

Patients and clinicians have different priorities when discussing pain in the IBD clinic

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ABSTRACT

Objective Pain in inflammatory bowel disease (IBD) is frequently neglected/overlooked, particularly in ulcerative colitis, and communication about pain can be suboptimal. The current study juxtaposes clinicians' conceptualisations of patients' pain with patient narratives. The aim was to inform the development of a pain reporting tool and provide guidance for better communication about IBD pain.

Methods In-depth semistructured interviews with 13 IBD clinicians in the UK: gastroenterologists (n=5), colorectal surgeons (n=2), specialist nurses (n=4) and psychologists (n=2). Primary analysis of these data and secondary analysis of earlier interviews about pain in IBD with clinicians (n=12) and patients (n=71) followed principles of reflexive thematic analysis. Themes were compared across participant groups.

Results Clinicians state that they regularly ask about pain in Crohn's disease, but not ulcerative colitis. Patients, however, report inconsistent attention to pain in either condition, with power dynamics constraining their pain report. Some clinicians acknowledged that they assume that patients manage their pain independently, leading to insufficient follow-up (Theme 1: Contradictions and ambiguities when discussing pain in IBD). Inadequate acknowledgement of pain by clinicians was attributed to time constraints and systemic issues. Where inflammatory or structural causes were lacking, some clinicians default to attributing pain to irritable bowel syndrome, contributing to patients feeling uncared for (Theme 2: Consequences of limited tools and time for pain). Addressing pain was further complicated by the reluctance of some patients to express discomfort or pain and others who avoided activities that might lead to pain (Theme 3: Addressing pain in patients who do not complain).

Conclusion The study emphasises the importance of consistent pain evaluation and management, advocating for more open dialogues between clinicians and patients.

INTRODUCTION

Pain affects around 70% of patients with inflammatory bowel disease (IBD), persisting for five or more years in 49%–55%.¹ Pain is associated with heightened levels of distress² and has a profound impact on quality of life.^{1 3} However, patients report that it is insufficiently addressed in gastroenterology clinics. A UK-wide survey reported that 29%

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Pain in inflammatory bowel diseases, particularly in ulcerative colitis and cases without clear underlying pathology, is often under-recognised and insufficiently managed.

WHAT THIS STUDY ADDS

⇒ Analyses of clinician and patient interviews reveal discordance between clinicians' intended pain management and patients' experiences. Findings highlight how systemic issues, power imbalances, diagnoses of secondary irritable bowel syndrome and patient hesitancy to articulate pain hinder effective pain management.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ The study underscores the need for clinicians to proactively enquire about pain and for patients to feel empowered to express it. Insights may guide the development of tools and strategies to enhance inflammatory bowel disease pain reporting and assessment.

of patients with IBD are not asked about their pain during consultations⁴ and a cohort study involving 2152 participants highlighted that pain is undertreated.¹

Clinicians acknowledge that they focus on objective parameters of IBD activity and complications rather than pain management.^{5 6} This is rooted in the expectation that treatment of disease-associated factors alleviates pain,⁷ compounded by time constraints, difficulties in pain assessment and interpretation, and limited options for IBD pain management.^{5 6 8} However, pain is common during remission: up to 34% of people with endoscopically confirmed quiescent IBD report moderate to severe abdominal pain.⁹

Clinicians may hesitate to address pain directly due to uncertainty about its psychosocial dimensions.⁵ This is understandable but unhelpful; IBD clinicians are the primary point of contact for individuals

with symptoms and often serve as gatekeepers to other services. Open dialogue offers opportunities to consider additional support, including services provided by pain clinics, psychologists, dieticians and community services,¹⁰ underpinning comprehensive care. Moreover, conversations about pain are important in exploring comorbidities, coping, and potentially problematic use or adverse effects of medications.¹¹

Patients may not discuss abdominal pain because they find it hard to articulate their experiences¹² and believe that pain is not taken seriously by clinicians.^{12 13} The current study is part of a larger initiative to develop a tool facilitating pain reporting in IBD. The assumption is that improved reporting will lead to more meaningful discussions around pain, resulting in improved care and better outcomes, if clinicians respond effectively to pain reports.

This study describes how clinicians conceptualise and address pain in the context of patient narratives of daily life with pain. The aim was to identify barriers to communication around IBD pain and explore opportunities to improve it.

METHODS

We conducted semistructured interviews with clinicians (n=13) to uncover their perspectives on pain monitoring and discern how they addressed pain in the clinic; we also analysed pre-existing original transcripts from interviews with clinicians (n=12) and patients (n=71) concerning related topics. See [table 1](#) for an overview of the studies from which data were obtained, including their aims, participant characteristics and ethical approval.^{5 13–16}

Participants and procedures – interview study with clinicians

We used our professional network to invite IBD nurses, gastroenterologists, surgeons and psychologists to participate in our study. Participant information sheets were disseminated online (Qualtrics, Provo, UT) and via email. Participants completed an informed consent form generated in Qualtrics (Provo, UT).

Three members of the research team—a psychologist pain researcher (DH), a nurse IBD researcher (CN) and a gastroenterologist (MP)—formulated key questions and prompts, drawing on clinical experience and literature. Questions focused on ascertaining (1) the aspects of pain that clinicians found important, (2) the rationale, timing and methods clinicians used to address IBD pain, and (3) clinicians' perspectives on the feasibility and utility of a pain reporting tool or application. Interviews were conducted online via Microsoft Teams (V.1.7.00.156). DH, a female experienced in qualitative research methodologies, flexibly followed the topic guide, allowing emerging insights to guide questioning (online supplemental table 1). Audio recordings were transcribed verbatim by a professional transcriber and destroyed after cross-checking by the researcher. We

adhered to the COREQ checklist for reporting (online supplemental table 2).¹⁷

Analysis

Reflexive thematic analysis, which views researcher subjectivity and reflexivity as resources, was performed by DH using Braun and Clarke's six recursive stages: familiarisation with data through thorough reading of transcripts, generation of initial codes through line-by-line coding, refinement of codes and initial categorisation into themes, revision and refinement of themes by comparison against quotations and the dataset, articulation of theme definition and creation of a narrative, and presentation of findings.¹⁸ Analysis was supported by note-taking to aid reflection¹⁹ and NVivo software (V.14). DH and CN regularly reviewed interim findings and compared two independently coded transcripts to ensure rigour and minimise bias. We started by analysing clinician transcripts. Patient data were then explored to see how they mapped onto identified themes in clinician transcripts. Relevant aspects not previously mentioned by clinicians were integrated into new (sub)themes. Participants were not asked to comment on results.

RESULTS

The 13 new clinician interviews were conducted between April 2023 and February 2024 and lasted 62 min on average (range 37–76 min). [Table 2](#) presents the socio-demographic characteristics of all clinician participants (n=25). They were between 25 and 62 years old and the sex balance was stereotypical: 1/12 of the gastroenterologists and all of the nurses were female.

[Table 3](#) reports the sociodemographic characteristics of 71 people with IBD across four studies: 41 with Crohn's disease (CD) and 30 with ulcerative colitis (UC). Most were female (70.4%) and white (85.9%). Age ranged from 16 to 75 years (median=38 years). We generated three themes (see [table 4](#)): Contradictions and ambiguities when discussing pain in IBD, Consequences of limited tools and time for pain, and Addressing pain in patients who do not complain.

Contradictions and ambiguities when discussing pain in IBD

Narratives of people with IBD described the profound impact of pain (see [figure 1](#)), many using emotional language such as 'unbearable' (female, CD, study 3). Clinicians may find these expressions 'less useful [...] at least in terms of mapping to particular problems' (gastroenterologist, study 1). While recognising the need to assess if symptoms signified 'a flare or a complication that needs to be investigated and treated', and their impact on quality of life and 'therefore the management of the symptoms' (gastroenterologist, study 1), clinicians often preferred to rely on tests.

Four subthemes in this theme explored if, and how, comprehensive evaluation and management of pain is achieved: Contrasts in the perceived significance of UC pain, Contrasts in the perceived significance of CD pain,

Table 1 Overview of the studies from which data were obtained

Study	Reference	Population	Aim of interviews	Themes	N	Ethical approval
1	Current study	IBD nurses, gastroenterology specialist nurses, junior/senior gastroenterologists, consultant colorectal surgeons, psychologists with speciality in gastroenterology	To explore what clinicians want to know about patients' pain, how they discuss pain and under which circumstances, and what their wishes are for a pain reporting tool		13	MRSP-20/21-226851*
2	Huisman, Fernhout ⁵	IBD nurses, gastroenterology specialist nurses, junior/senior gastroenterologists	To explore how clinicians view, manage and explain pain and secondary IBS during quiescent disease	Theme 1: Focus on disease activity, not pain and associated symptoms Theme 2: Idiosyncratic and uncertain explanations for pain during remission Theme 3: Shared decision making vs shared sensemaking	12	MRSP-20/2122685*
3	Huisman, Sweeney ¹³	People with IBD who experience pain during remission	To explore beliefs about the pain of individuals experiencing abdominal pain during remitted IBD, as well as perceptions of IBS in the context of IBD	Theme 1: Distinguishing and navigating pain during quiescent IBD Theme 2: The meaning of pain during quiescent IBD Theme 3: Consideration and helpfulness of the IBS label in IBD	23	MSRP-19/20-19284*
4	Sweeney, Moss-Morris ¹⁴	People with IBD who experience IBD-related pain	To explore the experiences of individuals with IBD and pain, the pain management strategies they use, and the need for future pain management interventions	Theme 1: Vicious cycles Theme 2: Finding solutions Theme 3: Attitudes	14	17/LO/1527†
5	Kacorova and Williams ¹⁵	People with IBD	To explore how individuals with IBD understand their pain	Theme 1: Making sense of my pain Theme 2: Navigating my care and support Theme 3: It takes its toll	20	19517/001‡
6	Andrews ¹⁶	People with IBD with a recent experience of pain lasting >3 months	To explore the language that people with IBD use to express their pain in clinical and social settings	Theme 1: Language describing pain Theme 2: Pain severity: mild, moderate and severe pain Theme 3: Expressing pain in different settings Theme 4: Attitudes and coping strategies on pain	14	HR/DP-22/23-34861§

*Approval granted by the University Research Ethics Committee at KCL (King's College London).
†Approval granted by the London Surrey Borders Ethics Committee.
‡Approval granted by the UCL (University College London) Ethical Committee.
§Approval granted by the Health Faculties Research Ethics Subcommittee at KCL (King's College London).
IBD, inflammatory bowel disease; IBS, irritable bowel syndrome

Discrepancies between intentions and practices of clinicians, and Inadequate acknowledgement of pain and imbalances in power dynamics.

Contrasts in the perceived significance of UC pain

Clinicians reported not always enquiring about pain in UC because it is typically linked to urgency: 'Abdominal pain isn't specific enough to establish elevated disease activity' (gastroenterologist, study 2). Two clinicians

specified that 'inflammation of the mucosa, nobody feels that' (gastroenterologist, study 2). This view, however, contrasted with experiences of patient and other clinicians: 'Unless patients are very, very sick they are meant not to get pain [...] in the real world that's not how it works. People still get pain in ulcerative colitis' (gastroenterologist, study 1). People with UC confirmed that they are rarely asked about pain and related that—when

Table 2 Sociodemographic information—clinicians (n=24)*

Females	11 (46%)
Age in years, mean (SD)	44 (10.0)
Country of practice	
The UK	20 (83%)
The Netherlands	4 (17%)
Years working with patients with IBD, mean (SD)	14 (11.1)†
Profession	
IBD nurse	6 (25%)
Gastroenterology specialist nurse	2 (8%)
Senior gastroenterologist	8 (33%)
Junior gastroenterologist	4 (17%)
Consultant colorectal surgeon	2 (8%)
Psychologist with speciality in gastroenterology	2 (8%)

*The number of participants (n=24) does not match the number of interviews (n=25) because one IBD nurse participated in both studies.

†One of the nurses had worked less than 1 year with patients with IBD; the value for this variable was set to zero.

IBD, inflammatory bowel disease.

questioned—clinicians focus more on assessing the severity of a flare than on addressing pain directly ‘They’re more interested in how bad is the flare, rather than what’s the pain’ (female, UC, study 6). This seems unhelpful, as pain could still be a problem, ‘I need

Table 4 Overview of the themes and subthemes

Theme 1: Contradictions and ambiguities when discussing pain in IBD
Subtheme 1: Contrasts in the perceived significance of UC pain
Subtheme 2: Contrasts in the perceived significance of CD pain
Subtheme 3: Discrepancies between intentions and practices of clinicians
Subtheme 4: Inadequate acknowledgement of pain and imbalances in power dynamics
Theme 2: Consequences of limited tools and time for pain
Subtheme 1: Defaulting to secondary IBS as an explanation for pain
Subtheme 2: Increasing stress among patients
Theme 3: Addressing pain in patients who do not complain
CD, Crohn’s disease; IBD, inflammatory bowel disease; IBS, irritable bowel syndrome; UC, ulcerative colitis.

somebody to [...] help sort the pain out. I am struggling’ (female, UC, study 6). The severity of the pain experience should not be underestimated, as described by a patient who said: ‘It feels like your insides are being ripped out completely’ (female, UC, study 5).

Contrasts in the perceived significance of CD pain

Pain in CD was reported to receive more attention due to its distinctive characteristics: ‘With Crohn’s disease the inflammation is transmural [...] and can excite the

Table 3 Sociodemographic information—patients (n=71)

	Crohn’s disease (n=41)	Ulcerative colitis (n=30)	Total (n=71)
Gender			
Female	29 (70.7%)	21 (70.0%)	50 (70.4%)
Male	12 (29.3%)	9 (30.0%)	21 (29.6%)
Age			
16–25	6 (14.6%)	5 (16.7%)	11 (15.5%)
25–35	13 (31.7%)	7 (23.3%)	20 (28.2%)
35–45	9 (22.0%)	7 (23.3%)	16 (22.5%)
45–55	9 (22.0%)	6 (20.0%)	15 (21.1%)
55–65	2 (4.9%)	4 (13.3%)	6 (8.5%)
65–75	2 (4.9%)	1 (3.3%)	3 (4.2%)
Ethnicity			
White	37 (90.2%)	24 (80.0%)	61 (85.9%)
Asian/Asian British	0 (0.0%)	2 (6.7%)	2 (2.8%)
Black/African/Caribbean/Black British	0 (0.0%)	2 (6.7%)	2 (2.8%)
Mixed ethnicity	4 (9.8%)	2 (6.7%)	6 (8.5%)

Percentages are presented within disease. Categories are based on studies that provided the least detailed data which meant age needed to be transformed into categories. Borderline values (eg, 25 and 35) were included in the lower age category. Two people were reported to experience both Crohn’s disease and ulcerative colitis; they were included in the Crohn’s disease group.

The experience

"I can't even speak. I just have to shut myself away if I can, and just curl up and just deal with it" (female CD, study 5).

"What really makes me anxious is [that...], it's completely out of my control" (female, UC, study 4).

The consequences

Social isolation

"I sort of don't make social plans anymore [...] I'd have all these great intentions and think, 'Oh yes it would be nice to kind of meet my girlfriends,' or whatever. And then [...] have to cancel because I would just, feel too unwell, or couldn't bear, kind of going out" (female UC, study 4)

Lost sense of normality

"Trying to tolerate the side effects of the medication [for pain] against being able to live a normal life [is...] what I've struggled the most with" (female, CD, study 3).

Heightened sense of threat

"You hear all these stories about how it can get pretty bad [...] surgery and stuff is kind of a big fear of mine [pain is...] a reminder of what could happen" (male, CD, study 4).

Reduced mental health

"[Pain] has fear attached to it. It's the fear that I'm going to get a blockage there [...] that's the psychological part of it, that can be difficult" (female, CD, study 5).

Figure 1 The profound impact of pain. Patients described the experience of pain (left plane) pain as inherently limiting, isolating, and anxiety-inducing. They related that it affects numerous aspects of life (right plane). Challenges were voiced regarding the lack of control, especially when balancing other responsibilities, and maintaining a sense of normality was found difficult. Pain was also reported to feel threatening, serving as a reminder of potential complications, which could impact mental health.

peritoneum. [Stretch is felt when food runs...] into a stenosis somewhere' (gastroenterologist, study 2). Clinicians said they focussed their enquiries on determining probable inflammation, the need for further tests and identifying pain patterns suggesting complications. By contrast, people with CD reported inconsistent questioning: 'They don't ask about the pain [...] the gastro team doesn't really [...] ask you on a regular basis' (female, CD, study 6). This discrepancy may result from clinicians using prompts rather than specific questions to initiate enquiries: 'They'd ask you how you are [...] if I didn't mention abdominal pain they wouldn't ask' (female, CD, study 3).

Overall, people with CD found enquiries superficial and conventional tools inadequate: 'They say to me [...] 1 to 10 what is your pain level with it? And literally I just have to say it's like 100. It makes you want to scream' (female, CD, study 5). The diagnostic intent behind other pain assessment methods, 'I use more how it is impacting your life and if it has improved [...] rather than numbers' (gastroenterologist, study 1), might remain implicit which maintains a power difference (see below).

Discrepancies between intentions and practices of clinicians

Clinician narratives indicated a discrepancy between intentions and practices in addressing pain: 'You can get caught up in the objective things, [...] but what's actually important is that: what does the patient want?'

(gastroenterologist, study 2). One gastroenterologist reported that he assumed that patients handled their pain independently so did not follow it up: 'You end up fobbing it off, not fobbing it off, just empathising and then kind of moving on and then they [...] just carry on and deal with it, I suppose' (gastroenterologist, study 2).

Insufficient action can undermine good intentions. Some people with IBD, despite confirming that clinicians were 'sympathetic' (male, CD, study 6), voiced frustration that there is no protocol on how pain is managed: 'Sometimes even with the same person, I communicate one thing [...] get a different response in terms of what they're saying to do about it.' (male, CD, study 6). Others adopted more dismissive attitudes, asserting that many gastroenterologists 'don't particularly care about the pain' (male, CD, study 6). Statements like these suggest a miscommunication that can have far-reaching consequences. One patient expressed losing faith in her gastroenterologist, 'In her [the clinician's] head my IBD was mild, and in my head, it was moderate [...] but the pain was bad for me, and I could feel in my body that the treatment wasn't right' (female, UC, study 6). She discontinued visits and when she eventually returned, her disease had worsened.

Inadequate acknowledgement of pain and imbalances in power dynamics

Patients reported multiple instances when their pain was not acknowledged, 'I've been told there are people sicker than me [...] makes you feel [...] you shouldn't be there, and you shouldn't be taken seriously' (female, CD, study 5), making them feel uncared for: 'they don't see me as a whole being with pain' (Female, UC, study 6). One person with UC, after experiencing left-sided abdominal pain at the time of diagnosis, was informed by her clinician that her pain 'wasn't, couldn't be, linked to my colitis' (female, UC, study 5). The clinician's authoritative dismissal, which undermines insights from lived experience, reflects a broader tendency among some clinicians to discount pain: 'Some people can't cope with even mild pain' (gastroenterologist, study 1). This can undermine a patient's sense of self: 'You think you're [...] perhaps just kind of imagining all this stuff that's going on' (female, UC, study 5).

One individual felt she was taken seriously 'because they don't hear from me when everything is going fine' (female, CD, study 3): people may believe that their symptoms are more credible when they refrain from seeking frequent support. This exemplifies a dynamic where clinicians determine which concerns require attention, as emphasised by a patient who felt she needed 'permission' to talk about pain, 'You almost need a statement [that] it's OK' [...] you don't want to overburden them (female, UC, study 6). One female patient described how power differences are inherent in patient-clinician interactions: 'They're sat behind a desk, and they've got a uniform, and you're, kind of, often going to A&E in your pyjamas, feeling a bit vulnerable' (female, CD, study 5). She recounted instances, when asking about alternative options, of being met with resistance: '[I] don't think they expect that from a young woman, especially if it's an older man, and sometimes they can get quite argumentative with me and angry' (female, CD, study 5).

A clinician explained why he prefers people not to come in with preconceived ideas: 'Some of them will try and manipulate their symptoms to fit it because they want that checked out' (gastroenterologist, study 1). However, patients may feel forced to research their condition: 'With the joint pains they didn't bring it up, I brought it up [...] because I'd been looking on the internet' (patient, UC, study 3).

In sum, power imbalances were evident when clinicians asserted authority and appeared inherent to the consultation format, where patients depend on clinicians for diagnosis and treatment decisions. The imbalance was compounded by clinicians' workload and patients' perceptions of it. Patient accounts largely drove this theme, as clinician interviews did not explore this aspect.

Consequences of limited tools and time for pain

Clinicians frequently cited time constraints and pressure as causes for limited pain care: 'What people are trying to do is get the patient onto a pathway, so they can say right

that one is done [...] let me get on with the next because I've got a list of patients to see [...] there's too much pressure' (gastroenterologist, study 1). Both patients' and clinicians' reports indicated frustration with this minimalist form of care: 'Oh yes, if you're having a flare, we'll deal with the flare and somehow the pain will dissipate' (female, UC, study 6). Additional consequences of limited pain management resources were explored in two subthemes: Defaulting to secondary IBS as an explanation for pain and Increasing stress among patients.

Defaulting to secondary IBS as an explanation for pain

In instances where pain appeared unrelated to pathology, some clinicians invoked irritable bowel syndrome (IBS) explanations: 'I think what tends to happen is that, if they don't have active inflammation, they are just told that [it is IBS] and then left to get on with it' (IBD nurse, study 1). This approach raises two key concerns. First, patients might endure persistent, unmanaged symptoms with delays in diagnosis of other conditions. One gastroenterologist cautioned against diagnoses based on preconceived notions: 'you've got a busy doctor who says, right abdominal pain, Crohn's, we'll do a colonoscopy. Nothing there, [...] off they go treatment for IBS. So, [...] you are already narrowing your field: is it inflammatory or functional?' (gastroenterologist, study 1).

Second, the diagnosis of IBS was found to be vague and unhelpful by some patients, who referred to it as 'a non-descript for active bowel that they don't know the reasoning behind' (female, CD, study 3), and may diminish trust when perceived as inaccurate. This was illustrated by a person with CD whose symptoms were initially attributed to IBS by his general practitioner (GP): 'This is where I lose faith in GPs to a certain extent. Because GPs don't see IBD very often, but the symptoms are extremely similar' (male, CD, study 3). Although the participant understood the clinician's limitations, he struggled to remain engaged with the care offered by this GP. Some clinicians noted that patients do not necessarily need definitive answers, emphasising the importance of transparency and clear communication in maintaining trust.

Increasing stress among patients

Patients often mentioned that stress increased pain, with several feeling overwhelmed by managing the healthcare system and not being heard: 'I get angry with the doctors [...] inside. [...] I think I'm going around in circles, and I can't make anybody stop and listen' (female, CD, study 5). This patient's fear of 'strong drugs' and subsequent non-adherence to medication led her clinician to disengage, '[He] brushed his hand with me'. A more empathetic and collaborative approach was evident in the practice of one gastroenterologist who offered especially complex patients 1 hour appointments over consecutive weeks: 'All we're doing then, you'll be surprised, is actually not a lot of medical stuff but just listening to a patient talking [...] just tweaking the medication slightly.' He

presumed that it helped alleviate the pain because ‘they feel they’re being looked after [...] we are taking their pain as an important symptom, and they’re not just trying to fight the system, trying to get an appointment, or trying to speak to a physician’ (gastroenterologist, study 2), underscoring the benefits of extended consultations and focused attention on pain.

Addressing pain in patients who do not complain

It may be mistaken to assume that people who do not complain require no care, as patients may not fully acknowledge or articulate their pain: ‘Some people [...] don’t realise what they are actually living with on a daily basis’ (IBD nurse, study 1). This notion was supported by a patient’s account of an acquaintance with CD: ‘They think he’s on the biological treatment and it’s working, but what they don’t know is how much pain he’s in because he hasn’t told them’ (female, CD, study 3). Reasons for not reporting symptoms may be patients’ aim to ‘stay positive’ (female, CD, study 5), the awareness that clinicians are ‘very busy’ (female, UC, study 6) and the ‘hassle’ of ‘more tests’ (male, CD, study 6). Additionally, some people avoided, or limited, activities out of fear of triggering pain as illustrated by a patient who would not walk far ‘because I’m worried about having this pain and not being able to walk any further’ (female, CD, study 5). Such avoidance can result in patients under-reporting their pain, as it may mask the severity of their pain.

Addressing pain in individuals who do not report it was described as ‘tricky’ by one IBD nurse, ‘you don’t want to draw attention [to pain...] that’s going to make the pain worse’ (IBD nurse, study 1). Despite initially relaying that some people do not realise what they are living with, she advocated a pragmatic approach wherein pain is not brought up by clinicians, ‘if someone is coping quite well even though they’ve got pain perhaps that’s a good thing, because what’s the alternative?’ (IBD nurse, study 1). This perspective is likely to be counterproductive. By not addressing pain directly, clinicians may miss opportunities to provide essential support and validate patients’ experiences. Other clinicians appreciated educating patients on ‘normal’ and ‘abnormal’ symptoms, when time allowed.

DISCUSSION

The challenges of addressing IBD-related pain in health-care constituted three distinct themes. Contradictions and ambiguities when discussing pain in IBD highlights that clinicians consider pain to be an unreliable indicator of disease activity, particularly in ulcerative colitis. This often remained implicit, underpinning divergence between clinicians and patients on the significance of pain. Pain was inconsistently discussed and managed, despite clinicians’ recognition of patients’ needs as important. Additionally, poor communication, compounded by power imbalances, caused distress for patients and some disengagement from healthcare.

The theme of Consequences of limited tools and time for pain described how prioritising disease management over pain led to frustration and stress for patients, with clinicians tending to label pain during remission as IBS (which is not always helpful for patients, undermining trust) and a lack of transparency in addressing pain. The final theme, Addressing pain in patients who do not complain, discussed reasons for not disclosing pain and challenges for treatment. Overall, the themes elaborated complexities of pain assessment, communication and management.

Although pain is an unreliable indicator of pathology,^{9 20 21} it is informative. Clinicians report using pain severity and patterns to determine the likelihood of inflammation and complications, guided by illness scripts, frameworks developed through clinical experience that aid in pattern recognition and interpretation of clinical information.²² Using illness scripts is practical; some are formalised in disease activity indices and they can streamline clinical decision-making. However, ‘(stereo)typical’ illness manifestations overlook comorbidities, such as endometriosis,²³ and discount individual differences.²²

When pain is not associated with underlying pathology and illness scripts fall short, clinicians may default to diagnosing secondary IBS. While this avoids extensive investigations that may induce anxiety in patients,²⁴ it overlooks other probable diagnoses and insufficiently addresses patients’ symptoms and concerns (alongside comorbidities and problematic self-management strategies). We advocate for more extensive exploration of pain, based on evidence that the belief that discussions around pain worsen the experience and are best avoided is mistaken. People with pain value and benefit from validation, acknowledgement,²⁵ reassurance²⁶ and information.^{27–29} Good communication generally enhances understanding, adherence, clinical outcomes and overall patient satisfaction.^{30 31}

Improving communication requires careful consideration of power imbalances in the clinician-patient relationship,³² an imbalance that stems both from clinicians assuming authority and patients’ dependency on clinicians, leaving some patients hesitant to express their pain and concerns.³³ Clinicians who are unaware of this may, under time constraints, prioritise disease factors over holistic care or attribute pain to IBS without explanation.⁵ This unintentionally reinforces the position that pain is unimportant, causing patients to feel neglected, undermining the therapeutic alliance and compromising patient well-being.^{34 35} Given the disparity in how clinicians conceptualise overlap between IBD and IBS,⁵ it is important to evaluate the appropriateness of a secondary IBS diagnosis. Clinicians are advised to (1) not just use generic prompts but explicitly ask about pain, (2) explore patients’ understanding of symptoms, alongside illness history and health literacy,¹³ and (3) discuss the possibility of IBS ahead of investigations if warranted.⁵

Explaining that pain does not necessarily signify disease complications may benefit patients.³⁶ Nociceptive

signals from the spinal cord to the brain involve input from primary sensory neurons innervating the gut and are modulated by descending controls originating from supraspinal structures encoding emotional regulation and learning.³⁷ Dysregulated modulation is implicated in chronic pain and offers a biological explanation for the anxiety and distress frequently experienced by individuals with pain.^{20 21} Establishing a shared model of pain is important: clinicians often use psychogenic formulations for chronic pain while patients use mechanistic models.³⁸ This disparity likely undermines the patient-clinician relationship and the effectiveness of pain management strategies.

Notably, some clinicians believe that superficial mucosal inflammation, characteristic of UC, is not inherently painful. This view is challenged by patient experiences as well as research. Inflammatory mediators infiltrating gastrointestinal tissue heighten the excitability of sensory nerves.³⁹ While the degree of infiltration and changes in nerves correspond with structural abnormalities—more pronounced in CD than in UC—even mild inflammation may lead to such changes,⁴⁰ explaining much pain in UC,⁴¹ and highlighting it as an important treatment target, *pace* current guidelines.⁴²

Our study presents both limitations and strengths. First, recruitment cannot represent the entire canon of beliefs of people with IBD. But sample size and diversity were enriched by aggregating data from multiple studies with varied purposes and the credibility of our interpretations was enhanced by reflective thematic analysis and discussion within the research team. Second, description of participants lacks medical detail as it depended on data in the studies included in our secondary analysis. This is offset by the extent and diversity of the sample so that further specification is not required to interpret themes. Third, most patient studies did not specifically address patient-clinician interactions, but their importance is evident: even in the least constrained study, participants spontaneously described interactions with clinicians.¹⁵ This suggests it is important to clarify what happens during consultations. Fourth, while our clinician recruitment strategy did not attract clinicians with a specific interest in pain, it resulted in an over-representation of clinicians from two hospitals, potentially limiting the diversity of perspectives. To enhance heterogeneity, we included a range of clinicians at various career stages and reanalysed transcripts of an earlier study involving clinicians.⁵ Fifth, since we did not directly observe clinical encounters, our explanations for contradictions between narratives are speculative and require further investigation.

In conclusion, a balanced approach is needed, where clinicians attend to long-term disease management and patients' wishes for pain management. Power imbalances interacting with time constraints appear to contribute to under-recognition of pain. Observational research, bypassing recall and social desirability biases,⁴³ may directly capture the dynamics that fuel these power imbalances and could explain discrepancies between

narratives. This understanding could help mitigate the negative impacts of time constraints and power imbalances.

Furthermore, there is a need for further research on patients who continue to have pain due to ongoing inflammation or complications: 28% of patient respondents to a Europe-wide survey regularly used analgesics to alleviate IBD pain⁴⁴ and a UK multicentre study reported opioid use among 11.9% of outpatients.⁴⁵ The risks associated with long-term opioid use¹¹ particularly underscore the need for pain management strategies that work alongside inflammation control.

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