

Crohn's Disease Patient Experiences and Preferences With Disease Monitoring: An International Qualitative Study

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Background: Strategies incorporating objective disease monitoring in Crohn's disease (CD), beyond clinical symptoms are important to improve patient outcomes. Little evidence exists to explore patient understanding of CD treatment goals, nor preferences and experiences with monitoring options. This qualitative study aimed to explore patient experiences and preferences of CD monitoring to inform monitoring strategies, improve patient engagement, and optimize a patient-centered approach to care.

Methods: This study used a patient-oriented, qualitative descriptive design. Convenience and snowball sampling were used to recruit adult participants diagnosed with CD who had experience with at least 2 types of disease monitoring. Online focus groups were conducted and data were analyzed using thematic analysis.

Results: This international study included 37 participants from Australia, Canada, United Kingdom, and the United States. Overall, participants preferred more noninvasive types of monitoring [eg, intestinal ultrasound (IUS)] but were willing to undergo more invasive monitoring (eg, colonoscopy) if required. To improve disease monitoring, participants wanted increased access to IUS, establishment of a patient-centered interdisciplinary team and access to information and self-testing. Participants identified challenges with communication between patients and providers and stressed the importance of participating in shared decision making and being equal team members in their care.

Conclusions: It is imperative to incorporate patient-driven preferences into how we can best structure monitoring strategies, to ensure equitable access to those preferred modalities and embrace a shared decision-making approach to disease management in CD.

Lay Summary

This study used group interviews to understand patient experiences and preferences of Crohn's disease monitoring. Study results can be used to inform monitoring strategies, improve patient engagement, and optimize a patient-centered approach to care.

Key Words: Crohn's disease, disease monitoring, patient-oriented research, qualitative research

Introduction

Although symptom resolution and improvement in quality of life are important patient-centered goals in Crohn's disease (CD) care, targeting clinical symptoms alone does not consistently correlate with adequate control of inflammation. Symptom control, does not consistently lead to substantive changes in outcome, such as reduced hospitalization or surgery.^{1,2} Therefore, a strategy targeting objective resolution of CD activity has been widely adopted in clinical practice, often referred to as a “treat-to-target” (T2T) approach.^{3,4} There is

mounting evidence that targeted strategies are cost effective, reduce morbidity associated with CD and improve patient outcomes.⁵ A T2T approach requires tight monitoring with systematic, serial assessment of interval targets of disease activity that allow for treatment adjustments until a target is reached. There are a number of potential options available to objectively monitor disease activity in CD; however, there is limited extant evidence to provide insights into patient preference and experience with the various modalities.⁶

Endoscopic healing is considered the current gold standard target in clinical practice, with evidence to support prolonged

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urable clinical remission in addition to reduction in inflammatory bowel disease (IBD)-related surgery, hospitalization, and even colon cancer.⁷ Although considered the most important target, there are challenges in monitoring with ileocolonoscopy (IC) in CD: the procedure is invasive, requiring a purging preparation in addition to intravenous sedation. It is not feasible nor acceptable for frequent repeated use and it is costly. Patients consistently report preference for noninvasive tests over IC.⁶ There is limited qualitative evidence to explore CD patient experience regarding IC, which they need to repeat at regular intervals, given the chronicity of their disease. However, Ryhlander et al deftly report patient insight into the importance of IC, but also their sense of a loss of control, the significant impact on everyday life, the expectation of pain and embarrassment, and the reminder of their chronic illness.⁸

Alternative, noninvasive biomarkers such as C-reactive protein (CRP) and fecal calprotectin (FC) provide objective measures of disease activity, used routinely in clinical practice to overcome the shortcomings of symptom reporting.^{9,10} The results, however, are often not available at the bedside, do not reflect the site(s) or extent of disease, and therefore cannot be used to exclude complications and/or concomitant infections.^{11,12} False negatives and positives are common, resulting again in need for verification of disease activity by IC or imaging.¹² Further, a number of patients report difficulty in collecting the stool sample necessary for FC with 1 large survey in the United Kingdom suggesting the majority of patients prefer blood sampling over stool.⁶ Yet, noninvasive testing wins out over endoscopy.^{13,14}

Cross-sectional imaging such as computed tomography with enterography (CTE), magnetic resonance enterography/imaging (MRE/I), and intestinal ultrasound (IUS) are integral to both diagnosis for disease mapping, in addition to monitoring for treatment response.¹⁵ A number of systematic reviews demonstrate equivalent accuracy for these modalities.^{16,17} There are important advantages and disadvantages for each: CTE imparts radiation, therefore repeated use is not recommended but CTE has excellent resolution while MRE is costly without easy access, in addition to the need for intravenous contrast enhancement.¹⁸ IUS is well tolerated, easily repeated, but not widely available.¹⁹ Evidence consistently suggests that patients, if offered, choose IUS over other imaging modalities, including MRE and endoscopy.^{6,20,21} When disease monitoring is defined as the proactive use of any of the above: endoscopy, FC, or imaging with CTE or MRE, in a large American population study by Limketkai et al, only 49.5% of patients with CD underwent objective monitoring for disease activity within 12 months of initiation of biologic therapy.²² At 2 years, only 56.4% of CD patients had undergone monitoring. This suggests, despite widely accepted recommendations to objectively monitor CD patients serially at regular intervals,⁹ that this is not being achieved.

Monitoring strategies developed to date, have not been informed with substantive patient input and are thus, not personalized. Although there are a number of publications reflecting the importance of patients sharing in decision making for treatment, very little, if any, data exist regarding the importance of jointly developing treatment goals, nor monitoring expectations or preferences.²³ Engaging patients as equal partners in discussing and planning of CD monitoring is essential. The aim of this qualitative study was to explore

patient experiences and preferences of CD monitoring to inform monitoring strategies, improve patient engagement, and optimize a patient-centered approach to care.

Materials and Methods

Research Design

This study used a patient-oriented, qualitative descriptive design.^{24,25} Individuals living with CD were active and equal members of the research team throughout all stages of the research process from study design through to manuscript writing. Qualitative descriptive studies offer comprehensive summaries of events and seek descriptive validity of the meaning which participants assign to those events.²⁴

Setting and Sample

This international study included participants who were: (1) individuals diagnosed with CD; (2) 18 years of age or older; (3) reside within Australia, Canada, United Kingdom, or the United States; (4) speak and understand English fluently; and (5) have experience with at least 2 types of disease monitoring (ie, endoscopy, MRE, CT, IUS, blood and fecal biomarkers). Exclusion criteria: those with ulcerative colitis or indeterminate colitis, patients with CD diagnosed within the last 6 months (ie, new diagnosis without experience of monitoring), patients less than 18 years and those who were non-English speaking. Convenience sampling was used to recruit individuals with CD.

Recruitment

Following ethical approval, a recruitment poster was shared online and on social media (Facebook and Twitter) through national Crohn's and Colitis organizations. The recruitment poster was shared with gastroenterologists and nurse clinicians in each country to share among their patient and professional networks. Individuals interested in participating or had questions about the study contacted the research coordinator directly. Snowball sampling was used, where enrolled participants shared the study poster with others. The research coordinator confirmed participants met the inclusion criteria and provided the consent and demographic form to be reviewed and completed by the participant. Upon completion of data collection, participants received a \$50 gift card to recognize their contributions.

Data Collection

Data were collected via 7 online focus groups conducted between October 28 and December 3, 2021 to understand patients' experiences, preferences, and insights regarding CD monitoring. Focus groups were arranged by country to accommodate time zones. Two research team members with lived experience of CD conducted the focus groups, each lasting approximately 3 hours with 3–7 participants per group. Focus groups were digitally audio and video-recorded using Zoom technology. Local session recording was saved to a university-managed device and secure server. Participants were encouraged to have their cameras on to facilitate engagement within the group, but cameras were not mandatory. Participants could also change their names on their Zoom screen to protect their identity. During each focus group session, participants were asked to indicate their most and least preferred preferences for disease monitoring anonymously

Table 1. Demographic information.

Characteristics (N = 37)	n	Mean	Range
Country of residence		—	—
Australia	9		
Canada	11		
United Kingdom	10		
United States	7		
Gender		—	—
Male	14		
Female	20		
Nonbinary	3		
Age		—	—
18–29 years		9	
30–39 years		8	
40–49 years		8	
50–59 years		7	
60–69 years		5	
Year of CD diagnosis	—	2003	1978–2021
Past surgery for CD		—	—
Yes	25		
No	12		
CD activity		—	—
In remission	17		
In partial remission	13		
Active/not controlled	6		
Other (active and controlled)	1		
Who helps you manage your IBD?		—	—
Gastroenterologist who specializes in IBD	28		
General Gastroenterologist	6		
IBD nurse	0		
Family doctor	2		
Other (no one)	1		
Racial or ethnic background		—	—
African	5		
Arab	1		
European	22		
Southeast Asian	1		
Other (White, Caucasian, Jewish, Australian, no answer provided)	8		
What types of monitoring have you experienced for your Crohn's disease? (select all that apply)		—	—
Bloodwork	36		
CT scan	28		
Endoscopy (colonoscopy, ileoscopy)	36		
MRE (magnetic resonance enterography)	22		
Intestinal ultrasound ^a	24 ^a		
Fecal calprotectin	32		
Do you feel that your Crohn's disease is being monitored		—	—
Too often	0		
Just the right amount	30		
Not often enough	6		
No answer provided	1		
Do you feel the work/time or effort involved in monitoring your Crohn's disease is of benefit to you?		—	—
Highly beneficial	22		
Somewhat beneficial	8		
Neutral	4		

Table 1. Continued

Characteristics (N = 37)	n	Mean	Range
Not really beneficial	1		
Not beneficial at all	1		
No answer provided	1		
What is your marital status?		—	—
Life partner	5		
Married	15		
Single	12		
Divorced	1		
Other (common law)	1		
Prefer not to say	2		
What is your level of education?		—	—
High school or equivalent	3		
Trades or post-secondary	1		
Some college or university	9		
Bachelor degree	14		
Graduate degree or higher	10		
Which of the following best describes your employment status?		—	—
Employed full-time	20		
Employed on a casual basis	4		
Unemployed	1		
Not able to work	6		
Retired	4		
Full- or part-time parent	1		
Other (full-time university student)	1		

Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; MRE, magnetic resonance enterography.

*Demographic forms were completed in advance of the focus groups. Upon discussion with participants during the focus groups, it was noted that several participants had experienced an abdominal ultrasound, but not an intestinal ultrasound (IUS). The count for IUS is 11.

using a whiteboard and were given the opportunity to verbally explain their choices if they felt comfortable doing so.

Data Analysis

Recordings were transcribed verbatim by a medical data transcriptionist with lived experience with IBD. Once transcribed, the transcripts were reviewed for errors or omissions by comparing them with the Zoom recordings by a research team member who was present at the focus group session. All data were deidentified, and transcripts were cleaned, and analyzed using thematic analysis.²⁶ Data analysis was facilitated by using NVivo12 Pro software. Broad-based categorization was initially applied to establish collections of data pieces that could be further interrogated and determined as fundamentally connected or not. A secondary pass at the data consisted of scanning and locating poignant quotes driving the conversation applicable to the research aim. Final coding involved the reorganization of the data by taking the initial broad categories and dividing or submerging themes or subthemes and housing data extracts in their most appropriate categories.²⁷ This analysis approach involved remaining inductively close to the data and the constructed social meanings were cultivated from individual and group experiences. Categorizations were only applied as needed to sort ideas and avoid premature enticements to code data into specific categories.²⁷ All quotes extracted for analysis are verbatim participant language. Honoring perspectives brought forth by the participants means their words and their wording

only were flagged and coded. Whiteboard data were extracted and frequencies were calculated.

Ethical Considerations

Ethical approval was obtained from the University of Calgary (REB21-1038) prior to participant recruitment.

Results

Demographic Data

Thirty-seven persons with CD participated in 7 focus groups (see Table 1). Their age ranged from 18 to 69 years with a mean disease duration of 18 years. Most participants ($n = 28$) believed their CD was "in remission" or "in partial remission." The healthcare provider who most commonly managed participants' CD was a gastroenterologist ($n = 34$).

Themes

Three main themes were identified in the data: Patient preferences for monitoring, emotional responses of monitoring, and improving disease monitoring. Each theme and corresponding subcategories will be described below.

Patient preferences for monitoring

The most common CD monitoring tools mentioned by participants included bloodwork, stool tests, colonoscopies,

and MRI. IUS had limited availability across the countries included and thus, was less often mentioned. Bloodwork (complete blood count, CRP, drug levels) and stool tests (ie, FC) were the most routinely used tests for assessing disease status. The frequency of colonoscopy varied from every 6–12 months to every 2–3 years depending on disease status, severity, accessibility, practitioner, and patient preference and tolerance. In general, appointments with a gastroenterologist occurred every 6–12 months. While many participants stated they would like to be actively involved in their monitoring and appointments, only a few felt they were. Some of the participants preferred to deal with concerns as they arose. Generally, participants indicated that the more active their CD, the greater the frequency and extent of disease monitoring they would prefer. One individual described monitoring as dynamic, depending on disease activity:

... when your Crohn's is bad, your monitoring becomes way more important, and you become more diligent with it. I had four years where I was on [adalimumab], and it worked like an absolute miracle. For that time, I was so lax. I think I got one colonoscopy in four years. I didn't push for any of that. But as soon as flare-ups start to happen, you start to become really regimented. I start remembering all the normal ranges for what tests should look like, and asking the questions, and all that kind of stuff. I guess you know it's important all the time. You just become lax on it when things are good. (AUS2)

Disease monitoring preferences

When asked about disease monitoring preferences, many participants said having monitoring options are preferred, as this strategy restores a sense of control over disease management. Most often, the underlying protective factor in disease monitoring is to only be as invasive as one must, while balancing the need for enough information and accuracy of results. Overall, one of the ways to understand participant perspectives around procedures is to categorize them by the least to most preferred and understand why participants have identified them as such. Patients reported the factors influencing the categorization depended primarily upon accuracy, convenience, and invasiveness, but also cost, the impact of the procedure on existing medications or conditions, frequency, and the availability to have real-time communication during the procedure.

The least preferred monitoring procedure across all focus groups was the colonoscopy (see Table 2). The preparation required to cleanse the bowel; the preparation time, the procedure, and recovery including the logistical inconvenience (ie, time off work, arranging a support person for transport); and the procedure invasiveness were cited as reasons for colonoscopy being the least preferred.

... for a colonoscopy ... you can't eat, and you have to go through a cleansing process. You have to plan ahead if you are working. What do you do? Do you take time off, not take time off? How many days do you take time off pre- and post? Sometimes I am tired two or three days afterwards.... The impact is longer on me. The preparation is harder. (AUS2)

Table 2. Preferences for disease monitoring.

Disease monitoring (N = 37)	n
Most preferred disease monitoring test	
Intestinal ultrasound	21
Bloodwork	12
Fecal calprotectin	6
Pill camera endoscopy	2
Magnetic resonance imaging	1
Computed tomography scan	1
Least preferred disease monitoring test	
Colonoscopy/endoscopy	18
Barium enema	14
Rectal exams	2
Stoma enema	2
Magnetic resonance imaging	2
Fecal calprotectin	1

Participants were asked to indicate their most and least preferred disease monitoring test on a whiteboard during the focus group session. Some individuals wrote more than 1 response.

Despite colonoscopy being the least preferred choice for CD monitoring, most participants valued the importance of accurate testing, so they were willing to undergo the procedure despite the challenges and discomforts, to ensure accurate monitoring of their disease and the ability make informed decisions about their care.

... the colonoscopy is the one that gives me the best peace of mind. ... It's ... what shows the ultimate health of how my bowel is doing. As much as I don't like the test, I don't mind going through it because it is the ultimate gold standard for me of what my disease is. If I'm feeling well and my scope looks great, that it's the best peace of mind I can get about managing my disease. It's not that I love it. ... I grin and bear it. (CAN2)

Though not all individuals experienced IUS, it was the most preferred monitoring choice mentioned in all focus groups, mainly because all groups discussed that it promises accuracy with minimal invasiveness (see Table 2).

I think an intestinal ultrasound would be phenomenal for many reasons. One being I like the idea that I would be able to lay there, look at it with the doctor, watch it happen, be able to discuss it; "I see this, I see that." "This is where my pain is, can you palpate over there with the probe." I think that is one really big advantage. (US1)

... it's [IUS] quick. It's painless. You can see what's going on. There is very minimal prep. There is not much recovery either. But I really like [participant]'s point about accuracy. And so, if they are able to get as good of an answer from the ultrasound, then that is like God's gift to people with Crohn's. (UK2)

I was introduced to ultrasound monitoring. That changed everything. I felt it was as accurate. There was no prep. There was no discomfort. I've had two of those now,

and that was a game-changer for me, as far as feeling comfortable with the monitoring. (CAN2)

Some participants report a fine balance between disease monitoring accuracy, frequency, and invasiveness. There is a relationship between the desire for information and the willingness to go through discomfort, repeatedly. All participants recognized the procedures/investigations were necessary for guiding treatment decisions and for providing reassurance. For example:

I think you always want things [monitoring tests] that are accurate, but you can kind of drop some of that accuracy for convenience and accessibility. For me, it feels like as long as I'm doing something every so often that is giving me a really clear picture of what is going on, I'm happy to do things that may be slightly less accurate, but easier. (AUS1)

For me it's a balance between accuracy and invasiveness and health risks associated with the testing. If we do too many CT scans or x-rays or something. Over time it's not the best. (CAN1)

Above all, CD participants recognized the importance of monitoring, despite the potential discomfort, given the unpredictable nature of the disease.

I'm like, "just do what you need to do." Because when you are in certain circumstances, especially when you are very ill. Whatever they need to do. (AUS1)

Short-and long-term disease monitoring goals

Participants were asked whether they had short- and long-term disease monitoring goals established between themselves and their care providers. Due to the unpredictable nature of CD progression, disease monitoring was reported to involve a hybrid model of planned and reactive care. Therefore, participants felt they must be flexible and comfortable positioning themselves as both proactive (ie, communicating symptoms, assessing options, obtaining and understanding results, seeking referrals) and responsive to their own needs as their disease changed over time. Short-term, trial-and-error monitoring primarily entails medication monitoring; when one stops working, another one is started. Sometimes severe, sudden onset or quick fluxes in disease states precipitate heavier monitoring. This scenario reflects the changes in short-term monitoring:

In my case I didn't have a long-term plan because when it started, it [Crohn's] started severe, and at that time I left the hospital, and they said, we'll see you in a month, and we'll give you these medications and so on. Well, I was back in the hospital a week later because it was so bad. So that changed the whole earlier plan. So, while I was there, things developed further, and the situation kept changing as my situation kept changing. (AUS2)

Advanced care planning is not necessarily feasible given the unpredictability of the ebbs and flows of CD activity and disease monitoring.

I'd love to have a long-term plan. I'd love to be given options. But I think if you said to me, "here's a potential five-year plan as to what this could look like," you'd be giving me 600 strands that could go anywhere. I don't think that actually investing the time to create that plan would be a worthwhile exercise. (AUS2)

The unpredictable nature of CD makes treatment plan development and goal setting difficult. In fact, goal setting could set oneself up for disappointment, as exemplified:

I don't know if that would even be particularly beneficial considering the nature of Crohn's. One second it will be totally fine, and then suddenly you are really unwell, with or without a reason. So, I kind of almost feel like goals being set for improvement might just make you feel like you've done something wrong, versus this is just how it goes sometimes. There's not always a predictable way up from being really unwell. Sometimes it just changes. I don't think goals would help me. (UK1)

Emotional responses of monitoring

One participant explains that tolerance does not necessarily build as a result of going through the same procedures repeatedly; each experience can be as uncomfortable as the one before, regardless of the amount of time one has been living with CD. They state:

One thing that I really noticed, with being a patient and dealing with all of this medical testing, hospital stays, needle pokes and everything, I don't think we build a tolerance. I think our tolerance goes down the more that we are exposed to. The less we have patience for. So definitely comfort level for the patient is huge. So ideally if you could make it [monitoring] painless. So the ultrasound really is the best. (UK2)

Being unwell and requiring frequent monitoring can cause worry and anxiety for individuals living with CD. The process of monitoring and living with a chronic illness can be so exhausting and overwhelming that sometimes patients will forego some aspect of monitoring to create a needed space between themselves and their disease.

I used to take a year break, what I would call "doctor vacation." Not make any doctor's appointments, as much as I could. I don't even want to pay attention to it. I'm just not in the mood for it. ... I just don't deal with it, personally. (US1)

The PTSD and the anxiety that comes with a lot of that monitoring, it's pretty burdensome, and it can really disrupt your life. I would kind of compare it to; thankfully I've never had cancer, but it reminds me of people when they go in for cancer re-checks, to determine whether or not they're in remission. You kind of hold their breath until they get that good news, "ya, everything looks okay. Maybe just come back next year. We'll do another scope or whatever that annual testing is." I understand the importance of doing it [monitoring], to see if anything needs to be changed. But there's also a lot of anxiety and fear that comes with that testing and monitoring, just because something could be going wrong. (US1)

It's about the time out ... the time out mentally and physically. Because when I am doing those tests, I'm out. I don't want to see anybody. I don't want to talk to anybody. I just want to be reclusive and home to recover mentally and physically from those repetitive experiences. (AUS2)

As previously mentioned, monitoring frequency does change over time depending on disease activity. Participants recognized that monitoring can be exhausting and frustrating, but is often time limited:

As somebody who is relatively recently diagnosed, ... the onslaught of diagnostic requirements at the beginning of the diagnosis process can seem never-ending, invasive, upsetting, violent, disruptive, pointless. Think of all those negative emotions, and you're having those on top of all of the problems that [participant] was just talking about, from money and insurance and logistics, and the brain fog. But the message to new patients would be that it does slow down. You can get to remission. And your interventions, whatever diagnostic tests that you're looking at, they're not always that frequent. (US1)

Monitoring to me is important, and I am sort of scheduled on a regular iteration of blood work. I'm stable right now so I've actually graduated to only getting a colonoscopy every three years. For me that seems to be the sweet spot for me, as long as I'm stable. I know instantly when things aren't right. I don't think that in my entire 31 years with Crohn's, I have ever been surprised by a result that had picked up something that I didn't know, based on symptoms and how I was feeling. I appreciate all the monitoring things that I have ongoing on a regular basis. But it always just sort of confirms to me, "yes, I'm still doing okay." When I was more unstable, that obviously is like others have said, where you are getting a lot more testing and a lot more invasive things. But I feel like in a stable remission I have sort of hit the sweet spot. (CAN2)

Sociodemographic factors played a role in individual responses to disease management and monitoring. The level of patient engagement in disease monitoring is variable and depends on the patient. Disability, employment status, occupation, housing or family situations, national differences (insurance, availability of care), personality, lifestyle/leisure activities, age, geographic location (rural), sexual orientation, race and ethnicity, sex, and whether or not someone was a parent all had implications for disease management and personal resources.

As a student that was living away from my family, when my disease was quite active for a bit. I would ask random people in my class if they would pick me up from a procedure and take me home on the bus. It's hard, and I don't think that is really thought of. There's a lot of assumption that you have solid people in your life to help you out, and sometimes you don't. (CAN1)

Improving disease monitoring

Several suggestions were provided by participants as strategies to improve CD monitoring. The main ways in which CD monitoring can be enhanced, according to participants,

are access to IUS, encourage interactions with interdisciplinary care teams, access to information, availability of self-administered testing, enhanced communication, understanding disease monitoring and shared decision making (SDM), and recognizing patients as experiences and equal team members.

Access to IUS

Excitement was the main emotion and reaction that developed during discussions on IUS. Some participants were eager to learn more about this monitoring tool given its non-invasive, high-information yield potential. One participant expressed:

Because I'm such an advocate for the ultrasound tool as a monitoring process, I would think that a lot more resources need to be put into that technology in making it accessible across the country. There are people here that hadn't heard about it until today. Probably their specialists don't talk about it because they know it's not available. I think peer to peer training is important, and funding for that. And getting hospitals on board to provide that availability of the technology to their physicians. Whatever it takes to make that available. It needs to happen sooner rather than later. (CAN2)

Interactions with interdisciplinary care teams

Specifically, access to and participation in an interprofessional care team (IBD pharmacists, GI specialists, nurses, administration/care coordinators, dieticians, psychologists) was considered ideal by participants. While a few participants had this type of team available to them, most did not and felt their care journey was more siloed and isolated. Patient-centered care was deemed critical, positioning the patient as the expert, with lived experience of chronic disease, requiring continuity of care over their lifetime.

We know our bodies. ... But sometimes I feel if my gastroenterology team actually listened to me ... I wouldn't be having half the problems I have today. (UK1)

To go to a multi-disciplinary team meeting would be brilliant, because you would hear different discipline's input into your holistic care...that is what I would really like. (UK1)

Access to information

More communication, follow-up, and information are reported as desirable for individuals living with CD and were encouraged in all focus groups. Knowledge of treatment options and results delivered efficiently was believed to lead to a greater sense of choice and control, which participants expressed wanting. An app that allows for timely access and communication of results (hard data, clinical interpretations) was perceived as invaluable to participants. Charted ranges or bands of "normal" could allow them to prepare for "flare-ups" and ensure these are not missed in the system that is already burdened. Specificity, details and visualization of results would be a tremendous gain, increasing the "knowing" aspect of disease management that many of the participants longed for. The more information they feel they have, the better they

can detect what is really happening (despite appearances or symptoms or lack thereof) and move forward accordingly.

My specialist sees like a thousand people. It's a public system. I can't trust that he is going to get everything. I trust him fully. He's great and he's amazing. But I feel like things can get missed. If my drug levels are coming down, and there is a higher chance of having a flare up. Those are things that I would love to be able to see myself. (AUS2)

I need the hard numbers. I don't want this generic information. When they're glossed over, or the doctors say that the numbers are "good." I don't care. I want to know if it's 12.1 or it's 11.5. Because if it's closer to the okay limits, or it's soaring high, then that means more to me. Or seeing how my trends are. (US1)

Availability of self-administered testing

Easier preparation and more comfortable testing were believed to improve patient care. Any tests or sampling that could be self-administered and monitored would be beneficial psychologically and logistically. If self-testing could work in tandem with the mobile application for the sharing of results, 2-way communication would improve between patients and care providers to expedite informed care. Participants expressed thoughts on what this could look like and how it would be beneficial:

I would have something like what diabetic people have, a blood test that you can do at home, and it gives you an immediate response. You can do it regularly. So you will have your own monitoring. (AUS2)

Enhanced communication

Patients rely on gastroenterology healthcare professionals to know about how to best monitor and track their disease and to receive information and results in a timely manner. A lack of communication with these providers decreases trust, and the lack of alliance is exacerbated if mental health issues or comorbidities are not understood or recognized by the provider. This reliance should be characterized by hope and reassurance that the best available care is being implemented. However, processes are often not customized to individual needs, and the patient may not be viewed as an expert nor treated as an equal partner in collaborative care. Thus, a lack of trust based on negative experiences that have accumulated over time can occur. When results are not willingly communicated and referrals are withheld, patients are frustrated with the health system. One participant described accessing their bloodwork results and the communication that resulted with their provider:

I rung my consultant and said, "hey what's this all about?" He was like, "oh ya, well it's nothing really to worry about, but we may need to keep an eye on it." It was like, "okay but shouldn't you really have told me that" (UK1)

Participants also spoke of care that requires interdisciplinary, doctor-to-doctor communication which is often absent and leaves individuals scrambling as their own care coordinator, compiling information from various sources and finding

integrated solutions. The quality of care is also inconsistent across providers and health systems. Participants spoke of a "lottery" and "luck" in terms of having a gastroenterologist who is on top of things, and whether their experiences in care are positive or negative. Regrettably, there are considerable gaps in trust, bedside manner, systemic operations, and access to data and information that are only addressed with a patient's will to fight for themselves to get answers they need, often as a solo endeavor. One participant captures the essence of this uphill battle:

...if you do not speak up with your doctor. If you do not force them to meet with you, make the time, make the appointment, exchange that information, be pro-active, you absolutely will get nothing from them. Doctors are so over-run, so overworked. The healthcare system does not support collaborative planning and discussions. If you want to be part of your healthcare journey and be an advocate for your own body and what's going to happen to it, you have to force that issue. It's very difficult. You just can't expect that that will be your outcome if you don't speak up and make it happen. (US1)

Participants had positive experiences based on either exceptional, individualized care from a professional/GI specialist, nurse, or administrative staff, available (accessibility of preferred procedures like the IUS) healthcare in general. Some participants described personal satisfaction from learning about disease management and test results, allowing them to correlate the information within the context of their lives. The following excerpts validate pleasant aspects about CD monitoring:

I just accept now that anytime I have sent in a sample, or I have been in for bloods, she [doctor] follows it up in writing and she confirms everything. It's not just the tests, it's also about what we have spoken about. So she will feed back to me what I have said to her, in terms of if I've had a low mood, or I've had a flare up. So she will actually document our conversation, as well as any treatment or tests that we do, and test results. So, I have a nice file full of lots of information. That is the way I want it. I want to know what's going on (UK2)

My doctor has been great as far as sharing the results. Spending time, I think that's the important thing too. My doctor, and maybe most I hope, spends time, answers all the questions I have, and takes her time with me. That part of the testing has been really positive for me. (CAN2)

Participation and communication between the patient and provider were not seen as a 1-way initiative with the provider being proactive. Individuals believed that, as patients, they needed to be strong advocates for themselves and assist with facilitating those positive, reciprocal relationships:

You need to be engaged. All of us are our own best case managers for our own disease. It can be a really tough role, when you're vulnerable and not feeling well. But I've just learned over the years that I know myself better than anyone. I have worked hard to build up a great relationship with my specialist that I trust. Together we have built up a really good plan of monitoring that works for me. But a lot

of it is not being afraid to advocate for yourself. Because if you're passive and sit back, you might get lost in the system, or people won't necessarily be following up with you. You really have to have a strong voice to advocate. (CAN2)

Understanding disease monitoring and the importance of SDM

Individuals in this study had or wanted access to their monitoring results. Having hard evidence and understanding of monitoring results aids in SDM, providing reassurance and reminders of disease status, mentally preparing patients for procedures or whatever is next, and empowering the patient to be more actively involved in managing their care. Though certain personalities enjoyed delving into hard data more than others, most recognized that with Crohn's, knowing is managing.

I like being able to have the results, and being able to see, "oh yes, I am actually doing better." This is good, so I can kind of reassure myself sometimes. I convince myself I am having a flare-up, and then I stress about it, which causes more symptoms. It's just this cycle. So being able to look at the hard evidence, and be like, "no, I'm actually okay." I found very beneficial. (AUS2)

Recognizing patients as experts and equal team members

Tensions noted across all focus groups between patients and the healthcare system or providers. In some cases, CD monitoring becomes a battle of the patient versus healthcare system. It is a battle to assert themselves as expert, be taken seriously, express what they need, get information, and receive psychologically safe care. Individuals were always appreciative when they were included as care team members, by being listened to and contributing to CD monitoring decisions.

It's just a sense of respect I think, being appreciated as an active member of the team. It has been really nice in the past where I have been treated as an important member of my care team. (CAN1)

I have a really good relationship with my doctor. We talk a lot about what works for me, and it's not just him prescribing. So, I think having someone you can trust, and you can have conversations about what you're doing, why you're doing it, how frequently, what the purpose is, and really what works best for your life as well. (CAN2)

Discussion

The current study adds a preliminary understanding of CD patient experiences, preferences, and disease monitoring insights and rationale. We also provide essential insights into monitoring adherence which is key to improving disease outcomes. Universally, the CD patient participants perceived monitoring as vital to their care, and participants reported explicit opinions about challenging and least preferred tests versus those they wished for improved accessibility. Participants consistently emphasized the importance of providers relaying the results to individual patients. This

information is believed to enhance engagement and facilitates clinical care and SDM.

SDM is the bidirectional information-sharing between provider and patient to determine consensus and agreement on treatment decisions.²⁸ SDM has been shown to enhance patient satisfaction with care, decrease anxiety regarding treatment decisions, and encourage commitment to the treatment plans.²⁹ However, provider and patient communication is critical for information sharing and for effective SDM. Participants often felt the treatment plan and care goals for care were not clearly communicated, nor did they feel that they were included in the decision-making process. Providers must share knowledge about the treatment plan and goals for care with patients for informed decisions to be made. The more comprehensive the IBD-related treatment information shared by IBD providers, the greater the sense of patient participation in SDM.²⁹ A study by Noiseux et al identified gaps in this core tenet, given the limited understanding about why IBD monitoring was being conducted or how treatment decisions occurred based on the monitoring results.³⁰ Participants from our cohort reflected similar beliefs, with little acknowledged understanding regarding monitoring rationale with lack of clarity regarding treatment targets. Yet, similar to data demonstrated in a recent systematic review by Al Houry et al, patients desire information, and expect access to their health information and monitoring results to best facilitate SDM regarding treatment plans.³¹ Optimized communication between providers and patients is needed for test rationale, results interpretation, and improved understanding of how results inform treatment decisions and goals of care. Ironically, the recent and now widely recognized international STRIDE II guidelines directing a T2T approach, lack patient input.⁹ Disease-related knowledge improves when information is shared with patients, resulting in informed decision making, patient engagement and improved self-management.³²

Within and between single countries, monitoring strategies vary. Many patients did not have access to IUS monitoring available to them, while most had easy and routine access to bloodwork monitoring. Published data suggest blood samples are the most frequently ordered diagnostic test, but also the most refused.³⁰ Not surprising, the least preferred test was colonoscopy. Similar to Noiseux et al, fecal tests were viewed as noninvasive and tolerable, thus considered a reasonable option compared with other more invasive tests. Therefore, this study provides additional insight into why monitoring tests may be challenged by patients, and even avoided, for example when the purpose or impact of testing remains unclear.

Similarities in preferences were noted across countries. Noninvasive or minimally invasive monitoring procedures (ie, IUS) were preferred over more invasive procedures (ie, IC) in the current study, consistent with previous reports.⁶ When IUS is available as an option for participants, consistent with published reports regarding patient preferences, IUS was preferred, reported here as acceptable, easier to engage with the provider to learn the results and better tolerated when compared with colonoscopy.^{6,32} Published reports also suggest patients prefer IUS over other noninvasive imaging tests such as MRI.³³ Furthermore, because the provider performs IUS at the bedside, patients receive disease-related information in real-time at the point of care. Published data have shown patients perceive increases in their disease-related knowledge

with IUS.³² Goodsall et al recommend patient experiences and preferences be considered when selecting diagnostic tests to encourage patient's active engagement in their monitoring.⁶ Participants within the present study noted that while colonoscopy was the least preferred monitoring strategy, they were willing to undergo this invasive procedure due to the accuracy of the results. Accuracy of monitoring results was also ranked as a top priority among participants with IBD in a study by Barsky et al.¹⁴

Limitations and Future Research

While focus group findings were consistent across countries, due to the nature of qualitative research and the limited sample size, findings are not generalizable. Generalization is not the intention, rather the findings support important theories that drive future research. For example, it is important to explore IBD-provider perspectives of CD monitoring qualitatively, to gather a more comprehensive understanding of how CD is monitored. The importance of SDM in IBD is much like other chronic diseases, which has been well documented in the literature, and requires the integration of both provider and patient perspectives. However, patient experiences of SDM around IBD care planning is lacking and should be explored.

Conclusion

This international, multicenter qualitative study provides important insights into CD patient experiences with disease activity monitoring with clear preferences. Patients prefer to be included as equal members of a multidisciplinary interprofessional healthcare team with efficient communication working towards a personalized hybrid model of planning and reactivity with the use of monitoring tools based on accuracy, convenience, and invasiveness. It is imperative to incorporate patient-driven insights into the structure of future monitoring strategies, to ensure equitable access to those preferred modalities and embrace a SDM approach to chronic disease management in CD.

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Conflicts of Interest

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Authors' Contributions

N.R., S.Z., and K.N. had substantial contributions to the conception or design of the work and to the acquisition, analysis, or interpretation of data for the work. N.R., S.Z., and K.N. drafted the work, and all authors revised the work critically for important intellectual content. All authors approved the final version to be published. All authors have agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Data Availability

The data underlying this article cannot be shared publicly to ensure the privacy of individuals who participated in the study.

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