Patient Experiences in the Management of Inflammatory Bowel Disease: A Qualitative Study

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Abstract

Background: Inflammatory bowel disease (IBD) can lead to substantial impairments of quality-of-life. Clinical guidelines and quality indicators aid physicians in practice but may not reflect the perspectives and experiences of patients with IBD. To address this, the objectives of this study were to understand patient experiences with IBD care and to explore priorities.

Methods: Based on a convenience sample of 36 participants, five focus groups were completed at four sites across Canada. Data were analyzed using a deductive thematic analysis approach to assess emergent themes and variability in participants’ experiences.

Results: Our results are organized by themes of structure, process and outcomes to illustrate common issues with respect to how care is organized in the healthcare system, how patients receive and experience care and how patients perceive the outcomes of their care. Our results frame a health systems quality approach that signal needed improvements in access to care, the need for innovation with respect to virtual medicine, the potential expansion of multidisciplinary team-based care and the importance of addressing the psychosocial dimensions for patients with IBD and their caregivers in order to better deliver patient-centred care.

Conclusions: The issues identified have the potential to impact priority areas in the system, IBD care delivery, and how outcomes can be improved by focusing on ‘lived experience’ and patient-centred care. The differing values and perspectives of all those involved in caring for patients with IBD underscore the importance of good communication with patients, caregivers and family members, as well as staying responsive to evolving needs.

Keywords: Access; Canada; Focus groups; Healthcare system; Inflammatory bowel disease; Patient-centred care; Qualitative research

INTRODUCTION

Inflammatory bowel disease (IBD) is characterized by chronic inflammation of the gastrointestinal tract. IBD currently affects approximately two million people in North America and that number is expected to increase to four million by 2030 (1). Due to its chronic nature, patients with IBD often require lifelong medical care for their disease, and their experiences are shaped by interactions with the healthcare system. In addition, psychiatric comorbidities often exist in higher proportions than in those without IBD (2), which itself can increase healthcare resource utilization (3). Within the Canadian healthcare system, coordinated care across different providers and settings can be challenging and fragmented, without addressing psycho-social needs (4).

Physician and patient perspectives may substantially differ with respect to patient concerns (5). This is changing, however, as a standard set of outcomes was created with patient input, for use in different healthcare settings (6). The IBD patient’s ability to feel empowered with respect to their care is important for managing IBD. More recently, a specialty medical home to treat patients with IBD has been advocated to provide patient-centred care (7). Creating these medical homes requires a significant investment and is not always feasible within the medical jurisdiction. Despite recent acknowledgements by physicians that care for patients with IBD can improve (8), there are still many areas where patient care is lacking. To better understand this, we conducted a qualitative study of IBD patients’ experiences across Canada.
MATERIALS AND METHODS

Recruitment

Given that the aim of this research was to explore the healthcare-related experiences of people living with IBD, a qualitative research design was most appropriate. The provinces where focus groups were selected to be conducted were on where previous focus group work had been done (Alberta, Ontario, Quebec) as part of the Promoting Access and Care through Centres of Excellence (PACE) initiative. Nova Scotia was additionally chosen as investigators in that province were planning similar focus group work and a decision was made to collaborate. Recruiting occurred through Crohn’s and Colitis Canada. Patients were sent email invitations to participate in the study using a registry maintained by Crohn’s and Colitis Canada. These were patients who had agreed to be contacted regarding research. Individuals who expressed interest in participating were sent the informed consent forms before the focus group in order to give them an opportunity to read it and have any questions answered before the date of the focus group. Over 960 invitations were sent over the course of several months and the 93 positive responses (9.7% response rate) were forwarded to the study team to coordinate local focus groups.

Focus Groups

These focus groups were designed as a follow-up study to build on insights gained from focus groups from a previously conducted study where the analysis was used to inform development of quality indicators for management of IBD. In that study, participants discussed their opinions and attitudes about their IBD care, specifically with respect to the services provided, the availability of services, and information about IBD, treatment options and prognosis (9).

For the current follow-up focus group study, a structured focus group guide was developed to further examine some of these experiences for people living with IBD (Supplementary Data 1). These questions were broadly organized using the Donabedian (10) model (Figure 1) to facilitate an understanding between the related concepts of structure, process and outcomes in healthcare in relation to IBD patient experience. In addition, a ‘least-most’ exercise (Supplementary Data 2) was employed to gain additional insights into themes that were identified in previous focus groups, and how patients with IBD, based on their experiences, would prioritize certain elements of their care.

All focus groups were conducted in the spring and fall of 2018 by three qualitative researchers (RM, GM, and CH) and were audio recorded and transcribed verbatim. The transcript data were managed using Quirkos 2.0 software. Data derived from text-based transcripts were subject to deductive thematic analysis, which allowed for researcher acclimation to the data (11). The aim of this type of analysis is to establish patterns and describe the phenomenon of interest (12). Concepts from the Donabedian model (10) were used to help frame the coding of the qualitative data and guide the data analysis in terms of patient interactions with the healthcare system, care processes and participants’ assessment of their care outcomes. Data analysts remained open to adding novel themes that emerged from the data (12,13).

Ethical Considerations

Research ethics board approval was obtained for the study at the Sinai Hospital System and at each focus group site. Individuals who emailed the research coordinator received the informed consent form. At the beginning of each focus group, participants were given a paper copy of the informed consent form. Participants then had the opportunity to read it and ask any questions before the focus group began. The study was approved by the Research Ethics Board at the Sinai Hospital System and at each focus group site.
RESULTS

Patient Characteristics

Five focus groups were held, with a total of 36 participants, in major cities across Canada including Toronto, Montreal (English), Montreal (French), Calgary and Nova Scotia. The focus group size ranged from five to nine participants and duration was 120–180 min long. Women comprised the majority of participants (n = 27). Just over half of participants had been diagnosed with Crohn’s Disease; the rest had been diagnosed with ulcerative colitis, with the exception of two participants who had IBD-unclassified. Participants’ ages ranged from 20 to 74 years (mean = 40 years). The focus group findings are described here in three sub-sections: structure, process and outcome.

Structure (S)

In structure, we describe participants’ experiences with the context of care in the Canadian healthcare system for patients with IBD. These findings are outlined under five headings: healthcare access, care coordination, technology enablers, service knowledge and patient-centred care (Tables 1 and 2).

Theme Si: Healthcare Access

“...And access. If I’m having a flare-up, I want access to a professional. I don’t want to have to wait 18 months [to see a specialist] and be in severe distress...”

An overarching theme emerging across the focus groups was the intersecting issue of access and care coordination that shaped the experience of care. Access was a critically important aspect of IBD care and was something that transcended participants’ care journeys. Participants described struggling at times to get access to a variety of resources, including but not limited to a diagnosis, timely follow-up and allied health professionals.

Theme Sii: Care Coordination

“I’ve been accessing everything on my own. Every person that I’ve been dealing with is a silo.”

When reflecting on care experiences, focus group participants discussed the ‘siloed’ nature of care provision—where not only were the individuals working in IBD care working alone, but the patients themselves would have to coordinate and access their own care. The discussion about access often segued into reflections on the coordination of care, and how to better prioritize the needs of patients with IBD. The Monday–Friday 9 AM to 4 PM nature of many IBD specialty clinics, and the difficulty accessing a person that could help one gain access to needed care, meant that many people with IBD end up in the Emergency Department (ED).

Theme Siii: Technology Enablers

“I think the one that stood out to me is probably patient portal, or rather just access to my medical records, actually, would be nice.”

The healthcare ‘system’ in which IBD care is embedded is outdated and no longer meets the needs of the ‘current’ IBD patient. ‘Inefficiencies’ in the system with regard to their experiences were often discussed by participants in the context of digital health. Focus group participants reflected on the potential benefit of online interactions and communications. Participants appreciated the option of being able to connect with their IBD specialist virtually, rather than always having to attend the clinic in-person and suggested that technological innovation in the field needs to be a priority. Many participants felt they would benefit from an electronic portal, where they could easily access their medical records to share with other providers, and to consolidate and update files.

Theme Siv: Service Knowledge

“I think on the education component... I think [immediately] following diagnosis, it sounds even ridiculous, but even a pamphlet, something, like, give me something I can come home with.”

The care providers that study participants interacted with often did not understand their health literacy or information needs, and a consistent account from participants was that there was a lack of education for all stakeholders. With regard to the education of healthcare professionals, participants remarked that access issues were exacerbated by the fact that clinicians whom they encountered in general practice—for example, in the emergency department—were often not trained in IBD care. More opportunities for training clinicians in IBD care and for IBD patients themselves were identified as priority areas to improve access and the delivery of quality care. Some participants felt that they too were often not properly educated about their diagnosis, and as a result, felt unprepared to manage their care at home or to actively participate in care decisions.

Theme Sv: Patient-Centred Care

“It’s the structures of our healthcare system, I would say... I would say, no care is truly patient-centred.”

Many of the negative experiences that participants discussed with regard to their IBD care were described by them as ‘structural’. Focus group participants discussed how they would like individualized care and the prioritization of a ‘whole person’ approach. This approach, in practice, would acknowledge each individual’s unique life circumstances and context and could lead to personalized care, treatment and support. This would be a top priority in a truly patient-centred care model for IBD. From the perspective of study participants, this would also mean that the person with IBD needs to be enabled to participate in their care, seen as a respected and integral part of their own care team, and with their lived experiences truly valued in the clinical setting.

Process (P)

In process, we describe how persons with IBD experienced the various system interfaces with providers and other stakeholders (e.g., caregivers and family members), and how IBD care is delivered in the Canadian healthcare system.
**Table 1. Quotes illustrating key themes**

| Theme                      | Illustrative quotes                                                                                                                                                                                                 |
|----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Structure                  | “Access is a big one, and another just along those lines is process, like, how processed my illness has become. And how, in order to do the things I need, I know I need to follow X next steps... If I feel a little bit ill, I know I need to try and get in the system...”  
“If that overwhelming threat is more access... just the bulk of appointments and things you need to coordinate in your life, in a system that just kind of sucks when it comes to coordinating that. It's really difficult when you're someone with Crohn's, who has literally all of theldapay list of things that you need to manage and all of the people that you could potentially need to see, your GP, your GI, your rheumatologist, your gynecologist, all of the people. Never mind, the annual tests and things, and drug coverage and stuff like that. So, I think it's the access, because there's no clear kind of person to help run things by, answer your questions quickly, in a life when you also need to kind of manage your day-to-day life.” |
| Sii) Care coordination     | “…I would say lack of coordinated care [is the biggest challenge] because it's hard in the off hours when you can't talk to your GI and you have to go to Emerg, and I personally hate doing that... and the ER doctor put me on [meds],... and you want to trust them. Then as soon as I got a hold of my GI doctor, she was like...I have to wean you off everything...”  
“I only have a GI specialist... It's just him and his secretary. And, yeah, she's a [blank] to be clear, but I feel like she knows who I am now and when I call, she makes things happen a little bit.” |
| Siii Technology Enablers   | “I think if there was an online system in which I could see that my referrals are being processed because I find that's been one of the biggest things... There's no single referral [where] they've actually called me and said you're on our list...I've had to track them down myself, call their offices, and do all these things... So, if there was a way for me to go online and say okay, I see that referral to GI has been processed and now I'm in the queue, here's the estimated wait time, then I would at least know. And I think that would, if we're talking about solutions, I think that certainly would have helped my journey.” |
| Siv) Service Knowledge     | “I think creating protocols in Emergency Rooms would be the most important thing... Although there's lots of education out there for doctors and health professionals... people are not given the right treatment and just left on their own to maybe go home and get sicker or not get the right help they need.”  
“I think on the education component, I would like to add directly following diagnosis... just leaving that office with the diagnosis and no other information, other than that medication, I think really it was hard physically, but it was really hard mentally too. I think following diagnosis, it sounds even ridiculous, but even a pamphlet, something, like, give me something I can come home with.” |
| Svi) Patient-Centred Care  | “It's the structures of our healthcare system, I would say. It's the... cookie-cutter approach to it. I would say, no care is truly patient-centred... So, I think it's the ability to really tailor it to the patient's specific needs and that would require kind of getting to know the patient, which I think the system doesn't really allow them to do.”  
“Yeah, I sort of feel like it doesn't matter what I say, like, my appointments, I wait for an hour and a half, I go in there and I'm in there for maybe five minutes, ten minutes on a good day. I write notes about all of my symptoms and I come in armed with tons of information that I think will help guide my care, none of that is acknowledged or asked for... Okay, we need to up this dose or let's try this medication or let's try this. My symptoms and my journey is, I feel, totally irrelevant to the treatment that's being provided.” |
| Process                    | “I have had to wait so long for certain things, especially when getting diagnosed. I find you wait a long time. The doctor I had, at least, didn't really take me seriously, because I didn't have a diagnosis yet and she couldn't figure out what was wrong with me. So, she didn't take my symptoms seriously. She would kind of just talk to me for like two minutes, look at her watch, not really listen to what I was saying, and then be like, okay, see you in six months. And, I'm just like, I'm not living. I'm surviving, but I cannot live my life how I am. I just had really had experiences there. I actually had to see a different GI to get diagnosed, because this GI, they did a colonoscopy on me, which showed that I had Crohn's disease, but they didn't tell me that. I had to go to a different hospital, where they sent the same test results, and then I had to have a nurse practitioner look at this and be like, oh, yeah, it says right here, you have Crohn's, that's what the results were.”  
“I think we've all learned our bodies and we know if something isn't right. I just think being heard I guess is probably the hardest part of it, being heard by healthcare professionals, even more so than some of the lifestyle pieces I would say. It's really frustrating when the people, which you want to support you and you go to for help, aren't able to help you in the way you need help easily.”  
“I think, for me, just understanding the transition points from patients who are... coming from the paediatric system to the adult system... from a patient and family centred model to a patient-centred model where you become in charge of everything... your parents are managing your care when you're in paediatrics, clinically, then when you come to the adult land, you are expected to know everything and do everything. Like, you are the keeper of yourself. And, I found there was little room for your family...”  
“I would say the most frustrating thing of my overall IBD experience, through all the years that I've had it, was getting the diagnosis, as I shared earlier. But, as a more frustrating thing that's ongoing as you deal with the illness is, similar to what RM said, with the lack of mental health care... So, I think it is really important to get help for people, like, mentally as well as physically.” |
| Pi) Multidisciplinary teams | “I just would have liked it if the nutritionist was with the doctor in the same... Maybe they could talk to each other more and see a bit more... in the same meeting, in the same network, in the same clinic.”  
“Yeah, in my dream clinic there will be a nutritionist, there will be an osteopath, also they have, mssothérapeute (massage therapist) and a coach, like, workout coach, this guy or girl that's strong and could show you exercise...” |
findings in this section are outlined under three thematic headings: timeliness, multidisciplinary teams and communication. (Table 2).

Theme Pi: Timeliness

"...I have had to wait so long for certain things, especially when getting diagnosed. ... And, I'm just like, I'm not living."

Timely initial diagnosis was a problematic point for many participants. With regard to the process of receiving IBD care, this was the top priority that study participants wanted addressed. This issue was also described as what initially shaped a cascade of subsequent negative experiences and interactions with the healthcare system. Many participants experienced long wait times as well as problems with communication, including times when they did not feel heard or included.

Table 1. Continued

| Theme                  | Illustrative quotes                                                                 |
|------------------------|--------------------------------------------------------------------------------------|
| Pi) Communication      | “I think communication between departments as well so I think everybody talking to each other I guess. That would be something that’s been not helpful in receiving information. It’s I can keep up my chin with people telling me two different things in terms of what’s okay and what’s not okay. So, I think trying to talk to different groups and finding different information from two different sources has been something that has not been helpful in the journey I guess. So, sometimes just talking to various sources.” |
|                         | “And well...the things I repeat all the time, all the time to him and to the rheumatologist, and to other doctors, even to the surgeon because I had a piece of my intestine removed, it was really that no one listened to me when I was changing the way I ate, which helped me a lot, but no one listened to me... As I said, no one listened to me. They aren’t open to listening to people.” |
| Outcomes               |                                                                                       |
| Oi) Quality-of-life    | “Having a normal life, having a normal life. I could eat this, I could drink this, I could go for a walk, I could have sex, everything, that I have a normal life.” |
|                         | “I put quality-of-life just because that’s more all-encompassing, because generally if you have some baseline quality-of-life, then hopefully you can pursue your career goals, your relationship goals, all your other goals.” |
|                         | “It’s very isolating, I find...This is the most people that I’ve met with this disease but it’s so interesting...so there’s a lot of shame I think with the disease given that it’s your bowels and it’s gross and stuff. And so, nobody really talks about it but it’s amazing how many people though other people I’ve met that I do in fact have this disease and suffer with it in isolation.” |
|                         | “...the increase of my overall quality-of-life, physical and mental health. Just because, you know, it’s like RF said earlier, sometimes it’s up, sometimes it’s down. I could be having a good time, I could be having a bad time. I’m in remission as well, I’m doing well for the most part, but then there are times I’m going to need a little support and my mental health, just like, why is this still happening to me, I’m in remission. And, in regards to reduced negative impact, I mean, at that point, I know if people can’t handle it in my life, in my social life or in my relationships, then they’re not people who are going to be in my life, because this is who I am, it’s part of who I am. I’m learning how to live with it, this is what you get, no returns.” |
|                         | “I mean, it was sort of touched upon, but I think, let’s just say, in my experience, adequate pain control is, let’s say, lacking, especially these days with the stigma with, whatever, pain killers. Even though there are alternative ways of reducing pain. Gone to behavioural therapy, mindful meditation, those are all, whatever, valid options, but I know that it’s a challenge for other IBD patients to get appropriate pain control. I understand the ultimate goal of treatment is to induce remission and reduce inflammation to the point where hopefully you have no inflammation, but getting to that point sometimes takes three, six, eight months, a year, years. In the meantime, if you're in pain and it's not controlled, that reduces your quality-of-life.” |
| Oii) Medicines         | “It’s been 35 years that I’ve had a disease. Okay. I had it when I was pregnant. Before having a child. And what I can tell you is that there has been a lot of evolution that has occurred in the medical system. Thirty-five years ago, there were treatments, they didn’t care anything, as we say. It’s an autoimmune disease. But what I can say is we had good care despite maybe fewer medications. Today, what I’m experiencing right now. You know when you’re older, when you’re approaching 65, you’re in another category. And I just wanted to mention that. Medical accessibility now...it’s very difficult.” |
|                         | “And just to know that you can email her [GI specialist] and she’ll email you back as soon as possible and she takes it seriously which is lovely...” |
|                         | “Right now, I would say, the biggest obstacle to dealing with the Crohn’s is the drug coverage and coordination of drugs.” |
| Oiii) Social Support   | Yes, same thing for me. Instead of getting a ready to use solution, one designed for most patients, listen to the patient. There are those who, with a medication will have certain side effects that do not bother them, while other people will be really bothered. Combine that with a life plan too. Often these people start when we are quite young. So, the person evolves with their disease, but career plans, family plans, plans are different from one person to the next. You eventually just kind of figure it [the IBD] out. And, growing up with a great social network and friends and, honestly, just great parents who have taught me to get there in terms of my confidence within. Along the same lines, the support network. When I was diagnosed, I heard through someone who was friends with somebody else who was part of the Crohn’s & Collitis Foundation at the time. When I went to one of their meetings, they said, we’re not a support group, but we are a supportive group. They were doing fundraisers and organizing and things like that, so they were very helpful in telling me what their experiences were or if they were parents what their kids’ experiences were. So, luckily, I got to know many people through that.
| Structure                                                                 | Process                                                                 | Outcomes                                                                                                                                 |
|--------------------------------------------------------------------------|--------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|
| Elements of the systems of care for patients with IBD; How care is organized within the system; The capacity of the system to respond to the needs of IBD patients | How patients with IBD experience the interfaces with providers and other stakeholders (i.e. caregivers, family members) within the system; What gets ‘done’ to patients and with patients; What are the needs of patients | The results and health outcomes; What happens to patients, what happens to their health, physical functioning, psycho-social well-being as a result of their interactions with the system, providers and stakeholders |

| Theme                        | Subthemes               | Theme                         | Subthemes                        | Theme                        | Subthemes               |
|------------------------------|-------------------------|-------------------------------|----------------------------------|-------------------------------|-------------------------|
| Access Issues                | Waittimes (+)           | Multidisciplinary team        | Care team                        | Quality of life               | Uncertainty             |
|                              | Quick release program   |                               | Dietician                        | Cause                         | Environmental           |
|                              | Wait times (-)          |                               | Nurse                           | Genetics                      | Social                  |
|                              | Follow-up               |                               | IBD Nurse                        | Stress                         | Family                  |
|                              | Institution             |                               | Nurse Practitioner               | Stress                         | Friendships             |
|                              | Hospital                |                               | Family physician                 | Stress                         | Career/Employment       |
|                              | Clinic                  |                               | Social worker                    | Stress                         | Disclosure              |
|                              | Medical records         |                               | Counselor                        | Stress                         | Physical                |
|                              | Test Results            |                               | Psychiatrist                     | Stress                         | Nutrition               |
|                              | Physical location       |                               | Specialist                       | Stress                         | Diet                    |
|                              | Travel                  |                               | Surgeon                          | Weight loss                    | Exercise                |
|                              | Distance                |                               | GI Specialist                    | Helplessness                   | Emotional               |
|                              | Community               |                               | Pharmacist                       | Helplessness                   | Diet                    |
|                              | Silos of care           |                               | Naturopath                       | Helplessness                   | Helplessness            |
|                              | Access to all professionals |                           | Team Approach                    | Helplessness                   | Psychological           |
|                              | Drug coverage           |                               | Relational                       | Helplessness                   | Loss of control         |
|                              | Bathrooms               |                               | Continuity of care               | Helplessness                   | Family impact           |
|                              |                         |                               | Seen together                    | Helplessness                   | Mental health           |
|                              |                         |                               | Pain management                  | Helplessness                   | Psycho-social well-being |
The diagnosis itself was an important point of certainty for people with IBD: in many ways, participants felt relief at finally knowing what their issue was, but many expressed anxiety prior to arriving at a diagnosis and often could not access the care that they needed until they received a formal diagnosis. They suggested that prioritizing ‘self-care’ (mental, physical and social) was important to maintain their well-being while waiting for a diagnosis or for care.

Theme Pii: Multidisciplinary Care Team

“When you have a multidisciplinary team…and they are in the same space [physical or virtual] …. there’s also a clinician comfort with making…certain decisions in partnership with a patient that doesn’t exist when…you see multiple providers [at different times].”

When participants were asked about their ‘ideal’ IBD clinic, many suggestions centred around the concept of multidisciplinary care teams. The team approach was perceived to be more ‘relational’ in nature and could address a number of structural and procedural issues at once. Additionally, to provide the opportunity for better continuity and communication, study participants suggested having persons with IBD be in the same room with all their multidisciplinary health providers to facilitate discussion of treatment issues and collaboration to find solutions. In addition to the traditional care teams comprised of physicians, pharmacists and nurses, the ‘ideal’ care team would include a dietitian, a social worker, a psychiatrist, a massage therapist, a physiotherapist, and potentially a naturopath.

Theme Piii: Communication

“I think communication between departments as well …”

Closely linked to many of the ‘process’-based elements of care for patients with IBD was the theme of communication, and how those involved in the patient’s care communicated with one another. Communication issues were experienced when participants perceived that healthcare providers lacked empathy or active listening. Study participants suggested that a priority in addressing communication issues should be the inclusion of caregivers and family members in care decisions and planning. Caregivers and family members play an important role in relaying health information, monitoring health and managing medications across various settings of care. Finally, good communication among health care professionals supporting a person with IBD could also allow for any conflicting information to be reconciled.

Outcomes (O)

In this section, we describe participants’ self-reported health outcomes and their reflections on the impacts that their care and treatment experiences have on them. These findings are outlined under three headings: quality-of-life, medicines and engagement (Table 2).

Theme Oi: Quality-of-Life

“Being able to function, to work, to go back to school. Having optimal wellness and being able to accomplish something with your life.”

When asked about their care and the outcomes they desired, the priority outcome for focus group participants was a better quality-of-life, or as some described it ‘as normal a life as possible’. From their experiences, participants voiced the importance to remain responsive to the health of the individual which is often in flux with IBD; they emphasized the need to recognize that overall health encompasses social, mental, and physical well-being. The social element of quality-of-life was frequently framed around important relationships. How well the person with IBD was doing often tied to how supportive their family and friends were.

Theme Oii: Medicines

“Right now, I would say, the biggest obstacle to dealing with the Crohn’s is the drug coverage.”

In the sample of participants that participated in focus groups across the country, all of them discussed how treatments were delivered as important as what treatment was delivered and that this directly impacted their quality-of-life. As one participant remarked, none of the medications were viewed as ‘curative’ and the more expensive, newer medications—sometimes not covered by drug plans—did not necessarily translate into better outcomes. The use of complementary therapies was a commonly discussed topic in these focus groups with a wide range of perspectives regarding access and usefulness. Some participants felt that a priority area regarding treatments for IBD should be greater inclusivity and openness to complementary alternative medicine (CAM), which included considering CAM providers as potentially valuable members of the IBD team. Participants felt that they had good access to complementary medicine in the community. The kinds of complementary therapy discussed include: naturopathy, acupuncture, massage, mindfulness, cannabis and other kinds of supplements (e.g., vitamins and minerals).

Theme Oiii: Support System

“Thankfully, I have great friends and family around me to help feel supported, but, honestly, just the bulk of appointments and things you need to coordinate in your life, in a system that just kind of sucks when it comes to coordinating that…”

Access to care was also not experienced as holistic or streamlined. People with IBD were navigating multiple ‘silos of care’ with regard to healthcare professionals. At the same time, they were also dealing with the employers, educators and others who were often not seen as stakeholders in the care experiences, but were impacted. The amount of time and energy it takes to navigate the health care system, and to coordinate one’s care within and outside of the clinical setting (e.g., requesting sick days, arranging benefits) was described by many as something that significantly affected their quality-of-life. Having a strong support system of friends and family helped to address some of the gaps in care, especially the psychosocial aspects of care.

DISCUSSION

Our findings are relevant for understanding the experiences of healthcare delivery, for exploring priorities for transforming
IBD, and what outcomes are important for patients with IBD in Canada. The focus group findings suggest that quality in IBD care and access can be improved by critically examining the interplay between the structure of the healthcare system, the processes and resultant outcomes. Ensuring that patient values are acknowledged can help improve the patient’s experience and ultimately their quality-of-life. From the findings, it is important to recognize that ‘patient-centeredness’ requires a wider lens to account for contextual factors, including the patient and caregivers, and that experiences of patients with IBD are dynamic.

Although there are guiding principles for patient-centred care (14,15), how these principles are prioritized by patients with IBD is influenced by a multitude of factors. By examining IBD health services through the lens of the Donabedian model, a framework for understanding what matters to patients with IBD within the Canadian healthcare system, in their interactions with healthcare providers, and their expectations of care can be better illustrated (Figure 2). Here we explore how these factors can contribute to advancing policy, practice and research.

The issue of timely access to healthcare mainly relates to structure. Long wait times, especially for a formal diagnosis, may impact patients’ mental health outcomes and overall quality-of-life. An important area for policy work in the IBD field is improving and prioritizing wait times for diagnosis. Diagnosis of IBD was the most time-consuming part of the IBD journey, and a recent evidence brief suggested that challenges associated with a timely diagnosis were linked to primary care clinicians lacking awareness of IBD (16). From the results, the service knowledge theme is important for highlighting how inadequate knowledge or training in IBD can lead to negative interactions between primary care professionals and IBD patients, especially in emergency departments. Interestingly, those who receive a diagnosis of Crohn’s disease had a longer time to diagnosis than those who are diagnosed with ulcerative colitis (17). Delays in diagnosis and treatment can lead to increased complications (such as strictures) and depending on the age of the individual may also introduce new challenges associated with co-morbidities (18). A systematic evaluative study from 2012 reported that long diagnostic delays of between 12 and 24 months were associated with IBD patients that were males over the age of 40 (19), and if not appropriately supported during this time, may lead to less-than-optimal healthcare experiences for these patients.

Building on previous work by Nugent et al., the results from the current study highlight that where an patient with IBD receives care matters (20). The emergency department was identified as a place where patients expected suboptimal care due to lack of appropriate training in IBD. Even with the expectation of suboptimal care, as study participants described, IBD patients still reported attending the emergency department, as suboptimal care was considered better than no care especially under desperate circumstances. Overall, compared to other chronic diseases, research on access to IBD care in Canada remains thin (21); however, findings from a study by Bennett et al. share our findings that primary care settings are not optimized to serve the needs of patients with IBD and adds context into why location and context of care does matter (22). Furthermore, Benchimol et al. found that while ‘lag time’ prior to diagnosis with IBD was similar in rural and urban communities, rural communities faced barriers to specialist access, increased frequency of visits to emergency departments, and higher rates of hospital stays (23), and in a resource stretched healthcare system, better ways to provide ‘the right care’ are needed.

Based on the findings from this study, the concept of ‘urgent’ or ‘walk-in’ care specifically for IBD patients is an area

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**Figure 2.** Health care services, quality and patient-centred care in IBD.
worthy of further exploration. Urgent care is similarly related to the notion of timely care from our results, and there remains great subjectivity with respect to how these concepts are considered in practice. One study from Newfoundland and Labrador reported ‘urgent colonoscopy’ having a wide range of time to procedure from 8-58 days (24). Even within patient groups that are labeled ‘urgent’ there are priority patients, for example, those patients needing fluids or immediate pain relief. This means that wait times may vary across other patient groups, based on triage protocols (16).

Unsurprisingly, research findings consistently highlight that optimal patient experiences are often tied to information and education (25). Principles of patient-centred care such as Levesque et al.’s dimensions of ‘acceptability’ (26) suggest that individuals, in theory, should be able to ‘accept’ and assess the appropriateness of the provided care. The principles of patient-centred care highlight that in order to be responsive to patient needs, patients first need to be empowered with the right information and welcomed as valuable and respected members of their healthcare team.

Our findings agree with prior research (27) that patients seek the information related to their IBD from clinicians and that the information they seek extends beyond the disease and their medicines and includes quality-of-life considerations. For example, patients with IBD desire information about their medications, but they also wanted knowledge about their diet and how to plan for their holidays as part of living with and managing IBD (27). Knowing that patients with IBD prefer to receive their education from a clinician, a recent study (2020) that explored the role of an IBD nurse delivering education reported that overall hospital admissions were reduced (28). With limited access to IBD specialists, reevaluating the role and training of the members of the multidisciplinary IBD team is warranted to enhance IBD care.

Supporting people with IBD through the diagnosis to ‘maintenance’ phases of IBD may best be handled through a ‘care team’ approach. This ‘care team’ approach is understood in the literature as “the provision of health services to individuals and families by at least two health professionals working collaboratively… on shared goals within and across settings” (29). Team-based care, where two providers see the same patient together, may help address issues of communication and bridge gaps in the continuum of care. Furthermore, a team-based approach with patients as part of this team may help address continuity of care issues across settings if a community-based IBD nurse partners with a hospital-based physician (14), and this may increase the frequency of interactions, if they patient desires.

Participants expressed their concerns during focus groups about the relationship between mental well-being, disease status and quality-of-life for themselves and their care partners. A study by Walker et al. found that people living with IBD had higher rates of depression and panic disorder than those who did not have IBD (30). This study emphasizes the reality that living with IBD has major impacts on mental health and wellbeing, suggesting that continued research on addressing this issue remains very important. Many participants described using complementary therapies, such as acupuncture and marijuana. Although it is known from the literature on chronic illness that patients often access complementary and alternative medicines (31,32), the rationale for accessing these treatment modalities and how it may improve outcomes is another area for future research.

A few limitations of this project need to be acknowledged. The number of focus groups conducted (N = 5), sample size per group (N = 5–9) and overall sample (N = 36) was appropriate for data analysis and to reach saturation for individuals living in Canada with IBD and associated with the Crohn’s and Colitis Canada foundation. However, the sample, drawn from a nationally representative sample, is a convenience sample with a low response rate (9.7%)—which is typical for this type of research—and may not allow for generalizability to all patients with IBD in a Canadian context or beyond. Participants who expressed interest in the study may be more likely to have concerns regarding their care, thus introducing a selection bias. Moreover, the study did not inquire about patient ethnicity or whether participants resided in rural versus remote areas or received their care through academic centres or community hospitals.

CONCLUSION
Understanding IBD patient care experiences is an important step in ensuring that system priorities for the management of IBD, often determined by clinicians, academics and policymakers, are also reflective of patient values and perspectives. This study helps us better understand the management of IBD, from a patient perspective, regarding the structural issues, the processes, and the outcomes experienced by those living with IBD, and what issues participants felt need a priority focus. Of all of the aspects of their experiences with IBD that individuals could highlight, emphasis was placed on issues related to accessing care, the need for timely diagnosis, the coordination of care, the desire to see a team of collaborative care providers, and quality-of-life considerations that acknowledge the psycho-social toll of managing IBD. While the themes described in this study have been previously identified in other studies, our analysis provides the patient experience from a Canadian perspective in the context of interactions within a universal healthcare system. Further research should explore: how to improve wait times and continuity of care, potentially through tech or virtual solutions; what patient-centred care, which takes a ‘whole person approach’ looks like for people living with IBD; how to better support patients with IBD through a more ‘complete’ system of care; and why patients with IBD turn to alternative therapy.

Supplementary Data
Supplementary data are available at Journal of the Canadian Association of Gastroenterology online.

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### Conflict of Interest
The authors declare no financial disclosures or conflict of interest.

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