

## Identifying and Predicting the Goals and Concerns Prioritized by Individuals with Inflammatory Bowel Disease

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## ABSTRACT

**Background and Aims:** In order to provide high-quality care, providers need to understand their patients' goals and concerns. This study aims to identify and predict the goals and concerns prioritized by patients with inflammatory bowel disease (IBD) in the outpatient setting.

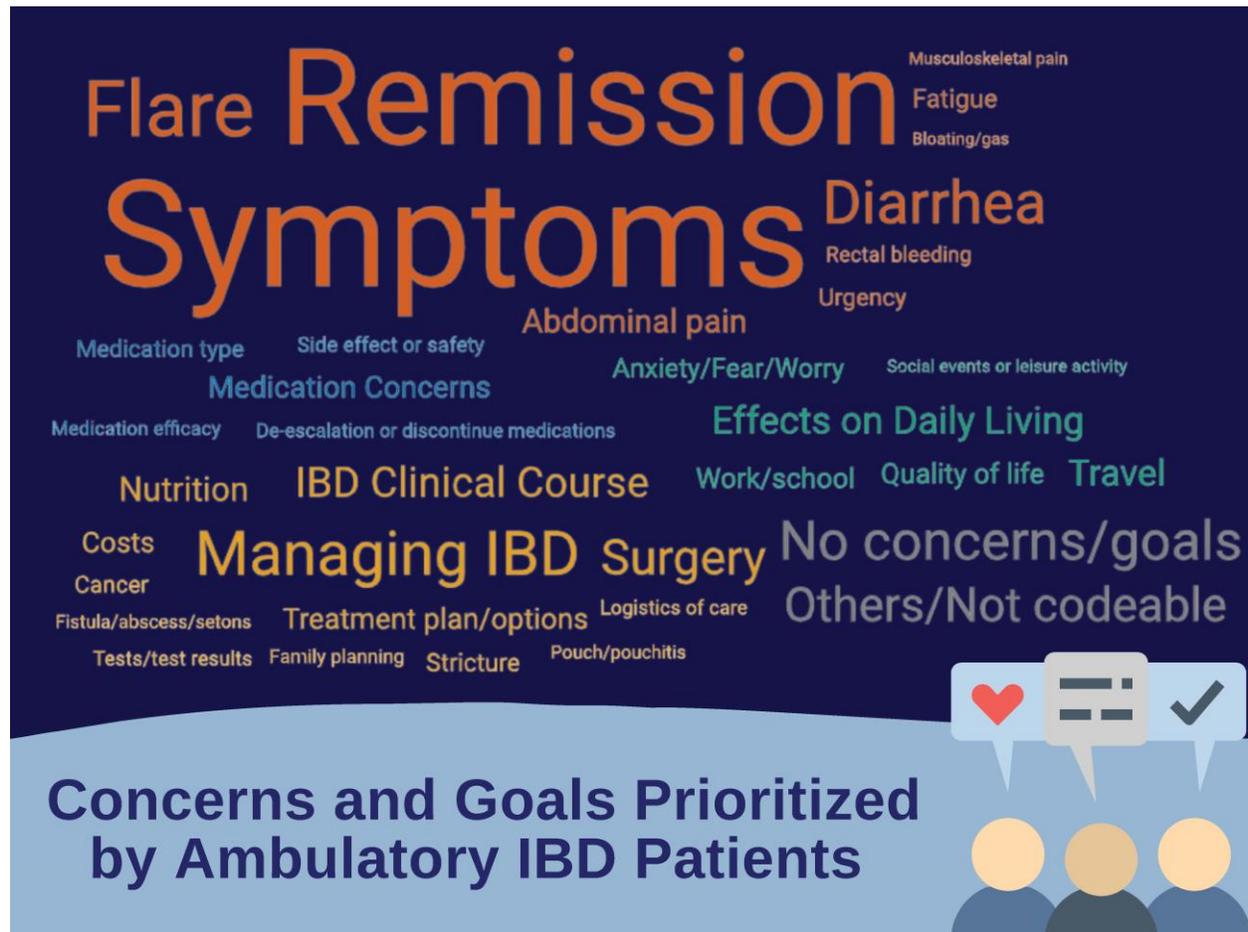
**Methods:** Mixed-methods analysis was performed to identify the types, frequencies, and predictors of IBD patients' goals and concerns using 4,873 surveys collected between 2016-2019 at 25 gastroenterology clinics across the United States participating in the Crohn's & Colitis Foundation's IBD Qorus Learning Health System.

**Results:** Patients with IBD most often prioritized goals and concerns related to symptoms/disease activity (50%) and clinical course/management (20%), while psychosocial/quality of life (12%) and medication (6%) concerns were less frequent. Females (OR 22.1, 95% CI 5.3-91.5) and patients in clinical remission (OR 2.2, 95% CI 1.2-4.1) were more likely to prioritize family planning. Patients >60 years old (OR 3.1, 95% CI 1.5-6.5) and patients with active disease (OR 3.2, 95% CI 1.4-7.6) were more often concerned about traveling. Smokers were more often concerned about nutrition (OR 4.2, 95% CI 1.9-9.2). Surgery was more often a concern of patients with perianal Crohn's disease (OR 2.1, 95% CI 1.2-3.5), active disease (OR 1.9, 95% CI 1.1-3.4) and those with recent hospitalizations (OR 2.5, 95% CI 1.2-5.4).

**Conclusions:** IBD patients prioritized the remission of physical symptoms as treatment goals and that they were less frequently concerned about medications and their side effects. Patients' demographics, IBD characteristics, and healthcare utilization patterns can predict specific types of concerns/goals.

**Keywords:** inflammatory bowel disease; clinical management; treatment goals; patient-provider relationship

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## INTRODUCTION

Inflammatory bowel disease (IBD) is a chronic relapsing-remitting incurable gastrointestinal (GI) disorder that affects more than 6.8 million people worldwide.<sup>1</sup> Although tremendous therapeutic developments have occurred over the past several decades,<sup>2</sup> navigating the plethora of pharmacologic, surgical, and dietary treatment options can be challenging for patients given the complex risk-benefit profiles.<sup>2,3</sup> A patient's treatment preference is influenced by their personal expectations, health literacy, socioeconomic circumstances, and access to health resources.<sup>4</sup> Understanding and appreciating what matters most to patients – their goals, values, and concerns – is important for shared decision making, medication adherence, patient satisfaction, and healthcare costs.<sup>5-7</sup>

To date, most studies investigating patient preferences<sup>8,9</sup> have been conducted prior to the introduction of biological therapy, a cornerstone in the current therapeutic armamentarium for IBD.<sup>10</sup> Indeed, a recently published large multinational study, IBD GAPPs (IBD Global Assessment of Patient and Physician Unmet Need Survey), found notable discrepancies between the perspectives of gastroenterologists and their patients on disease remission and medication efficacy/side effects,<sup>11</sup> supporting results from prior smaller studies in the post-biologic era.<sup>12,13</sup> There is a need for more contemporary and comprehensive evaluation of patient preferences, goals, and concerns to meaningfully incorporate them into care management and medical decision-making.

In this study, we conducted a nationwide survey across the United States between 2016-2019 to identify the types, frequencies, and predictors for goals and concerns that patients with IBD prioritize in the outpatient setting. This can aid providers in tailoring individualized

treatment strategies that align with patients' goals and preferences, particularly given the social, healthcare, and economic impacts of this complex disease.

## MATERIALS AND METHODS

### *Study Design*

A total of 6,275 surveys were collected from IBD patients at 22 GI clinics across the United States participating in the Crohn's & Colitis Foundation's IBD Qorus Learning Health System, a consortium of academic, community, and private GI practices formed to improve IBD quality of care and health outcomes.<sup>14</sup> Mixed-methods analysis was performed to identify the types of goals and concerns reported directly by patients (inductive thematic analysis), quantify their frequency (summative content analysis), and identify predictors (multiple logistic regression analyses) (**Figures 1 and 2**). Consistency analysis was performed to determine persistence in patient-reported concerns and goals between visits (**Figures 1 and 2**).

### *Materials and Setting*

Adults ( $\geq 18$  years old) with IBD completed pre-visit surveys containing questions about their current symptoms, disease activity, recent healthcare utilization, and an open-ended question for IBD-related goals or concerns:

*“Currently, what is your number ONE concern or goal related to your IBD? This could be related to a specific symptom (e.g., diarrhoea), worry for the future (e.g., need for*

*surgery, cost of care) or how IBD might impact an upcoming life event (e.g., wedding, travel). Or you can report that you have no current concerns or goals.”*

While patients may have more than one goal/concern, prioritizing discussion points is often necessary in real-world GI practices’ with limited time and resource constraints. Nevertheless, patients still have the option of expressing more than one concern/goal in the open-text response.

Two datasets were used in this study: a cross-sectional sample of anonymous paper surveys (n=1,863) and a convenience sample of online surveys (n=3,010) that contained detailed clinical information (**Figure 2**). Anonymous paper surveys were collected in the waiting room from all patients with IBD at 22 IBD Qorus sites between March, 2019 and April, 2019 as part of a quality improvement initiative specifically focused on improving access to urgent care.<sup>15</sup> Paper surveys were excluded from analysis if a diagnosis other than UC or CD was reported (e.g., ‘other’) or if the goals and concerns response was left blank. Online surveys were obtained from a subset of patients who consented to participate in the IBD Qorus Learning Health System across 25 GI clinic sites between February, 2016 and November, 2019. Patients who consented to IBD Qorus had their IBD diagnosis verified by a healthcare provider and were assigned a unique patient identifier (not linked to their clinical medical records) that allowed tracking of subsequent survey responses at follow-up clinic visits. In the online survey, a response was required for the goals and concerns question and patients specified in writing if they did not have any goals or concerns.

### *Qualitative Content Analysis and Codebook Development*

Using an inductive approach, two independent codebook developers (CT and WKvD) thematically coded patients' responses from a purposeful sample of surveys from five IBD Qorus sites (a mix of academic and private practices at rural and urban locations) collected between February, 2016 and January, 2018 (**Figure 2**). Using sets of 100 successive online responses, the codebook developers discussed the themes that emerged, classified them into codes, and compared their similarities and differences (**Figure 1**). A gastroenterologist (SS) was asked to provide independent analysis for any disagreements that emerged. Feedback was obtained from three patients with IBD and the IBD Qorus leadership team during the codebook development process. Codebook development was completed when the list of themes were comprehensive and mutually exclusive (i.e., saturation of concepts and content validity) and the inter-coder agreement was >80% between the codebook developers (i.e., construct reliability and definitional clarity)<sup>16</sup>. The final codebook contained the themes' definitions, coding instructions, and quotation examples (**Supplement Table 1**).

Symptoms and Disease Activity (Flare/inflammation and Remission/IBD control/being healthy) were interrelated themes that were distinctly, but not mutually exclusively, coded depending on the terminology used in patients' responses. (**Supplement Table 1**). Symptoms are physical or mental features indicating a condition of disease that is apparent to the patient. Disease Activity was coded when patients used the words 'flare', 'inflammation', or 'remission', which reflected goals/concerns for preventing flares, currently being in a flare, wanting to achieve remission, or stay in remission (**Supplement Table 1**).

### *Coder Training and Survey Response Coding*

Four independent coders (AVC, BR, NF, ML) were trained to use the codebook and then coded the study responses with 10% overlap with the codebook developers to ensure >80% inter-coder reliability (**Figure 1**).<sup>16</sup> After coding, themes with  $\geq 1$  disagreement(s) between the coders and codebook developers, as well as themes that were classified as Others/Non-codeable, were systematically reviewed and recoded as appropriate by the codebook developers. Online responses that explicitly stated no concerns or goals were coded as No Concerns/Goals. Each patient response could be coded with more than one theme up to a maximum of 8 themes.

### *Statistical Analysis and Summative Content Analysis*

Anonymous paper surveys (n=1,763) representing cross-sectional data were used to quantify the frequency of patients' goals and concerns in summative content analysis (**Figures 1 and 2**). Differences in the types of goals and concerns from patients with UC versus CD were compared using chi-square using the paper surveys (cross-sectional sample). Consistency analysis was performed on online surveys to determine the agreement of patients' concerns between the initial visit and at the first follow-up clinic visit (n=1,274 online surveys from n=637 patients). Multiple logistic regression analysis was performed on online surveys (n=2,510 surveys, 1,873 unique patients) from consented patients with rich clinical data to identify predictors for specific goals/concerns. Multiple comparisons correction was performed with Bonferroni adjustment ( $p < .0038$  from  $p = .05/13$  for 13 pre-determined independent variables) to

reduce Type II error. To adjust for possible associations among the independent variables, variables with  $p < .05$  on unadjusted univariate analysis (to reduce type I error) were modelled in multivariate logistic regression analysis with different models for each goal/concern. (**Figures 1 and 2**).

Descriptive and regression analyses were conducted by using JMP®, Version 14.1 from SAS Institute Inc. (Cary, NC, 1989-2019). Inter-coder reliability was analysed using R version 3.6.3 from R Core Team (Vienna, Austria, 2020) to calculate the percentage agreement and Cohen's kappa coefficient with adjustments for prevalence.<sup>16,17</sup>

### *Ethical Considerations*

Institutional Review Board approval for the IBD Qorus Learning Health System was obtained from the Dartmouth College (Study #00029226). Where required, local institutional review board approval was obtained before site initiation. All patients who completed online surveys provided electronic informed consent prior to participating in IBD Qorus. Due to the de-identified nature of the paper surveys, the research was determined exempt by the Dartmouth College Institutional Review Board.

## RESULTS

### *Goals and Concerns Prioritized by IBD Patients*

A total of 62 themes of IBD patients' goals/concerns were identified within 4 categories: Symptoms, IBD Clinical Course and Management, Psychosocial and Quality of Life, and Medications (**Figure 3**). The most common goals/concerns were related to Symptoms (n=877, 49.7%; n=1,763 cross-sectional paper surveys). The most salient symptoms were pain (n=167, 9.5%), diarrhoea (n=146, 8.3%), rectal bleeding (n=43, 2.4%), and fatigue (n=42, 2.4%) (**Table 2, Figure 3**). Specific mention of disease activity (avoid flares, be in remission) occurred in a quarter of clinic visits (n=458, 26.0%) (**Table 2**). Patients with UC more often expressed goals/concerns pertaining to remission (23.5% vs 16.5%, p=.0002), rectal bleeding (3.4% vs 1.8%, p=0.03), while patients CD more often expressed concerns about pain (5.3% vs 1.9%, p=.0001) (**Supplement Table 2**).

Disease complications (e.g., fistulas, cancer), family planning (e.g., pregnancy, breastfeeding, fertility), and logistics of care (e.g. scheduling infusions, provider referrals) comprised the second most common category of goals/concerns: IBD Clinical Course and Management (n=355, 20.1%) (**Table 2, Figure 3**). Patients with UC were more likely to be concerned about cancer (2.2% vs 0.7%, p=.0075), whereas patients with CD were more concerned about nutrition (3.8% vs 1.9%, p=0.01) and strictures/bowel obstruction (2.1% vs 0.4%, p=.003; **Table 2**). Hospitalization or ED visits comprised less than 1% of patient-reported concerns.

Psychosocial and Quality of Life goals/concerns were prioritized by patients in 12% (n=211) of clinic visits (**Table 2**). This includes feelings of loss of control and quality of life (n=51, 2.9%) with IBD adversely impacting their daily activities, such as going to work/school (n=32, 1.8%), leisure/social activities (n=21, 1.2%), and travelling (n=36, 2.0%) (**Table 2; Figure 3**). Anxiety, fear, and worry were the most commonly expressed emotions (n=71, 4.0%) (**Table 2**).

Medications were the least common category of goals/concerns (n=108, 6.1%), including safety/side effects (n=30, 1.7%), efficacy (n=25, 1.4%), and discontinuation/de-escalation (n=33, 1.9%).

#### *Predictors of IBD Patients' Goals and Concerns*

Family planning was a salient goal/concern among patients who were female (odds ratio [OR] 22.1, 95% confidence interval [CI] 5.3-91.5), in the 4<sup>th</sup> decade of life (OR 2.5, 95% CI 1.3-4.9), and in clinical remission (OR 2.2, 95% CI 1.2-4.1) (multivariate analysis in **Table 3**; univariate analysis in **Supplement Table 3**). Travel concerns were important to patients >60 years old (OR 3.1, 95% CI 1.5-6.5), have symptomatically active disease (OR 3.2, 95% CI 1.4-7.6), and in those with an ED visit within the last 6 months (OR 2.2, 95% CI 1.1-4.2). Surgery concerned patients with perianal Crohn's disease (OR 2.1, 95% CI 1.2-3.5), clinically active IBD (OR 1.9, 95% 1.1-3.4), and IBD-related hospitalization in the previous 6 months (OR 2.5, 95% CI 1.2-5.4). Active smokers were concerned about Nutrition/weight management (OR 4.2, 95% CI 1.9-9.2). None of the examined factors were associated with Anxiety/fear/worry.

### *Consistency Analysis*

One-fifth (19.7%) of goals/concerns remained the same between the first and second visit (in 637 patients with follow-up visits). The most consistent theme was Remission/IBD control/being healthy (34.0% agreement between visits), followed by concerns about fistulas/abscess/setons (33.8%), stress (30.0%), pain (27.9%), diarrhoea (27.9%), family planning (23.8%), and surgery (23.7%). One-tenth (10.5%) did not have any goals/concerns at either the initial or follow-up visit, although two-thirds (66.3%) of patients without goals/concerns in one visit did so in another.

Online (typed) responses were longer than written paper responses (both word and character count had  $p < .0001$ ). Online response had an average of 7 words and 41 characters, with a maximum of 8 themes. Paper responses had an average of 3 words and 20 characters, with a maximum of 4 themes.

## **DISCUSSION**

In this national sample of nearly 5,000 surveys from patients with IBD across the United States from diverse geographical locations and clinical settings, we found that patients predominantly prioritized symptom control. Surgery, family planning, treatment options, nutrition, and cost of care – categorized as IBD Clinical Course and Management – were a patient's top concern in 1 in 5 clinic visits. Conversely, medication concerns (efficacy, safety, de-escalation) were a top patient concern in only 1 in 20 visits, in contrast to the emphasis placed on medication management by many gastroenterologists.<sup>18</sup>

IBD patients' preferences for treatment efficacy, potential adverse effects, and surgical versus medical management modalities play an important role in clinical decision making.<sup>4</sup> Understanding patients' goals in therapy and their perception of the risks and benefits can vary greatly between patients.<sup>11,12</sup> In the present study, patients prioritized the management of symptoms (50% of clinic visits) much more often than the medication efficacy/safety (6% of clinic visits). While providers may be cognizant of the relationship between symptom control and inflammation control by way of pharmacotherapy (treat to target), patients may not have the same shared (explicit) knowledge.<sup>11</sup> Qualitative studies on patients' treatment preferences found that providers can better engage patients by considering their information needs, preference for medication-related factors (e.g., route of administration, efficacy, safety, dosing), and perception of the risks and benefits.<sup>4</sup>

Several demographic, disease, and healthcare utilization factors were identified in this study as predictors for specific goals/concerns. Women of reproductive age with IBD in remission were more often concerned about family planning, including fertility, pregnancy, and breastfeeding. A prior study of 1324 women with IBD between the ages of 18-45 found that 36% planned to have children at some stage and 17% were voluntarily childless. Poor IBD-related knowledge and not seeking medical advice were factors associated with voluntary childlessness. Providers can alleviate patients' concerns and/or correct misconceptions surrounding the impact of IBD and its therapies on pregnancy as women may otherwise unnecessarily stay childless.<sup>19,20</sup> We also found that patients above age 60, especially those with active disease and recent hospitalization, were more likely to be concerned about travelling. Travel is a desired activity among retirees and it often requires advanced planning. In an interview-based study, patients expressed frustration when they had to cancel trips when their IBD symptoms unexpectedly worsen.<sup>19</sup> Surgery was more often a concern among patients with active perianal Crohn's disease

and recent hospitalization, which might reflect their conversations with their providers as surgical management is often recommended for perianal fistulas.<sup>10</sup>

The most commonly used IBD patient reported outcome measures (PROMs) for patient concerns and quality of life, including the Rating Form of IBD Patient Concerns (RFIPC)<sup>9</sup> and the Inflammatory Bowel Disease Questionnaire (IBDQ),<sup>21</sup> were developed more than three decades ago.<sup>22</sup> There has since been significant advancement of steroid-sparing medical therapies and surgical techniques,<sup>9,10</sup> which may explain why concerns about body stigma and body image (e.g., feeling dirty or smelly, body image, and attractiveness) and sexual activity (e.g., intimacy, sexual drive and function) were not salient themes in the current study in contrast to prior PROMs.<sup>8,9,21</sup> Conversely, physical symptoms and the psychosocial impact of IBD remain at the forefront of patients' concerns.<sup>9,19,21,22</sup>

Strengths of this study includes the large, nationwide participant sample of patients with IBD in diverse settings, including private practice, community centres, and academic institutions in rural and urban areas. Another notable feature of this study is its rigorous mixed-methods qualitative and quantitative approach with the inclusion of patient advocates, clinicians, and researchers in the thematic content analysis. These strengths have the advantage of integrating key stakeholders' perspectives in assessing treatment goals and outcomes for IBD, while avoiding preconceived concepts that may introduce assumptions and may not reflect patients' perspectives.<sup>23</sup> Moreover, by using an open-ended question, patients were able to express personal goals and concerns in their own words, which offers more diverse answers and perspectives than close-ended questions (such as questionnaires with pre-determined thematic concepts and rating scales).<sup>24</sup>

Limitations of the study include the use of a non-validated question, which might have led to response bias as the question included several probes. Nevertheless, patients expressed diverse goals and concerns that were applicable to them, as evidenced by the many themes that emerged in the analysis as well as the narrative that accompanied some of the responses. While the use of validated PROM's can be used to quantify patients' concerns (e.g., 26-item RFIPC, 32-item IBDQ), it is often not feasible in the clinical setting to administer questionnaires to patients and for providers to review their responses.<sup>9</sup> Soliciting a patient's concerns/goals using an open-ended question is more reflective of the real-world GI practice experience, and this is readily translatable and directly applicable in the clinical setting. Moreover, the corresponding themes of physical symptoms and psychosocial effects reflects those of prior studies,<sup>9,19,25</sup> which provides external validation to support the types of patient-reported concerns in this study.

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In conclusion, patients with IBD have diverse goals and concerns that reflect their subjective illness experiences and priorities in life. Symptomatic remission remains at the forefront of patients' concerns, and a patient's age, gender, disease activity, and healthcare utilization patterns can help predict specific goals and concerns in advance of a provider visit. Anticipating these concerns can help providers tailor disease management discussions to better align treatment goals and targets with their patients. To apply these concepts into daily clinical practice, gastroenterologists can begin each consultation visit by asking their patients, "What is your priority for this visit today?" or "What are the top goals/concerns that you would like to address at this visit?" These open-ended questions can complement other surveys with numeric rating scales and yes-no questions, such as the IBD-Control questionnaire,<sup>26</sup> to help establish the clinical interaction to the patient's needs and preferences at the beginning of each encounter. Within the paradigm of a patient-centred clinical care model, these practices can help patients to feel understood, comply with treatments/tests, increase patient satisfaction, and participate in shared-decision making.<sup>5,6,12</sup>

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## TABLES AND FIGURE LEGENDS

**Table 1: Demographic and Clinical Details of Patients with IBD**

n (%)	Paper surveys (N=1,763)	Online surveys (N=1,873)
Age		
<30	450 (25.5)	444 (23.7)
30-40	417 (23.7)	519 (27.7)
41-50	248 (14.1)	319 (17.0)
51-60	267 (15.1)	274 (14.6)
>60	363 (20.6)	317 (16.9)
Missing	18 (1.0)	0 (0)
Gender		
Male	786 (44.6)	1051 (56.1)
Female	955 (54.2)	817 (43.6)
Other/unknown	22 (1.2)	6 (0.3)
IBD subtype		
Crohn's disease	1,019 (57.8)	1,048 (55.9)
Ulcerative colitis	744 (42.2)	682 (36.4)
Indeterminate colitis	N/A	45 (2.4)
Missing	N/A	98 (5.2)
IBD duration	N/A	
≤ 5 years		545 (29.1)
5-10 years		482 (25.7)
10-20 years		514 (27.4)
≥ 20 years		332 (17.7)
Ulcerative colitis extent (n=682)	N/A	
Proctitis		62 (9.1)
Left-sided		171 (25.1)
Extensive		327 (47.9)
Post-colectomy		35 (5.1)
J-pouch		32 (4.7)
Stoma		3 (0.4)
Missing		35 (5.1)
Crohn's disease phenotype (n=1,048)	N/A	
Non-stricturing, non-penetrating		506 (48.2)
Stricturing		263 (25.1)
Penetrating		272 (26.0)
Missing		7 (0.7)
Crohn's disease location		
Ileal		289 (27.6)

Colonic		210 (20.0)
Ileocolonic		483 (46.1)
Upper GI involvement		103 (9.0)
Perianal involvement		172 (16.4)
Post-colectomy		29 (2.8)
J-pouch		24 (2.3)
Stoma		5 (0.5)
IBD in symptomatic remission**	278 (15.8)	452 (24.1)
IBD-related care in last 6 months		
Urgent care	365 (20.7)	313 (16.7)
Emergency department visit	236 (13.4)	183 (9.8)
Hospitalization	191 (10.8)	156 (8.3)
Computed tomography	327 (18.5)	270 (14.4)
Current medication use		
Steroids	186 (10.6)	183 (9.8)
Narcotics	87 (4.9)	61 (3.2)
Smoking	N/A	71 (3.8)

\*Defined as symptoms that needed to be addressed within hours. \*\*Manitoba IBD Index.

Abbreviations: IBD, inflammatory bowel disease; UC, ulcerative colitis

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**Table 2: Frequency of goals and concerns reported by IBD patients at 22 outpatient gastrointestinal clinics**

Goals/Concerns Themes	Surveys (N=1,763)	Sample Quotations
<b>Symptoms/Disease Activity</b>	<b>877 (49.7)</b>	
Disease Activity (Remission / Flare)	458 (26.0)	“Stay in remission”; “staying in good health”; “to stay symptom free” “Reducing Inflammation”; “eliminate flare ups”, “dealing with a flare”
Remission / IBD control / being healthy	343 (19.6)	
Flare / inflammation	124 (7.3)	
Symptoms Description	438 (24.8)	“My stool is not formed and I am going to the bathroom 4-5 times daily” “Pain that doesn't go away for days”, “pain control”, “severe pain” “Stomach cramps on and off”; “abdominal discomfort” “Bloody diarrhoea”; “blood in stool”; “blood on tissue when wiping” “I feel very tired, can't seem to finish tasks due to fatigue.” “I have a constant and urgent need to go to the bathroom” “Excess gas and bloating”, “constant bloating”, “stomach gas” “Minimize body aches and arthritic symptoms”, “joint pain”
Diarrhoea/frequent stools	146 (8.3)	
Pain not otherwise specified	80 (4.5)	
Abdominal pain	68 (3.9)	
Rectal bleeding	43 (2.4)	
Fatigue	42 (2.4)	
Faecal urgency	34 (1.9)	
Bloating / gas	21 (1.2)	
Musculoskeletal pain	19 (1.1)	
Others (each <1%)	151 (8.6)	
<b>IBD Clinical Course and Management</b>	<b>355 (20.1)</b>	
Managing IBD	191 (10.8)	“Find a new treatment plan that gets symptoms and flares back under control” “Figuring out what food upsets me”; “diet as it relates to nausea/pain” “Cost of care/medication”; “treatment costs”; “health insurance premiums” “Concern about conceiving with IBD”; “remission through pregnancy” “Review recent pouchoscopy results”; “iron levels/anaemia” “Ensuring that I get my infusions on time, without hassle”
Treatment plan / options	63 (3.6)	
Nutrition / weight management	53 (3.0)	
Cost / care coverage	41 (2.3)	
Family planning	20 (1.1)	
Tests / test results	20 (1.1)	
Logistics of care	18 (1.0)	
IBD Clinical Course	170 (9.6)	“Avoiding any more surgeries”; “need for surgery eventually” “Post surgical status of Crohn's and stoma area blockages”; “intestinal obstruction” “Reduce colon cancer risk”; “increase risk of skin cancer due to meds” “To keep the fistulae closed”; “setons are painful, sitting walking etc.” “Making sure J pouch is healthy”; “chronic pouchitis”; “blood from pouch”
Surgery for IBD	84 (4.8)	
Stricture or bowel obstruction	24 (1.4)	
Cancer	23 (1.3)	
Fistula, abscess, or setons	18 (1.0)	
Pouch or pouchitis	16 (1.0)	
Others (each <1%)	14 (0.8)	
<b>Psychosocial and Quality of Life</b>	<b>211 (12.0)</b>	

Effects on Daily Living	135 (7.7)	
Quality of life/loss of control	51 (2.9)	“To have and continue a normal life style”; “better quality of life”
Travel	36 (2.0)	“I’m concerned that I will have symptoms while traveling”
Work, school, or disability	32 (1.8)	“Staying in remission so my job, wedding & life aren’t impacted”
Social events or leisure activity	21 (1.2)	“feel well for my daughter's wedding”; “IBD may impact wedding”
Others (each <1%)	27 (1.5)	
Emotions	81 (4.6)	
Anxiety, fear, or worry	71 (4.0)	“Worry for future: I do not want to have surgery or be on steroids.”
Others (each <1%)	13 (0.7)	
<b>Medications</b>	<b>108 (6.1)</b>	
Medication Concerns	86 (4.9)	
Deescalate / discontinue /dependence on meds / medication free	33 (1.9)	“Can I get off my meds”, “getting better enough to not take meds”, “getting off prednisone”, “get to manageable state with minimal drugs”
Side effects or safety	30 (1.7)	“Cancer risk of meds”; “long term effects of medication.”
Medication efficacy	25 (1.4)	“Afraid medication not working”; “is my current treatment working?”
Medication Types	52 (3.0)	
Infliximab	16 (0.9)	“Effectiveness of Remicade”; “long term effects of Remicade”
Steroids	11 (0.6)	“I want to taper off of prednisone”; “side effects from prednisone”
No concerns/goals	192 (10.9)	/
Other / not codeable	190 (10.8)	/

Abbreviations: IBD, inflammatory bowel disease

**Table 3: Multivariate analysis of the predictors for IBD patients' top goals and concerns at 25 outpatient gastrointestinal clinics (N=1,873)**

OR (95% CI)	Remission / flare (n=458)	Surgery (n=116)	Family planning (n=75)	Travel (n=65)	Nutrition / weight management (n=61)	Quality of life (n=54)	Work, school, disability (n=40)
<b>Gender (ref: male)</b>	0.8 (0.7-1.0)	/	22.1 (5.3-91.5)	/	/	/	/
<b>Age (years)</b>		/					
<30 (n=444)	Reference		Reference	Reference			
30-40 (n=519)	0.7 (0.6-1.0)		2.5 (1.3-4.9)	1.2 (0.6-2.6)			
41-50 (n=319)	0.6 (0.4-0.9)		0.2 (0.04-0.9)	1.0 (0.4-2.5)			
51-60 (n=274)	0.5 (0.4-0.8)		N/A	0.6 (0.2-1.8)			
>60 (n=317)	0.5 (0.3-0.7)		0.1 (0.01-0.9)	3.1 (1.5-6.5)			
<b>IBD subtype</b>		/	/	/	/	/	
CD (n=1,048)	Reference						Reference
UC (n=682)	1.6 (1.3-2.0)						1.0 (0.5-2.0)
IBD-U (n=45)	0.9 (0.4-2.0)						5.3 (1.7-16.8)
<b>Perianal Crohn's disease (n=172)</b>	/	2.1 (1.2-3.5)	/	/	/	/	/
<b>IBD duration (years)</b>	/	/		/	/	/	/
<5 (n=545)			Reference				
5-10 (n=482)			1.8 (0.9-3.5)				
11-20 (n=514)			0.8 (0.4-1.9)				
>20 (n=332)			0.9 (0.2-3.3)				
<b>IBD in remission* (n=452)</b>	/	0.5 (0.3-0.9)	2.2 (1.2-4.1)	0.3 (0.1-0.7)	/	0.5 (0.2-1.2)	/
<b>Urgent concern (6m) (n=313)</b>	1.4 (1.0-1.8)	/	/	/	/	1.2 (0.6-2.8)	1.0 (0.4-2.9)
<b>ED visit (6m) (n=183)</b>	/	0.7 (0.4-1.5)	/	2.2 (1.1-4.2)	/	1.5 (0.5-4.6)	1.5 (0.4-5.8)
<b>Hospitalization</b>	/	2.5 (1.2-5.4)	/	/	/	1.0 (0.3-3.0)	1.4 (0.4-4.9)



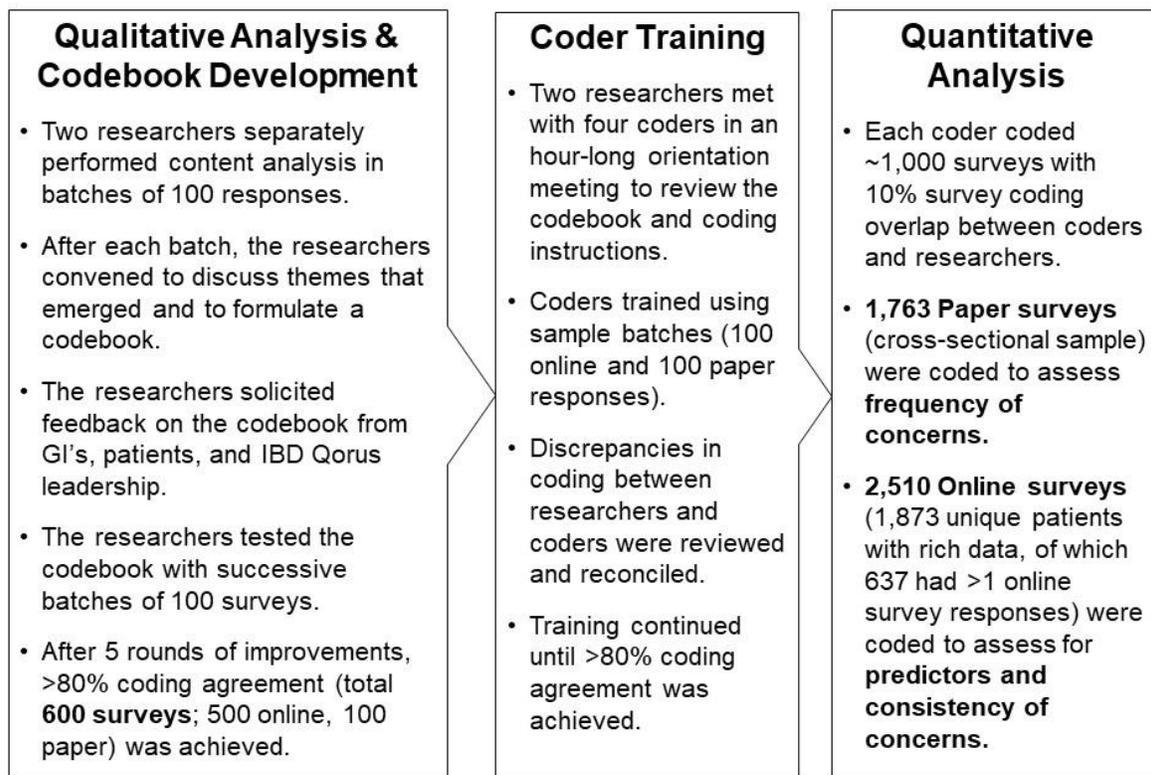
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<b>(6m) (n=156)</b>							
<b>CT scan (6m) (n=433)</b>	/	1.7 (1.0-3.0)	/	/	/	/	2.1 (0.8-5.3)
<b>Steroids (6m) (n=320)</b>	/	/	/	/	/	2.4 (1.2-4.9)	2.0 (0.9-4.6)
<b>Smoking (n=71)</b>	/	/	/	/	4.2 (1.9-9.2)	/	/

\*IBD remission per patient report on the Manitoba IBD index. Abbreviations: CD, Crohn's disease; CT, computed tomography; ED, emergency department; IBD, inflammatory bowel disease; IBD-U, IBD-unclassified; ref, reference; UC, ulcerative colitis

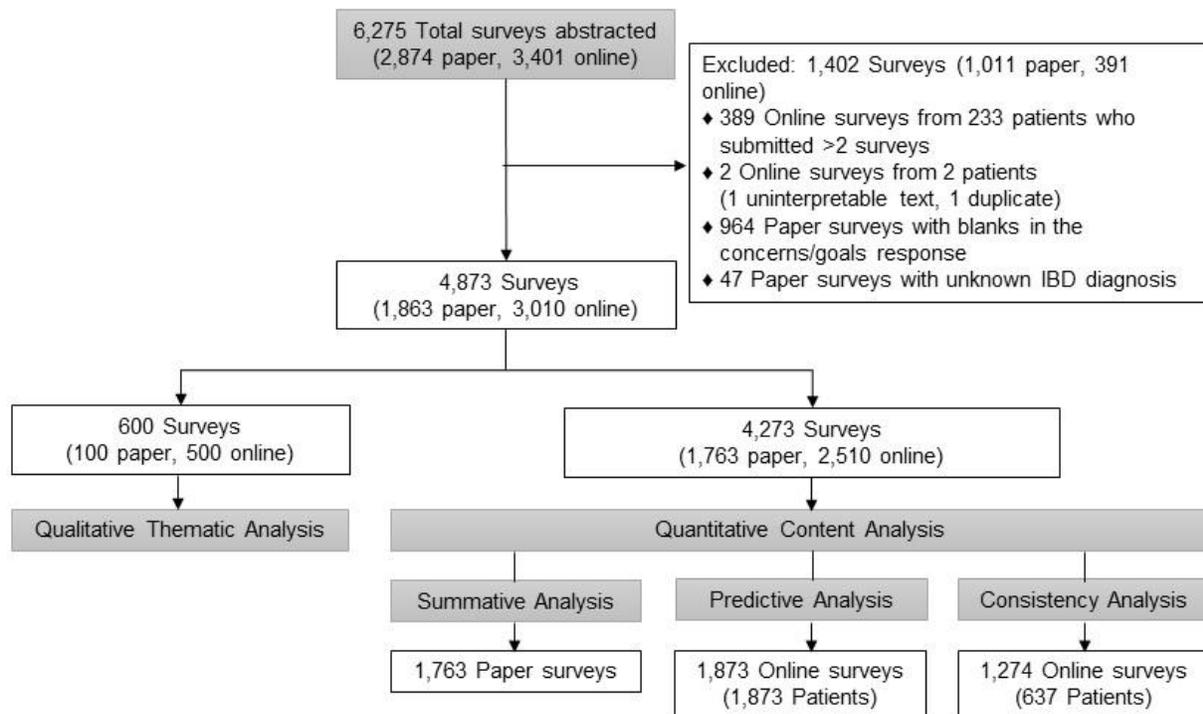
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## FIGURES



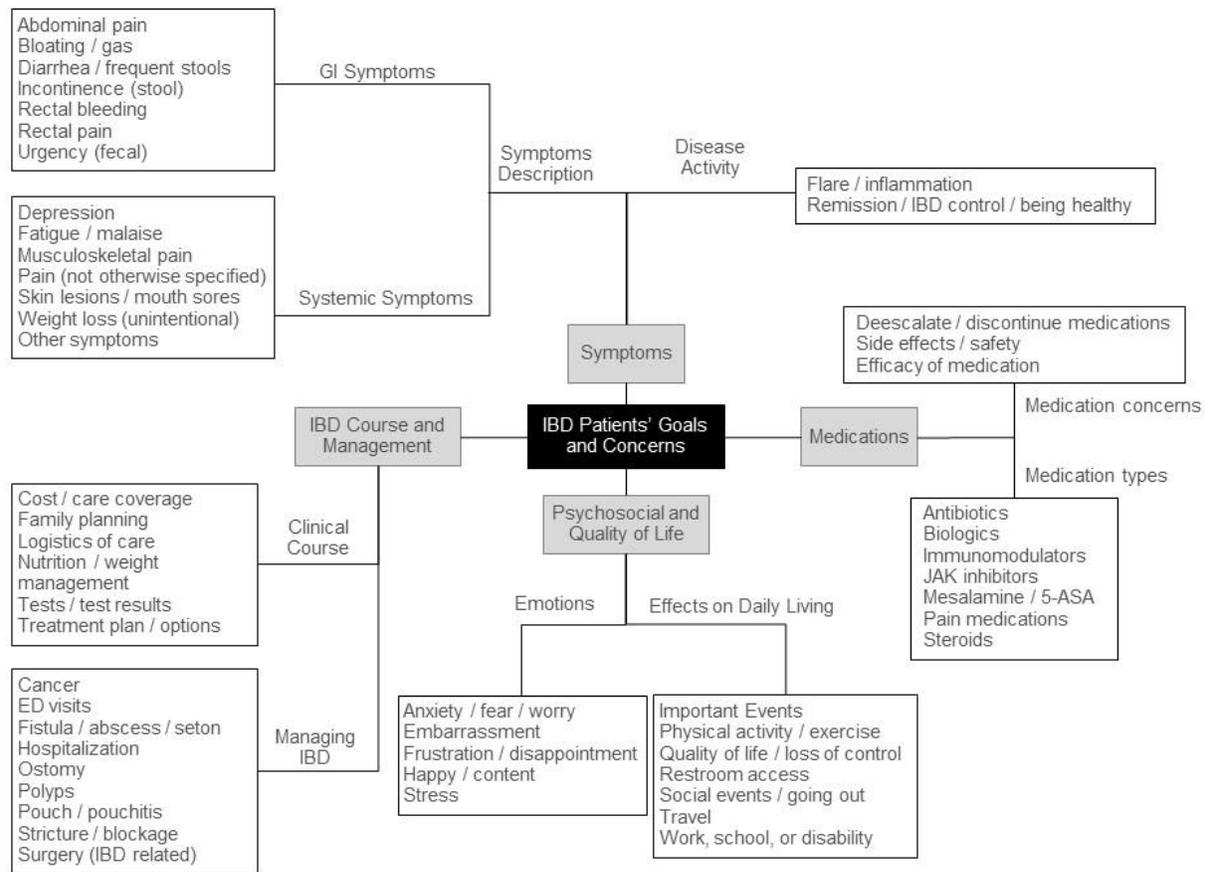
**Figure 1: Mixed-methods analysis of IBD patients' top goals and concerns from 4,783 surveys.** Qualitative analysis was performed on 600 surveys (500 online and 100 paper) to develop a codebook. Six coders were trained until >80% coding agreement was achieved. Quantitative analysis was performed on 1,763 paper surveys to identify the frequency of each type of goals and concerns from a cross-sectional sample. Another 2,510 online surveys from 1,873 unique patients from a sample with rich clinical data, of which 637 patients had at least 1 follow-up online surveys, were coded to assess for predictors of goals and concerns.

Abbreviation: GI, gastroenterologists.



**Figure 2: Flow diagram of the study participants and surveys used in mixed-methods analysis.** A total of 6,275 surveys were abstracted of which 1,402 were excluded for analysis due to duplicate or missing data. Qualitative analysis was performed on 600 surveys (500 online and 100 paper) to develop a codebook. Summative content analysis was performed on 4,273 surveys (1,763 paper, 2,510): 1,763 paper surveys were to identify the frequency of the types of goals and concerns from a cross-sectional sample and 2,510 online surveys from 1,873 unique patients (637 patients had at least 1 follow-up) with rich clinical data were used to analyse for predictors and consistency of goals and concerns. Abbreviation: IBD, inflammatory bowel disease.

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**Figure 3: Themes identified in goals and concerns reported by IBD patients in 600 surveys.**

A thematic codebook was developed to label the goals and concerns of patients with IBD, organized into four major categories: symptoms/disease activity, medications, psychosocial and quality of life, and IBD clinical course and management. A total of 60 themes were identified, in addition to ‘No concerns/goals’ and ‘Others’. Abbreviations: 5-ASA, 5-aminosalicylic acids; ED, emergency department; IBD, inflammatory bowel disease; JAK, Janus kinase.