers to assess improved accessibility of care.

Ethical Considerations

Ethics approval was obtained for each clinic recruitment site.

Results

About 63 participants responded and consented to participation in one of 14 focus groups across 8 Canadian provinces (Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, Alberta, and British Columbia), as summarized in [Table 1](#). Three main themes were identified: (1) patient as partner; (2) adapting IBD care to context; and (3) patient-defined IBD care priorities ([Figure 2](#)). Under each of the main

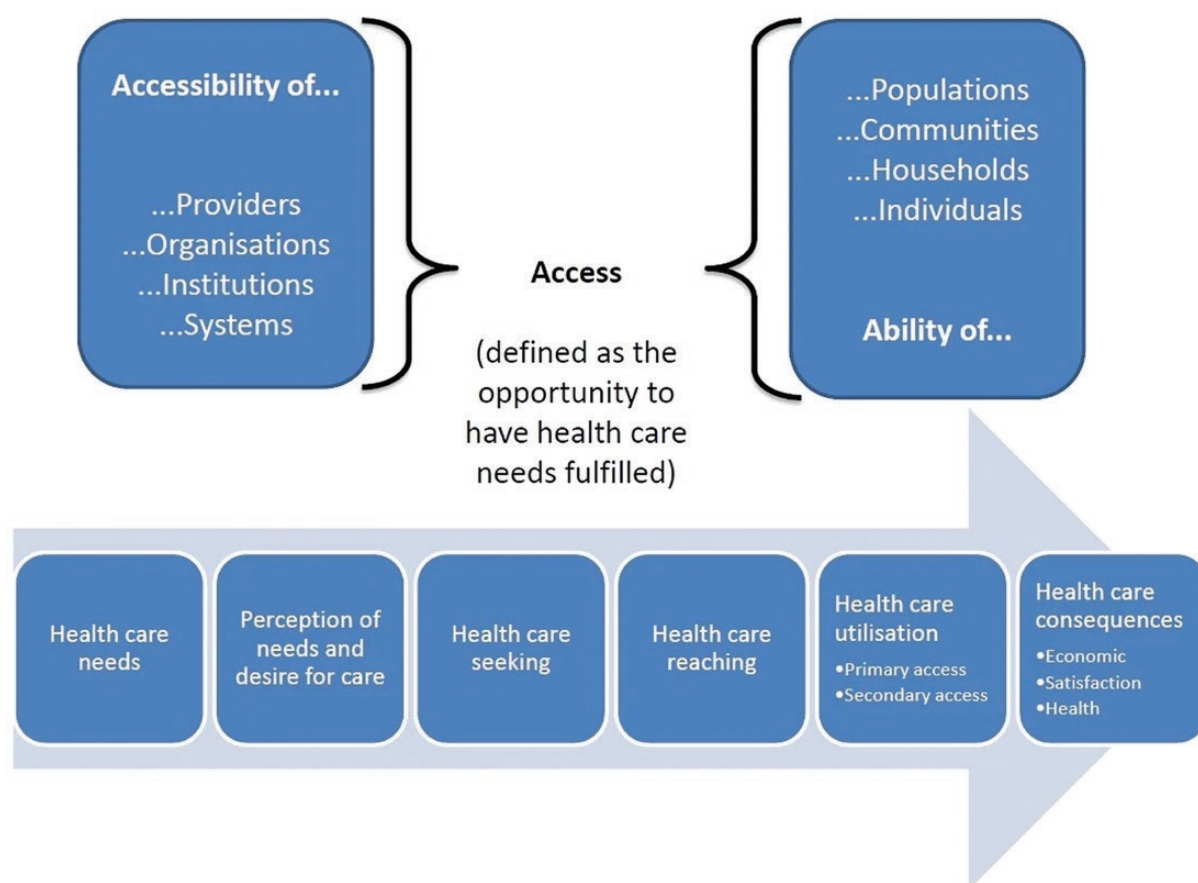


Figure 1. Levesque access framework¹⁹.

Table 1. Participant demographics

Province	Participants	Gender	Mean age	Ethnicity	Rurality
Nova Scotia	Patients: 3/4 (75%) Caregivers: 1/4 (25%)	Male: 3/4 (75%) Female: 1/4 (25%)	44.67 years (range 36–56 years)	White: 3/4 (75%) Middle Eastern: 1/4 (25%)	Urban: 3/4 (75%) Rural: 1/4 (25%)
New Brunswick	Patients: 4/4 (100%)	Male: 1/4 (25%) Female: 3/4 (75%)	37.75 years (range 24–55 years)	White: 4/4 (100%)	Urban: 0/4 (0%) Rural: 4/4 (100%)
Quebec	Patients: 6/6 (100%)	Male: 3/6 (50%) Female: 3/6 (50%)	50.67 years (range 28–67 years)	White: 3/6 (50%) Undisclosed: 3/6 (50%)	Urban: 4/6 (67%) Rural: 2/6 (33%)
Ontario	Patients: 15/15 (100%)	Male: 5/15 (33%) Female: 10/15 (67%)	46.27 years (range 23–67 years)	White: 13/15 (87%) Undisclosed: 2/15 (13%)	Urban: 12/15 (80%) Rural: 3/15 (20%)
Manitoba	Patients: 4/4 (100%)	Male: 3/4 (75%) Female: 1/4 (25%)	46.00 years (range 35–66 years)	White: 3/4 (75%) Undisclosed: 1/4 (25%)	Urban: 3/4 (75%) Rural: 1/4 (25%)
Saskatchewan	Patients: 5/5 (100%)	Male: 1/5 (20%) Female: 4/5 (80%)	42.33 years (range 30–61 years)	White: 5/5 (100%)	Urban: 5/5 (100%) Rural: 0/0 (0%)
Alberta	Patients: 1/1 (100%)	Male: 0/1 (0%) Female: 1/1 (100%)	49.00 years (range NA)	White: 1/1 (100%)	Urban: 1/1 (100%) Rural: 0/1 (0%)
British Columbia	Patients: 22/24 (92%) Caregivers: 2/24 (8%)	Male: 6/24 (25%) Female: 16/24 (67%) Undisclosed: 2/24 (8%)	54.14 years (range 29–77 years)	White: 21/24 (87.5%) Aboriginal: 3/63 (4.8%)	Urban: 5/24 (21%) Rural: 19/24 (79%)
TOTAL		Male: 22/63 (35%) Female: 39/63 (62%) Undisclosed: 2/63 (3%)	49 years (range 23–77 years)	White: 53/63 (84.1%) Middle Eastern: 1/63 (1.6%) Aboriginal: 3/63 (4.8%) Undisclosed: 6/63 (9.5%)	Urban: 33/63 (52%) Rural: 30/63 (48%)

themes, multiple subthemes were identified to further contextualize patient-identified access domains (Figure 2 and Tables 2 and 3). Many of the subthemes were related to multiple

domains of access from the Levesque et al. framework; therefore, instead of organizing the findings by the domains, we have classified the subthemes by domain in Table 2 and have

Subthemes	Domains									
	Approachability	Ability to perceive	Acceptability	Ability to seek	Availability & Accommodation	Ability to reach	Affordability	Ability to pay	Appropriateness	Ability to engage
1A. Lived Experience									✓	✓
1B. Autonomy & Power Dynamics			✓	✓						
2A. Diagnostic Journey	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2C. Comorbidities					✓	✓				
2D. Psychosocial Support	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2E. Coping Strategies			✓	✓						
2F. 'Right Care' by 'Right Person'			✓	✓			✓	✓	✓	✓
3A. Medical Information Management									✓	✓
3B. Disease education	✓	✓	✓	✓					✓	✓
3C. Trial and error							✓	✓	✓	✓

■ Levesque Health Services Domains
 ■ Levesque Patient and Community Domains

Figure 2. Thematic analysis from the IBD access focus groups (N = 63).

Table 2. Project subthemes and Levesque framework domains.

Subthemes	Levesque health services domain	Levesque patient and community domains
2A. Diagnostic Journey 2D. Psychosocial Support 3B. Disease education	Approachability <i>Includes: Transparency Outreach Information Screening</i>	Ability to perceive <i>Includes: Health Literacy Health beliefs Trust and Expectations</i>
1B. Autonomy & Power Dynamics 2A. Diagnostic Journey 2D. Psychosocial Support 2E. Coping Strategies 2F. "Right Care" by "Right Person" 3B. Disease education	Acceptability <i>Includes: Professional values Norms Culture Gender</i>	Ability to seek <i>Includes: Personal and social values Culture Gender Autonomy</i>
2A. Diagnostic Journey 2C. Comorbidities 2D. Psychosocial Support	Availability & Accommodation <i>Includes: Geographic location Accommodation Hours of Opening Appointments Mechanisms</i>	Ability to reach <i>Includes: Living environments Transport Mobility Social support</i>
2A. Diagnostic Journey 2D. Psychosocial Support 2F. "Right care" by "right person" 3C. Trial and error	Affordability <i>Includes: Direct Costs Indirect Costs Opportunity Costs</i>	Ability to pay <i>Includes: Income Assets Social capital Health insurance</i>
1A. Lived Experience 2A. Diagnostic Journey 2D. Psychosocial Support 2F. "Right Care" by "Right Person" 3A. Medical Information Management 3B. Disease education 3C. Trial and error	Appropriateness <i>Includes: Technical and Interpersonal quality Adequacy Coordination and continuity</i>	Ability to engage <i>Includes: Empowerment Information Adherence Caregiver support</i>

Table 3. Quotes for themes and subthemes.

a: Quotes for themes and subthemes			
Theme 1: Patient as Partner	Lived Experience	Autonomy and Power Dynamics	Advocacy and Support
	...because I was younger and also female, I was just like talked down to a lot. (Ottawa, Ontario)	It [the transition] was rude and abrupt, it was hard on everybody... You don't want to say anything. Your biggest fear is upsetting somebody in the medical system so you worry that you won't get the care that you are entitled to. (Vancouver, British Columbia).	"We were bullied [in the hospital], and I had to get [the healthcare providers] to understand that you may have some rules, but sometimes if a patient needs emotional care from another person, whether it's her mother or not, it is none of their damn business... [practitioner] Kicked me out ... because she is quiet and does not know how to advocate for herself. (Vancouver, British Columbia).
	This gastroenterologist [...] said yeah I know it's not typical to see IBD in this area but [...] at that point in time there was only three black males in the world that had Crohn's and they all lived in Halifax. (Halifax, Nova Scotia).		
Theme 2: Adapting IBD Care to Context	Diagnostic Journey	Living with IBD	Changing Expectations
	[In] 2011, [my condition] was dismissed as IBS and it was not until 2015 until it [IBD] was diagnosed. (Halifax, Nova Scotia).	I think it is more about the day-to-day stuff. Understanding that you are still having to go to work or you are still having to try to get to work on time even though you have got things to deal with in the washroom, like fifteen times, before you leave the house ... (Barrie, Ontario).	I think that my expectations changed. I think that my gastroenterologist has done a spectacular job in following my progress and ... when I think I'm doing well, he's the guy who usually says, "You're way too optimistic" ... your inflammatory markers are still way too high, so we are going to try something else. (Ottawa, Ontario)
	Psychosocial Support I just couldn't stop crying and at some point I told my mom, "I think I have to go see a shrink" and she was shocked and then she said "well, I guess if you have to" and it was the best thing I could have ever done because it helped a lot. It did not ease my symptoms, but it eased the way I lived with my disease. (Montreal, Quebec).	Coping Strategies I have [IBD], fine I can deal with this. I just force myself and do more and try to play with it and turn the negative feeling into positive actions but sometimes you're broken, and you are exhausted from being exhausted and feeling pain [...] even though it is like being in a dark room sometimes, again I always also think that it could be worse. (Halifax, Nova Scotia). I have since met some people [who] have since gotten the disease which is weird and so that is useful just to know "Yeah, this works" or "This doesn't work" or "You're in misery" and so am I that's just wonderful like. That you are not the only one trying to go to work with this, right? (Barrie, Ontario).	"Right Care" by 'Right Person' Another key thing is the doctor. ... One thing about [doctor's name] ... he talks to you, he examines you, he lays on hands, very important that he touches you, examines you. He just does not talk to you so he's really, really special. It is very important and a lot of [doctors] do not get that. (Montreal, Quebec).
b: Quotes for themes and subthemes.			
Theme 3: Patient-Defined IBD Care Priorities	Medical Information Management	Disease Education	Trial and Error
	Keeping record of all your symptoms and medications, timelines, doctors, pictures ... I have so many records on my computer [...] you're going to have to access so many dates and records. (Vancouver, British Columbia).	I was diagnosed and left on my own, like "Good luck and take your pills and you'll get better". I don't have any education on what Crohn's is, what's available. I just wish there was a little more. (Ottawa, Ontario). I was diagnosed and left on my own, like "Good luck and take your pills and you'll get better". I don't have any education on what Crohn's is, what's available. I just wish there was a little more. (Ottawa, Ontario).	I guess the repetition [...] I'd get sick and then I'd go back and there's drugs and I get better and then I get sick and then I'm on drugs or different drugs and get better. For me it was every year. (Barrie, Ontario).
c: Quotes for themes and subthemes.			
Theme 3: Patient-Defined IBD Care Priorities	Medical Information Management	Disease Education	Trial and Error
	Keeping record of all your symptoms and medications, timelines, doctors, pictures ... I have so many records on my computer [...] you're going to have to access so many dates and records. (Vancouver, British Columbia).	I was diagnosed and left on my own, like "Good luck and take your pills and you'll get better". I don't have any education on what Crohn's is, what's available. I just wish there was a little more. (Ottawa, Ontario). I was diagnosed and left on my own, like "Good luck and take your pills and you'll get better". I don't have any education on what Crohn's is, what's available. I just wish there was a little more. (Ottawa, Ontario).	I guess the repetition [...] I'd get sick and then I'd go back and there's drugs and I get better and then I get sick and then I'm on drugs or different drugs and get better. For me it was every year. (Barrie, Ontario).

referenced the domains throughout our presentation of the findings.

Theme 1. Patient as Partner

The most prevalent theme across Canada was *patient as partner*. This theme was a significant component of each of the 14 focus groups. Patients consistently expressed a desire to be seen as a significant partner and stakeholder in their IBD treatment and management and spoke about the need for healthcare teams to recognize their lived experience as a form of expertise that should be considered in clinical decisions that will ultimately influence healthcare access.

The Role of Lived Experience in Accessing and Navigating Access to Healthcare

Participants recognized that giving voice to IBD patients' lived experiences meant that sometimes a patient's views would be in contrast to that of the clinician. In some instances, participants stated that clinicians did not take the time or did not seem interested in addressing issues beyond the medical management of the disease. A common narrative from focus group participants was that decisions were made "for them" rather than "with them" often leading to tension. Focus group discussions also highlighted race and ethnicity as important considerations. In one focus group, a participant from the Middle East observed that some clinicians felt that IBD was limited to certain ethnic groups and that clinicians may be less likely to suspect IBD in a nonwhite person. This subtheme highlights the importance of appropriateness, as per the Levesque framework, in delivering patient-centered care.

With respect to lived experience and health system navigation, individuals who had been diagnosed when they were younger felt they gained more experience, expertise, and familiarity as they got older, as opposed to those who were diagnosed later in life. These individuals also felt that because of increased health system interactions, they made meaningful connections with important stakeholders, such as doctors, nurses, and allied health professionals in the health system that they could rely on for access to care.

Autonomy and Power Dynamics Influence Access to Care

The notion of patient as partner meant that IBD patients had the same "power" and could be "autonomous", but in actual practice power imbalances shaped the relationships between patients and clinicians. Patients lacked autonomy in many ways, from being able to choose who to be referred to and to who to ask for a second opinion. One context that was discussed by participants was the transition from pediatric to young adult to adult, and how this changed relationships and shifted autonomy and power dynamics. This subtheme highlights the impact of acceptability of care, as well as the ability to seek when seeking access.

The Role of Advocacy and Support in Accessing Care

Participants reported the importance of advocacy and support and ensuring their medical needs were being met when seeking care for their IBD. Participants acknowledged not always being physically or mentally capable of "speaking on their own behalf" (ie, as a result of pain medications or emotional distress as a result of acute illness). Caregivers

recognizing the need to be an advocate was often triggered by a negative experience or encounter. One participant described her negative experience attending an outpatient clinic with her daughter. The mother felt unable to advocate on her daughter's behalf due to the informal rules of the hospital not allowing anyone else to attend the appointment.

Theme 2: Adapting IBD Care To Context

Despite having a diagnosis in common, patients reflected on their unique access experiences and journeys from initial symptom presentation to the present day. Under this theme, six subthemes were identified.

Experience at Initial Diagnosis Influenced by Access to Care

A major access hurdle participants reflected on during the focus groups was the beginning of their *diagnostic journey*. Differences in their experiences of receiving their IBD diagnosis were noted. Participants described in great detail their diagnostic journey beginning when they knew "something was wrong" to the time that they received a diagnosis. Getting a definitive diagnosis was seen as especially challenging and a time of great uncertainty and was influenced by the availability of and access to knowledgeable practitioners. Given the expansiveness of one's diagnostic journey, all domains of access were relevant.

Experience Living with IBD Improves Healthcare Access Strategies

Study participants had been living with IBD for varying lengths of time. In some instances, the time before diagnosis and after the diagnosis, made it difficult for individuals to function with respect to their personal and professional responsibilities, and this was an added stressor. Living with and functioning with IBD, were seen as two different things. While one could live with the disease, IBD still presented unique challenges to daily functioning. Access to resources that support individuals living with IBD was limited. The impact of living with IBD on one's ability to navigate and access healthcare is often under-appreciated.

Comorbidities Complicate Access to Care

IBD patients are often faced with living with *comorbidities* including extraintestinal manifestations of IBD in addition to their IBD and require access to care for these conditions. Patients reported concern for potential drug interactions for treatment of co-morbid conditions, how co-morbid conditions could impact their IBD, as well as the ability to access care when relevant for these conditions. The presence of comorbidities indicates the necessity of considering accommodation in the delivery of care to ensure that care is accessible for all patients. Availability is also important so that those with complex conditions can receive quality care.

Need for Greater Access to Psychosocial Support

A consistent topic in each focus group involved the need for *psychosocial support*. Patients who had access to psychosocial support as part of their care team spoke of the invaluable nature of this care component to their overall physical, psychological, and emotional wellbeing. When readily accessible, patients reported feeling like they did not have to solely depend on their family and loved ones for this support.

Some participants reported either not being aware of psychosocial support services or being unable to access the services due to long wait times or financial limitations. Patients were often offered “general support” that was not tailored to the needs of an IBD patient. This was seen as a disadvantage for IBD patients who might have unique experiences and issues that are inseparable from their chronic illness. Some participants who did have experience with mental health care, often treated as separate from IBD care, suggested that it was suboptimal and that it should be integrated into IBD care to improve accessibility and appropriateness. Emotional and mental health challenges span a patient’s entire diagnostic journey and, therefore, multiple domains of access. Targeting all domains of access would be important to ensure that access to psychosocial care is available for IBD patients, and to limit the existence and impact of IBD-related stressors.

Patients Develop Coping Strategies to Access Care

A closely linked subtheme to psychosocial support is that of *coping strategies*. Patients and their loved ones reported needing to “toughen up” and be more assertive or develop “tricks of the trade” when accessing care for their IBD. Participants also spoke of the steep learning curve of knowing “who to talk to” when they need to book an urgent appointment with their specialist and, perhaps more importantly, “who not to talk to”. IBD patients were remarkably adept at creating a unique roadmap for navigating a complex system to access the care they needed. Participants also discussed how helpful it is to meet other individuals who have been diagnosed with IBD. IBD can be a stigmatizing and isolating disease and the opportunity to connect with others can be very beneficial. This subtheme speaks to ways in which patients and their loved ones address barriers to care, particularly when care does not meet their needs. As such, the acceptability of care is an important access factor.

Need for “Right Care” by “Right Person”

Receiving the “right care” by the “right person” was a topic that participants reiterated in the context of accessing treatments for their IBD. This was a particularly prevalent issue for participants in rural regions who did not have a specialist in their community and relied heavily on their primary care physician for their IBD management. Participants felt that clinicians and IBD patients should be together, and as a result, have to be a good “fit” for one another. Some patients preferred a paternalistic approach, while others suggested they needed a more collaborative approach. Perceived empathy and genuine, sincere concern were important to participants. A participant pointed out the differences in their experiences when they were seen by the “right” person versus the “wrong” person. Receiving care from the “wrong” persons suggests challenges associated with the acceptability of care. Further, in the case of patients without specialists in their community, efforts to find the “right” person may impart financial challenges (eg travel costs). Thus, the affordability of care must also be considered.

Theme 3: Patient-Defined IBD Care Priorities

Patient-defined IBD care priorities are the areas that patients and their caregivers perceive to be priority areas in the context of accessing IBD care. Participants remarked on the ambiguity of what constitutes the “correct process”

when it comes to seeking care for flare symptoms when to seek nutrition or psychosocial support, and how to best deal with conflicting medical information given by non-specialist practitioners. Under this theme, three subthemes were identified.

Medical Information Improves Access to Care

In the context of this study, *information management* was used to describe the responsibility of patients to *manage their own personal medical information*. The lack of coordination of health record documentation in a clinic or emergency department setting was noted. Patients and their caregivers reported frustration when repeatedly asked to recall their medical history, a challenge when the medical history may span decades or when opiates have already been administered to manage pain. In the age of readily accessible technology, patients reported confusion and frustration as to why such information could not be readily available to the healthcare team. The lack of integration of medical information resulted in a greater burden for an already vulnerable population when accessing care. Appropriateness of care can be measured in the technical quality of services. Therefore, improving the integration of medical information may improve access to care.

Need for Access to Disease Education

The uncertainty prior to the time an individual received a confirmed diagnosis was one that was described as a phase of discovery. In this phase, participants suggested that they would search for answers on their own (online, in consultation with others) in an informal way to try to understand what was happening to them. Even after receiving a diagnosis at a time when they were very sick, participants felt they were often left unsupported and lacked information and education on all IBD-related topics delivered by a team for a lay audience. Due to limited education provided within the healthcare system, patients reflected on their search to find alternative venues for IBD-related information. Participants who were diagnosed in the pediatric system reflected on the transition in care, varying information needs, and a lack of access to adequate education and information through the healthcare system. Limited disease education can present challenges to patients at many milestones throughout their diagnostic journey. The provision of quality disease education may support access to care by supporting the approachability, acceptability, and appropriateness of care.

Need for Access to Standardized Evidence-Based Approach to Care

Patients perceived *trial and error* in IBD diagnosis, treatment, and management. Variability of symptom presentation, ambiguity in deciding the “best” course of treatment for an individual, and accepting a possible loss of response from medications that have worked for years were all identified as part of this experience. This variability in approach to treatment highlighted the need for more consistent approaches to all aspects of IBD care in order to ensure that patients are gaining access to the most appropriate therapies and disease management approaches. Standardized care may help support the appropriateness and affordability of care and, thus, access.

Discussion

This study represents the largest, most geographically representative sample of individuals with IBD providing a comprehensive understanding of the patient experience specific to accessing healthcare for IBD. Patients' expectations play an important role in their assessment of care quality and delivery of health services.³³ The themes and subthemes observed in this study span multiple domains of the Levesque framework (Table 2), highlighting the complexity of IBD access as well as the relevance of each of the framework domains. It also underscores the importance of adopting a person-centered approach to the prioritization and improvement of health services interventions to improve access.

The themes identified in this study are central to understanding where the care gaps exist within IBD healthcare delivery models in the Canadian healthcare system. Rohatinsky et al. interviewed persons living with IBD from rural settings in Saskatchewan in order to understand their care experiences, barriers, and facilitators of accessing care.³⁴ The three key themes included communication, stressors and support systems, and coordination of care. The need for greater access to practitioners with IBD knowledge in the community was identified, in addition to improved communication and coordination of care with specialist centers.³⁴ Similar to themes observed in this study, the opportunity cost of not having access to a knowledgeable IBD practitioner in the community resulted in significant costs as a result of the need to travel, take time away from work, or arrange childcare.

The lifelong journeys of Canadians living with IBD have more commonalities than dissimilarities with persons living with IBD in other countries. Richard et al.,³⁵ explored how adults living with IBD in rural New Zealand manage their condition and engage with healthcare providers. Uncertainty at diagnosis and managing the burden of symptoms while also navigating diagnostic testing and hospitalizations was similar to themes observed in this study. Likewise, there was a desire for greater local support through family and friends (emotional support and stress management) and primary healthcare providers (PHCPs) (keeping care closer to community to cut down on the cost of travel). This finding highlights a need for greater access to knowledgeable healthcare professionals with expertise in the interpretation and diagnosis of gastrointestinal symptoms, high quality and accessible education, as well as improved communication between PHCPs and GI specialty providers. This finding also ties in the observed subtheme of *right care by the right person* observed in the current study.

Access to emotional and *psychological support* is needed to help to normalize the IBD experience as well as to develop coping skills. This need was observed in the current study as well as the Rohatinsky and Richard studies. The desire for a strong therapeutic alliance with specialists was noted in each study, including among patients residing in urban locales in our study. Patients valued a strong relationship built upon a foundation of trust, continuity, empathy, holistic care, and shared decision-making.

The theme of *patient as partner* and its relevance to the experience of accessing medical care deserves consideration when developing approaches to improving access to IBD care. Patients often felt their lived experience of IBD was devalued or not taken seriously by clinicians. The perceived power imbalances between healthcare providers and patients

resulted in a need for strong advocacy in order to be "heard" to ensure that appropriate care was provided. Factors leading to such perceptions likely arise from healthcare policy, medical culture, physician reimbursement policies, differing provider and patient expectations and valuations, and health system structures and processes. The current remuneration structure for physicians in healthcare incentivizes a focus on procedures and volume, not quality and complexity. This structure leads to shorter appointments that do not always provide the time required for adequate communication. Although the creation of multidisciplinary teams can help to overcome these shortcomings, limited support exists within public healthcare systems with which to fund allied healthcare professionals.³⁶ Even if funding does exist, it can often be challenging to overcome traditional roles as well as professional and cultural norms to facilitate the development of a high-functioning team providing integrated care in a cost-efficient way. A Spanish study evaluating IBD healthcare providers' views of the experiences of individuals living with Crohn's disease demonstrated a poor understanding of the impact of IBD on the psychological and social function of patients and their caregivers.³⁷ It also revealed that IBD care providers perceived a lack of professional skills and clinical resources or tools to adequately address the multifaceted needs of persons living with IBD throughout their journey. Lack of time, resources, training, and consistent application of standardized, evidence-based approaches to disease monitoring were all cited as deficiencies in real-world practice. In fact, Spanish healthcare providers expressed feelings of dehumanization and isolation in the management of the complexities of IBD. Burnout occurred as a result of the lack of adequately resourced multidisciplinary care teams.³⁷ This sentiment has been expressed by IBD healthcare providers within Canada and other jurisdictions as well.³⁸ A survey from Australia revealed that IBD care often did not meet Australian quality standards: only 32.4% of patients surveyed had access to IBD nurses; 30.9% had access to a dietitian; and 12% had access to a psychologist.³⁹ A Canadian survey of IBD care providers revealed similar results suggesting a lack of robust multidisciplinary care support, even amongst academic tertiary care centers.⁴⁰ It is of little benefit to recommend quality standards if there is limited capacity to implement these standards on the frontline of IBD care.

To provide cost-efficient, holistic IBD care, incorporation of standardized, yet individualized, approaches are needed to guide the allocation of resources. Consistent and personalized approaches to multidisciplinary care were a need identified by patients. Inconsistencies in access to and knowledge of medical, nutritional, mental health, and educational interventions were highlighted as a major barrier. This barrier is exacerbated further by the lack of medical information sharing across health systems and providers. The prioritization by patients of education and communication was also observed previously.³⁴ Lack of access to relevant personal medical information unnecessarily burdens people living with IBD. The need to repeat and recall the medical history may result in important gaps in medical information critical to appropriate clinical decision making, affecting the efficiency and comprehensiveness of a medical encounter.

Although this study will help to develop a framework for a patient-centered approach to improving access to healthcare for IBD, research relating to *how* healthcare professionals

can best help to improve access to high-quality medical care for IBD is much more limited.^{41–45} Previous studies highlight the importance of reducing travel to decrease costs associated with accessing care associated with in-person specialist appointments as well as improving the communication between community PHCPs and specialty care providers. Given the advances that have been made in virtual healthcare delivery during the COVID-19 pandemic, additional flexibility and options for accessing specialist care have been rapidly scaled in Canada and around the world.⁴⁶ IBD patients have expressed high levels of satisfaction with virtual modalities throughout the pandemic and these modalities have the potential to overcome some healthcare access barriers relating to the cost and time associated with travel. The creative use of virtual platforms to facilitate improved communications between PHCPs, specialists, and patients⁴⁶ may also present another opportunity to address the communication and informational concerns that Canadians living with IBD have described in this study.

This study's strengths include its national scope, large sample size, the richness of data, and the geographically representative nature of the participants residing in both urban and rural locales from multiple provinces in Canada. The sample also offered a broad age range and was relatively balanced by gender. The focus on the patient access experience, interpreted through the Levesque framework, is unique and offers a multifaceted understanding of the Canadian experience in accessing IBD healthcare. Although disease-related characteristics can affect perceptions of quality and access to care, these data were not collected, and analyses were not stratified by disease characteristics given that this was a qualitative study. Also, sample representativeness was more limited in relation to ethnicity and gender expression.

Conclusion

This study provides a valuable source of information to help to guide health system interventions focused on improving access to IBD care. A patient's perception of IBD care influences their overall assessment of care quality, and perceived quality of care ultimately affects a patient's quality of life.⁴⁶ Findings from this study offer major implications for the development of health policy and should inform targeted investments that support patient-centered redesign of the IBD healthcare delivery.

Supplementary Material

Supplementary data are available at *Crohn's & Colitis* 360 online.

Acknowledgements

The authors thank Crohn's & Colitis Canada for recruitment and the PACE Network for co-investigator networking. Also, a special thank you to our participants, collaborators, and contributors without which none of this would be possible.

Author Contributions

Courtney Heisler, MSc: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project ad-

ministration, Visualization, Writing—original draft, Writing—review & editing. Noelle Rohatinsky, RN, MN, PhD, CMSN(C): Methodology, Writing—original draft, Writing—review & editing. Raza M. Mirza, PhD: Formal analysis, Methodology, Software, Writing—original draft, Writing—review & editing. Olga Kits, MA: Conceptualization, Methodology, Writing—review & editing. Sandra Zelinsky: Conceptualization, Investigation, Methodology, Project administration, Writing—review & editing. Sander Veldhuyzen van Zanten, MD, PhD, FRCPC: Conceptualization, Funding acquisition, Methodology, Writing—review & editing. Geoffrey Nguyen, MD, PhD, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Jeffrey McCurdy, MD, PhD, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Mark MacMillan, MD, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Peter L. Lakatos, MD, PhD, DsC, FEBG, AGAF: Investigation, Project administration, Resources, Writing—review & editing. Laura Targownik, MD, MSc, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Sharyle Fowler, MD, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Kevin Rioux MD, FRCPC: Investigation, Project administration, Resources, Writing—review & editing. Jennifer Jones, MD, MSc, FRCPC: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing—original draft, Writing—review & editing.

Funding

Canadian Institute for Health Research (Recipient: Jennifer Jones) and the Nova Scotia Health Authority Research Fund (Recipient: Jennifer Jones).

Conflict of Interest

The authors have no financial or commercial interests to declare.

Data Availability Statement

Data not publicly available.

References

1. Ananthakrishnan A. Epidemiology and risk factors for IBD. *Nat Rev Gastroenterol Hepatol*. 2015;12:205–217.
2. de Souza H, Fiocchi C. Immunopathogenesis of IBD: current state of the art. *Nat Rev Gastroenterol Hepatol*. 2016;13:13–27.
3. Ananthakrishnan A, Bernstein C, Iliopoulos D, et al. Environmental triggers in IBD: a review of progress and evidence. *Nat Rev Gastroenterol Hepatol*. 2018;15:39–49.
4. Gecse K, Vermeire S. Differential diagnosis of inflammatory bowel disease: imitations and complications. *Lancet Gastroenterol Hepatol*. 2018;3:644–653.
5. Sartor B, Sandborn W. *Inflammatory Bowel Disease*. Philadelphia: Saunders; 2003.
6. Feagan B, Vreeland M, Larson L, et al. Annual cost of care for Crohn's disease: a payor perspective. *Am J Gastroenterol*. 2000;95(8):1955–1960.
7. Crohn's and Colitis Foundation of Canada. The Impact of Inflammatory Bowel Disease in Canada 2012 Final Report

- and Recommendations. Published online 2012;96. https://crohnsandcolitis.ca/Crohns_and_Colitis/documents/reports/2018-Impact-Report-LR.pdf. Accessed January 2021. <http://www.isupportibd.ca/pdf/ccfc-ibd-impact-report-2012.pdf>
8. Bernstein C, Wajda A, Svenson L, et al. The epidemiology of inflammatory bowel disease in Canada: a population-based study. *Am J Gastroenterol*. 2006;101(7):1559–1568.
 9. Crohn's and Colitis Canada. Inflammatory bowel disease: a Canadian burden of illness review. *Can J Gastroenterol*. 2012;26(11):811–817.
 10. Kaplan G. The global burden of IBD: from 2015 to 2025. *Nat Rev Gastroenterol Hepatol*. 2015;12(12):720–727.
 11. Nguyen G, Nugent Z, Shaw S, et al. Outcomes of patients with Crohn's disease improved from 1988 to 2008 and were associated with increased specialist care. *Gastroenterology* 2011;141(1):90–97.
 12. Schoepfer A, Dehlavi M, Fournier N, et al. Diagnostic delay in Crohn's disease is associated with a complicated disease course and increased operation rate. *Am J Gastroenterol*. 2013;108(11):1744–1753.
 13. Levesque J, Harris M, Russell G. Patient-centred access to health care: conceptualizing access at the interface of health systems and populations. *Int J Equity Heal*. 2013;12(18):2–9.
 14. Lix LM, Graff LA, Walker JR, et al. Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in inflammatory bowel disease. *Inflamm Bowel Dis*. 2008;14(11):1575–1584.
 15. Cámara RJA, Ziegler R, Bgré S, Schoepfer AM, von Känel R; Swiss Inflammatory Bowel Disease Cohort Study (SIBDCS) group. The role of psychological stress in inflammatory bowel disease: quality assessment of methods of 18 prospective studies and suggestions for future research. *Digestion*. 2009;80(2):129–139.
 16. Hoiwik M, Moum B, Solberg IC, et al. Health-related quality of life in patients with ulcerative colitis after a 10-year disease course: results from the IBSEN study. *Inflamm Bowel Dis*. 2012;18(8):1540–1549.
 17. Ananthakrishnan A, McGinley E, Binion D. Inflammatory bowel disease in the elderly is associated with worse outcomes: a national study of hospitalizations. *Inflamm Bowel Dis*. 2009;15(2):182–189.
 18. Kaplan GG, Windsor JW, Crain J, et al. Crohn's and Colitis Canada's 2021 Impact of COVID-19 & inflammatory bowel disease in Canada: a knowledge translation strategy. *J Can Assoc Gastroenterol*. 2021;4(Suppl 2):S10–S19.
 19. Coward S, Clement F, Benchimol EI, et al. Past and future burden of inflammatory bowel diseases based on modeling of population-based data. *Gastroenterology*. 2019;156(5):1345–1353.
 20. Nguyen G, Sheng L, Benchimol E. Health care utilization in elderly onset inflammatory bowel disease: a population-based study. *Inflamm Bowel Dis*. 2015;21(4):777–782.
 21. Benchimol E, Mack D, Nguyen G, et al. Incidence, outcomes, and health services burden of very early onset inflammatory bowel disease. *Gastroenterology* 2014;147(4):803–813.
 22. Nguyen G, Devlin S, Afif W, et al. Defining quality indicators for best-practice management of inflammatory bowel disease in Canada. *Can J Gastroenterol Hepatol*. 2014;28(5):275–285.
 23. Mathias H, Heisler C, Kits O, et al. Patient-ly waiting: a review of patient-centered access to inflammatory bowel disease care in Canada. *J Can Assoc Gastroenterol*. 2018;1(1):26–32.
 24. Heisler C, Mathias M, Currie B, et al. Evaluation of provincial geographic variation in access to inflammatory bowel disease care. *J Can Assoc Gastroenterol*. 2018;(CDDW abstract issue).
 25. Heisler C, Mathias H, Morrison JB, et al. Understanding access to IBD specialty care in Nova Scotia through the patient lens. *J Can Assoc Gastroenterol*. 2018;1(suppl_2):335–335.
 26. Sandelowski M. Focus on research methods: whatever happened to qualitative description? *Res Nurs Health*. 2000;23:334–340.
 27. Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health*. 2010;33:77–84.
 28. Neergaard M, Olesen F, Sand Andersen R, et al. Qualitative description – the poor cousin of health research? *BMC Med Res Methodol*. 2009;9:1471–2288.
 29. Plummer P. Focus group methodology. Part 1: Design considerations. *Int J Ther Rehabil*. 2017;24(7):297–301.
 30. Plummer P. Focus group methodology. Part 2: Considerations for analysis. *Int J Ther Rehabil*. 2017;24(8):345–351.
 31. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J*. 2008;204:291–295.
 32. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
 33. Pittet V, Vaucher C, Froehlich F, Maillard MH, Michetti P; Swiss IBD Cohort Study Group. Patient-reported healthcare expectations in inflammatory bowel diseases. *PLoS One*. 2018;13(5):1–16. doi:10.1371/journal.pone.0197351.
 34. Rohatinsky N, Boyd I, Dickson A, et al. Perspectives of health care use and access to care for individuals living with inflammatory bowel disease in rural Canada. *Rural Remote Health*. 2001;21:6358. doi:10.22605/RRH6358.
 35. Richard L, Noller G, Derrett S, et al. Patients' accounts of living with and managing inflammatory bowel disease in rural Southern New Zealand: a qualitative study. *BMJ Open* 2020;10(11):1–9:e041789 doi:10.1136/bmjopen-2020-041789.
 36. Schoenfeld R, Nguyen G, Bernstein C. Integrated Care Models: Optimizing Adult Ambulatory Care in Inflammatory Bowel Disease. *J Can Assoc Gastroenterol*. 2020;3(1):44–53.
 37. Garcia-Sanjua S, Lillo-Crespo M, Richart-Martinez M, et al. Healthcare professionals' views of the experiences of individuals living with Crohn's Disease in Spain. A qualitative study. *PLoS One*. 2018;13(1):e0190980.
 38. Jones J, Heisler C, Phalen-Kelly K, et al. Perceptions and preferences relating to IBD-associated psychological distress at a tertiary care center. *QEII Heal Sci Cent Dep Med Dalhousie Univ*. Published online 2020.
 39. Mikocka-Walus A, Massuger W, Knowles S, et al. Quality of care in inflammatory bowel disease: actual health service experiences fall short of the standards. *Intern Med J*. 2020;50(10):1216–1225.
 40. Miles M, Pena-Sanchez J, Heisler C, Jones J. The Canadian landscape of IBD care: are we keeping pace? Preliminary results from a nationwide survey. *J Can Assoc Gastroenterol*. 2018;1(3):214.
 41. Kemp K, Griffiths J, Lovell K. Understanding the health and social care needs of people living with IBD: a meta-synthesis of the evidence. *World J Gastroenterol*. 2012;18:6240–6249.
 42. Lesnovska K, Hollman Frisman G, Hjortswang H, et al. Health care as perceived by persons with inflammatory bowel disease—a focus group study. *J Clin Nurs*. 2017;26:3677–3687.
 43. Byron C, Cornally N, Burton A, Savage E. Challenges of living with and managing inflammatory bowel disease: a meta-synthesis of patients' experiences. *J Clin Nurs*. 2020;29:305–319.
 44. Kemp K, Griffiths J, Campbell S, Lovell K. An exploration of the follow-up up needs of patients with inflammatory bowel disease. *J Crohns Colitis* 2013;7:e386–e395.
 45. Haggerty J, et al. Continuity of care: a multidisciplinary review. *BMJ* 2003;327:1219–1221.
 46. Jones JL, Benchimol EC, Charles CN. Crohn's and Colitis Canada's 2021 impact of covid-19 and inflammatory bowel disease in Canada: health care delivery during the pandemic and the future model of inflammatory bowel disease care. *J Can Assoc Gastroenterol*. 2021;4(Supplement_2):S61–S67. doi:10.1093/jcag/gwab034.