

Living With Inflammatory Bowel Disease: Online Surveys Evaluating Patient Perspectives on Treatment Satisfaction and Health-Related Quality of Life

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Background: The quality of life of persons living with inflammatory bowel disease (IBD) is impacted by the physical and psychosocial burdens of disease, as well as by their satisfaction with the quality of care they receive. We sought to better understand (1) the drivers of satisfaction with treatment, including treatment goals, treatment selection, and attributes of patient/health care professional (HCP) interactions, and (2) how IBD symptoms affect aspects of daily life and overall quality of life.

Methods: Two online questionnaires were accessed via MyCrohnsAndColitisTeam.com. The Treatment Survey assessed desired treatment outcomes, past and present therapies, and experiences with the patient's primary treating HCP. The Quality of Life survey assessed respondents' most problematic IBD symptoms and their influence on family and social life, work, and education. Respondents had Crohn's disease (CD) or ulcerative colitis (UC), were 19 years or older, and resided in the United States. All responses were anonymous.

Results: The Treatment Experience survey was completed by 502 people (296 CD, 206 UC), and the Quality of Life survey was completed by 302 people (177 CD, 125 UC). Reduced pain, diarrhea, disease progression, and fatigue were the most desired goals of treatment. Biologics and 5-aminosalicylates were reported as a current or past treatment by the greatest proportion of patients with CD and UC, respectively. A numerically lower proportion of respondents with UC than CD reported use of biologic or small molecule therapy; conversely, a numerically greater proportion of respondents with UC than CD reported these drugs to be very or extremely effective. The HCP was key in the decision to switch to, and in the selection of, biologic or small molecule therapy. Overall satisfaction with an HCP was greatly driven by the quality and quantity of the communication and of the time spent with the HCP. Troublesome abdominal symptoms most impacted aspects of social and family life. Emotional challenges associated with IBD were experienced by most respondents.

Conclusions: Treatment goals of respondents seem to align with HCPs overall treatment goals, including control of gastrointestinal symptoms and prevention of disease progression. Persons with UC might be offered biologic and small molecule therapies less often, despite reported high efficacy by users. Feeling heard and understood by the HCP are key drivers of treatment satisfaction. Quality communication in the patient/HCP relationship enables a better understanding of the patients' goals, disease burden, and emotional needs, which are all key factors to consider when developing a personalized and comprehensive treatment plan and optimizing quality of life.

Lay Summary

Inflammatory bowel disease (IBD) greatly impacts daily life and physical and emotional health. Survey results highlight the importance of patient/health care professional communication to develop a comprehensive treatment plan and promote satisfaction in care and improved quality of life for persons living with IBD.

Key Words: quality of life, IBD, survey, treatment, satisfaction

Introduction

Inflammatory bowel diseases (IBDs) are characterized by chronic inflammation of the gastrointestinal tract and include Crohn's disease (CD) and ulcerative colitis (UC). The incidence and prevalence of IBD have been increasing not only in the Western world, but also globally in newly industrialized countries within South America, Eastern Europe, Asia, and Africa.^{1–4} In 2017, nearly 6.9 million people worldwide were living with IBD, representing a 6.1% increase in the age-standardized prevalence rate since 1990, with nearly a quarter of those patients residing in the United States.²

Intermittent episodes of remission and relapse that are typical of IBD may lead to significant structural damage to the gut and associated disease complications. The most common clinical symptoms of IBD are diarrhea, abdominal pain, blood in the stool, fever, weight loss, malnutrition, and fatigue. People with IBD may also experience extraintestinal manifestations, which most commonly involve the musculoskeletal system, skin, hepatobiliary tract, and eyes. In addition, patients with IBD often experience anxiety and depression.⁵

The primary treatment goal for IBD is mucosal healing, which has been proposed as a formal long-term treatment

target according to recently updated Selecting Therapeutic Targets in IBD (STRIDE-II) recommendations. Mucosal healing has been associated with decreased risk of relapse, hospitalization, complications, and need for surgery, as well as a higher quality of life.^{6,7} Biologic and small molecule therapies of varying mechanisms of action have been developed over the last 2 decades and have been shown effective for inducing and maintaining clinical remission in moderate to severe IBD, with newer therapeutics also delivering endoscopic improvement. However, the sociopsychological, relationship and professional health impacts of symptoms, as well as their impact on overall quality of life, is often overlooked when developing or optimizing treatment plan and remains a significant unmet need for many people with IBD.⁸

In order to obtain further insight into factors that shape the treatment experience with IBD therapies and IBD care, as well as the impact of the disease on quality of life, we developed 2 questionnaires. The first questionnaire was designed to understand real-life experience with IBD treatment and health care professional (HCP)-related factors that drive satisfaction with IBD care. The second questionnaire was designed to assess the symptom burden of IBD and the resulting impacts on daily life and quality of life. The overall objective of these surveys was to examine the effective impact of real-world IBD management on disease symptoms, satisfaction with care, and quality of life.

Materials and Methods

Participant Eligibility and Recruitment

Adults (aged ≥ 19 years) who self-identified as having CD or UC were invited to participate in both surveys. These surveys were administered in the United States and were accessed via MyCrohnsAndColitisTeam.com.

Survey Development

Two online surveys (Treatment Experience and Quality of Life) were developed by AbbVie and MyHealthTeams, a company that creates social networks for communities of people who have (or are caring for someone who has) a chronic condition, providing a forum for individuals to come together for support, advice, and education. MyCrohnsAndColitisTeam.com has over 149 000 members from 13 countries.

Survey questions were based on a review of organic discussions between members on MyCrohnsAndColitisTeam.com about the impact IBD has had on their quality of life, the most troubling symptoms and treatments goals and experiences. We used these patient-focused discussions as a starting point to develop the survey questions.

The IBD Treatment Experience survey was a 38-question English-language online survey capturing treatment experiences, including choice of treatment, most desired treatment outcomes, satisfaction with treatment, and experiences with their primary treating HCP. The IBD Quality of Life (QoL) survey was a 23-question English-language online survey designed to understand the overall impact of IBD on respondents' daily life, including the most problematic symptoms, subsequent work and personal life limitations, and effects on mental well-being. Some survey questions were partially closed ended and allowed subjects to provide answers not included in traditional answer options. Survey questions and answer options are provided in [Supplementary Materials: Supplementary Table 1](#) (Treatment Experience)

and [Supplementary Table 2](#) (Quality of Life). Surveys were evaluated for clarity and reliability by test population prior to going live. The IBD Treatment Experience survey was live from March 5–21, 2020. The IBD Quality of Life survey was live from November 11–18, 2019.

Ethical Considerations

These surveys were deemed exempt from Institutional Review Board (IRB) review by the Advarra IRB (Columbia, MD). Responses were anonymous.

Results

Treatment Experience Survey Response

The Treatment Experience survey was accessed by 666 men and women living in the United States via the MyCrohnsAndColitis.com website, of which 502 qualified and completed the survey. Of those completing the survey, 296 (59%) identified as having CD and 206 (41%) identified as having UC. Females comprised 77% ($n = 228$) of respondents with CD and 76% ($n = 157$) of respondents with UC. Most respondents were 50 years or older ($n = 192$ [65%] CD and $n = 150$ [73%] UC), and the greatest proportion of respondents indicated receiving their IBD diagnosis ≥ 11 years ago ($n = 159$ [59%] CD and $n = 84$ [41%] UC) ([Figure 1](#)). Approximately two-thirds of respondents self-reported their disease severity to be moderate to severe ($n = 237$ [80%] CD and $n = 150$ [73%] UC).

Treatment

The 3 most desired treatment goals for patients with CD were decreased abdominal pain (45%), to reduce diarrhea (39%), and to slow disease progression (36%) ([Figure 2A](#)). For patients with UC, the most desired goals were to reduce diarrhea (48%), improve symptoms quickly (34%), and to lessen fatigue (33%). Approximately 40% of respondents indicated that their symptoms were at least moderately disruptive on a daily basis ([Supplementary Figure 1](#)).

The majority of respondents with CD indicated taking or having taken a biologic (74%), followed by steroid drugs (eg, prednisone, budesonide; 68%), sulfasalazine or 5-aminosalicylate (5-ASA) drugs (57%), and immunomodulator drugs (thiopurine or methotrexate, 41%) ([Figure 2B](#)). Use of tofacitinib, a small molecule oral Janus kinase inhibitor (JAKi) approved as a second-line therapy (after anti-TNF) for moderate to severe UC, was reported among 7% of respondents with CD. In contrast, the majority of respondents with UC reported taking/having taken sulfasalazine or a 5-ASA (72%), followed by steroid drugs (67%). Less than half of respondents with UC reported being treated with a biologic (47%), while 24% reported use of immunomodulator drugs, and 9% reported taking tofacitinib.

Among all respondents that reported using/having used a biologic/JAKi, the most common therapies were vedolizumab (24% CD, 17% UC), adalimumab (8% CD, 20% UC), and infliximab (17% CD and UC), followed by ustekinumab (8% CD, 15% UC) ([Figure 2C](#)). Among respondents currently taking conventional therapies (corticosteroids, 5-ASAs, immunomodulators), 46% of those with UC and 22% of those with CD reported taking 5-ASAs, and 16% of respondents (both CD and UC) reported taking corticosteroids ([Figure 2D](#)). Use of thiopurines

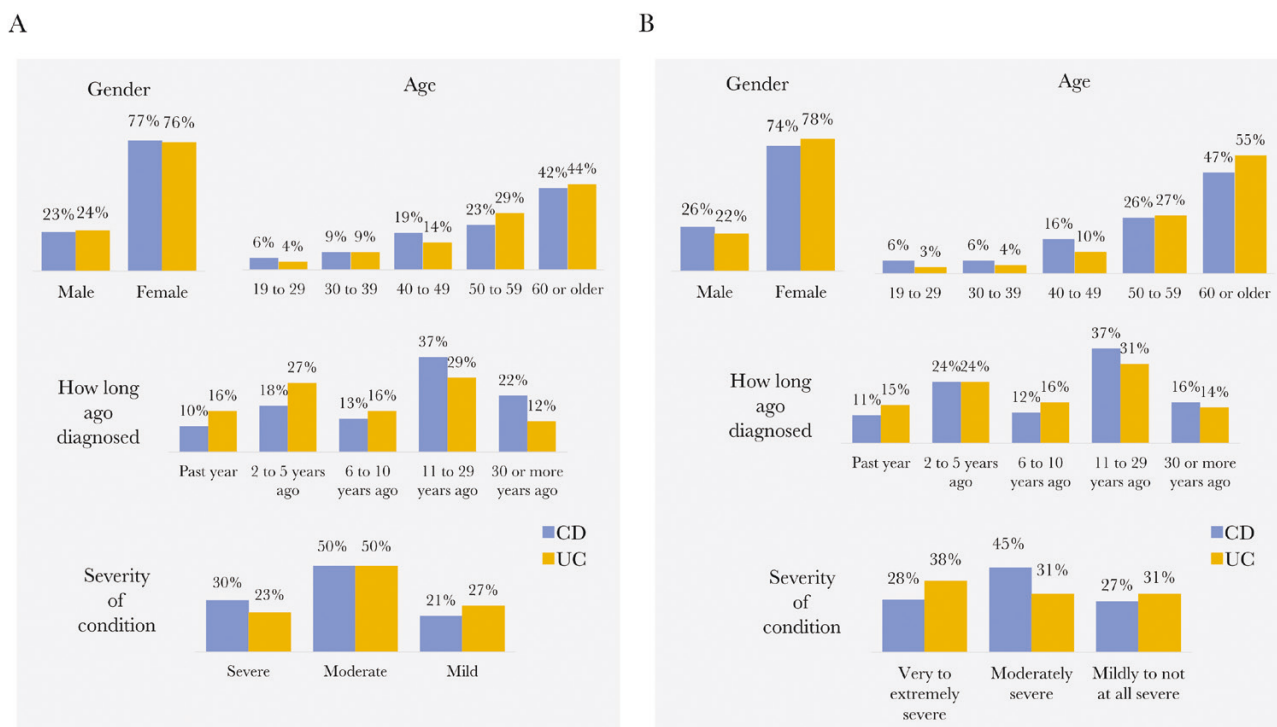


Figure 1. Demographics and disease characteristics. (A) Treatment Experience survey, sample size: CD, $N = 296$; UC, $N = 206$. (B) Quality of Life survey, sample size: CD, $N = 177$; UC, $N = 125$. Abbreviations: CD, Crohn's disease; UC, ulcerative colitis.

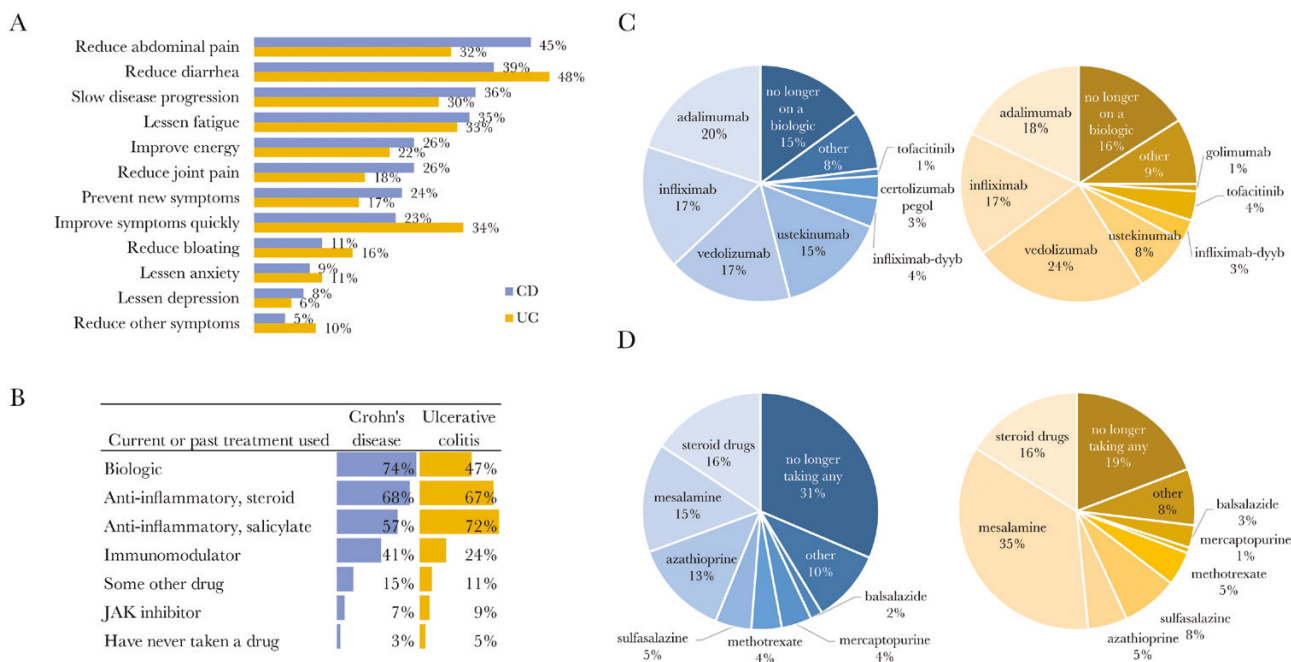


Figure 2. Past and present treatments and desired treatment effects. (A) When considering a drug's effectiveness in helping people living with Crohn's disease/ulcerative colitis, what is it that you would most want the medication to address? Please select up to your top 3 choices (sample size: CD, $N = 296$; UC, $N = 206$). (B) Which of the following are you either currently taking, or have taken in the past, to treat Crohn's disease/ulcerative colitis? (sample size: CD, $N = 296$; UC, $N = 206$). (C) Which one of the following medications are you currently taking to manage your Crohn's disease/ulcerative colitis? (Asked of respondents who have taken a biologic or oral IBD medicine) (sample size: CD, $N = 243$; UC, $N = 178$). (D) Which, if any, of the following anti-inflammatory or immunosuppressant medications are you currently taking to manage your Crohn's disease/ulcerative colitis? (Among those indicating they are taking/have taken.) (sample size: CD, $N = 223$; UC, $N = 103$). Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

(azathioprine, mercaptopurine) was reported by 17% of respondents with CD and 7% respondents with UC, while use of methotrexate was reported by 4% of respondents with CD and 5% respondents with UC. A numerically

greater proportion of respondents with CD (31%) reported no longer being on conventional therapy than respondents with UC (19%). The primary reason for discontinuing conventional therapy for both CD and UC respondents was due

to a switch to a biologic/JAKi (40% CD, 48% UC), followed by symptom severity, lack of efficacy, side effects, and safety concerns (Figure 3A). This decision to switch to was most often based upon the recommendation of the HCP (77% CD, 76% UC), followed by insurance coverage, convenience of home administration, effectiveness, and the ability to improve symptoms (Figure 3B).

About half of respondents currently taking a biologic/JAKi reported it to be very to extremely effective (46% CD, 60% UC) (Figure 4A), and a large majority felt that their symptoms improved (got better or much better [72% CD, 86% UC]) in response to a biologic (Figure 4B). A numerically lower proportion of respondents taking 5-ASAs or immunomodulators reported their treatment to be very or extremely effective (32% CD, 41% UC, and 37% CD, 48% UC, respectively), despite a numerically greater proportion

of respondents reporting symptom improvement (“gotten somewhat better” or “gotten much better”) (5-ASAs: 70% CD, 72% UC; immunomodulators: 69% CD, 62% UC). About half of respondents with CD or UC indicated that biologic/JAKi therapy reduced symptom severity, and over one-third indicated that it decreased their abdominal pain. Additionally, greater than one-third of biologic/JAKi users indicated halting of disease progression (Figure 4C). A numerically greater proportion of respondents with UC than with CD indicated that biologic/JAKi therapy reduced fecal urgency (28% CD vs 56% UC) and indicated that their flare symptoms had not returned (10% CD vs 30% UC).

HCP and Patient Satisfaction

The majority of respondents indicated that their main HCP was a gastroenterologist (85% CD, 86% UC), (Figure 5A)

A.

Reasons stopped taking any anti-inflammatory/immunosuppressants	Crohn's disease	Ulcerative colitis
Doctor wants me on a biologic	40%	48%
Symptoms were too severe	29%	23%
Stopped working	27%	16%
Symptoms never improved	27%	27%
Intolerable side effects	24%	14%
No benefit	21%	14%
Safety concerns	12%	11%

B.

Most important factors in choosing current biologic/oral IBD medication	Crohn's disease	Ulcerative colitis
Recommended by doctor	77%	76%
Covered by insurance	42%	33%
Taken at home	32%	24%
Improves symptoms quickly	28%	25%
Highly effective	25%	34%
Easy to take	23%	22%
Recommended by patients	20%	14%
On the market for awhile	15%	17%
Fits my lifestyle	15%	15%
Good clinical trials	14%	21%

Figure 3. Reasons for initiating and choosing a biologic/oral IBD medication. (A) What are the main reasons you stopped taking any anti-inflammatory/immunosuppressant medications? (sample size: CD, $N = 92$; UC, $N = 44$). (B) When you made the decision to go on your current biologic or oral IBD medication, which of the following factors were most important to you in your decision? (sample size: CD, $N = 189$; UC, $N = 87$). Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

A

		Medication Effectiveness				
Patient	Current medication	Not at all	Not very	Somewhat	Very	Extremely
Crohn's disease	Biologic/JAKi	4%	10%	40%	31%	15%
	Anti-Inflammatory	12%	53%	29%	6%	
	Immunomodulator	11%	52%	31%	6%	
Ulcerative colitis	Biologic/JAKi	10%	28%	36%	24%	
	Anti-Inflammatory	11%	45%	23%	18%	
	Immunomodulator	24%	29%	31%	17%	

B

		Change in Symptoms				
Patient	Current medication	Gotten much worse	Gotten somewhat worse	Stayed the same	Gotten somewhat better	Gotten much better
Crohn's disease	Biologic/JAKi	7%	20%	37%	35%	
	Anti-Inflammatory	5%	24%	46%	24%	
	Immunomodulator	5%	26%	47%	22%	
Ulcerative colitis	Biologic/JAKi	3%	10%	26%	60%	
	Anti-Inflammatory	5%	23%	36%	36%	
	Immunomodulator	3%	10%	24%	24%	38%

C

Benefits of Current IBD Medication

Lessened severity of symptoms	50%	59%
Lessened urgent need to use the restroom	28%	57%
Stopped progression	39%	46%
Stopped symptoms from returning	10%	30%
Relieved symptoms immediately	15%	20%
Decreased joint pain	15%	14%
Improved energy	13%	7%
Decreased abdominal pain	37%	38%

Figure 4. Medication effectiveness and symptom improvement. (A) How effective is your current medication? (sample size: CD, $N = 189$; UC, $N = 87$). (B) To what extent has your current medication improved your symptoms? (sample size: CD, $N = 189$; UC, $N = 87$). (C) Which of the following benefits, if any, have you gotten from your current biologic / oral IBD medication? (CD, $N = 189$; UC, $N = 87$).

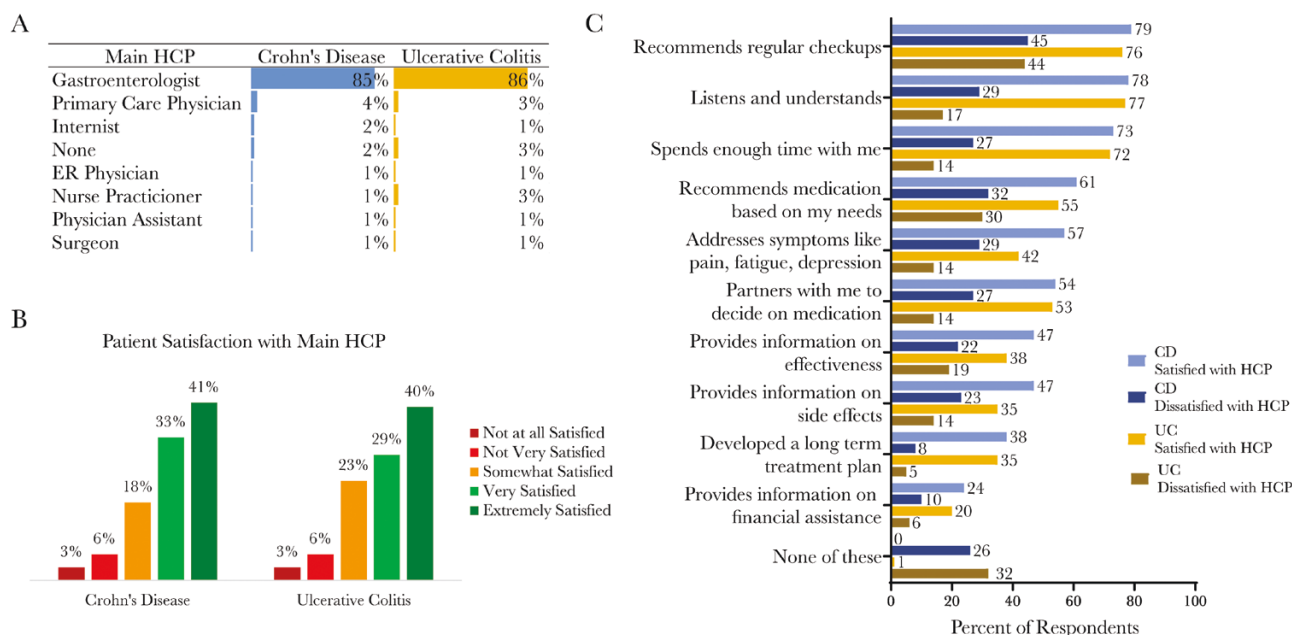


Figure 5. Determinants of satisfaction with HCP. (A) Which one of the following primarily treats your Crohn's disease/ulcerative colitis? (sample size: CD, $N = 291$; UC, $N = 200$). (B) How satisfied are you with the doctor who primarily treats your Crohn's disease/ulcerative colitis? (Among those who see an HCP) (sample size: CD, $N = 291$; UC, $N = 200$). (C) Which of the following reflect the discussions you have with the doctor or specialist who primarily treats your Crohn's disease/ulcerative colitis condition? (Among those who see an HCP) (sample size: CD, $N = 291$; UC, $N = 200$). Abbreviations: CD, Crohn's disease; HCP, health care professional; UC, ulcerative colitis.

and most respondents reported being very to extremely satisfied with their main HCP (74% CD, 69% UC) (Figure 5B). To better understand the basis of treatment satisfaction, respondents were asked to select positive descriptors reflecting discussions with their HCP. The most frequently cited descriptors were “recommends regular check-ups,” “listens and understands,” and “spends enough time with me.” A numerically greater proportion of respondents satisfied with their main HCP indicated that positive descriptors were reflective of patient/HCP discussions than did those that were dissatisfied (eg, “recommends regular check-ups” [satisfied: 79% CD, 76% UC; dissatisfied: 45% CD, 44% UC], “listens and understands” [satisfied: 78% CD, 77% UC; dissatisfied: 39% CD, 17% UC], and “spends enough time with me” [satisfied: 73% CD, 72% UC; dissatisfied: 27% CD, 14% UC]; Figure 5C).

Quality of Life Survey Response

This survey was accessed by 396 adult men and women living in the United States via the MyCrohnsAndColitis.com website, of which 302 people qualified and completed the survey. Of those completing the survey, 177 (59%) identified as having CD and 125 (41%) identified as having UC. Females made up 74% of respondents with CD and 78% of respondents with UC (Figure 1). Most respondents were 60 years or older. For both IBD populations, the greatest proportion of respondents were diagnosed 11–29 years ago (37% CD, 31% UC). Greater than two-thirds of respondents indicated their IBD symptoms to be moderately to extremely severe (73% CD, 69% UC).

Most Frequent and Problematic Symptoms

Over half of respondents reported that their IBD had a moderate impact on daily life (54% CD, 57% UC), while about 1 quarter reported IBD had a severe impact on daily life

(26% CD, 20% UC) (Figure 6A). Two-thirds of respondents reported urgency to go to the bathroom (66% CD, 65% UC), and around 10% of respondents reported the urgency to be uncontrollable (10% CD, 13% UC) (Figure 6B). Approximately one-third of respondents reported having 4–6 bowel movements per day (35% CD, 27% UC), and 14% of respondents with CD and 17% of respondents with UC reported having 7 or more bowel movements per day (Figure 6C).

On a scale from 0 to 10, with 0 being no pain and 10 being the worst imaginable pain, 43% of respondents with CD and 34% of respondents with UC reported their abdominal pain to be 7 or greater (Figure 6D), with worsening abdominal pain episodes occurring daily (42% CD, 46% UC) to a few times a week (24% CD, 18% UC) (Figure 6E). Greater than one-third of respondents experienced worsening of their IBD symptoms at least a few times a month (36% both CD and UC, Figure 6F).

Impact of Disease on QoL

Respondents were asked to indicate the degree to which they agreed/disagreed that IBD negatively affected their daily life, including social and family life, work and education, and other routine aspects. In general, the range of responses from patients with CD was similar to those with UC, with 50% or more respondents agreeing or strongly agreeing that symptoms impact most aspects of daily life (Supplementary Figure 2). With respect to social and family life, the most frequently cited impact of symptoms was related to time spent outside of the home (eg, limiting social activities [agree or strongly agree, 77% CD, 71% UC], traveled less [agree or strongly agree, 69% CD, 66% UC], and limited time outside of the home [strongly agree, 66% CD, 68% UC], Figure 7). A lower proportion of respondents

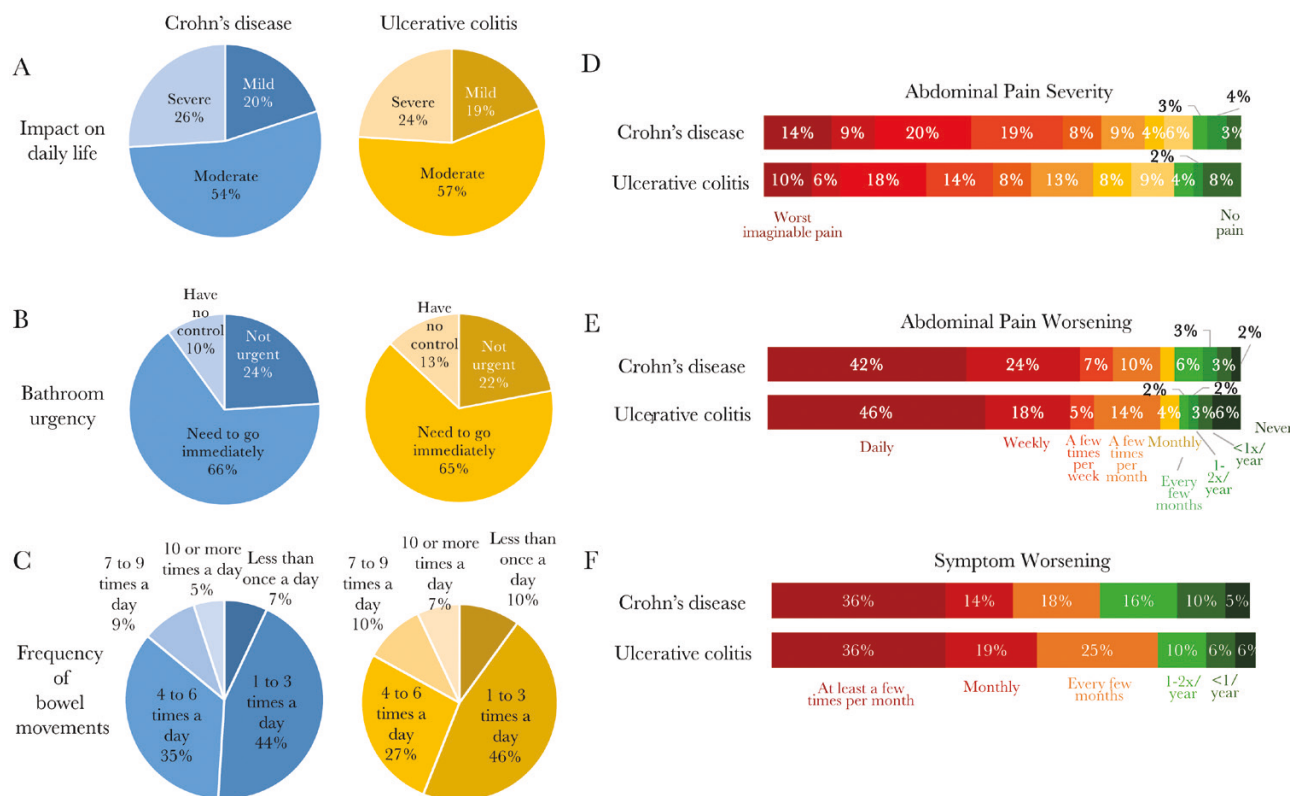


Figure 6. Impact of IBD on daily life. (A) How would you describe the impact of Crohn's/UC on your daily life? (B) Typically, how urgently do you have to go to the bathroom? (C) On average, how frequently do you have a bowel movement? (D) Please rate how severe your Crohn's/UC-related abdominal pain has been at its worst in the last 12 months (0 = no pain; 10 = worst imaginable pain). (E) How often do you typically experience a sudden worsening or increase in Crohn's disease/ulcerative colitis-related symptoms after a period of relatively mild symptoms? (F) How severe have your Crohn's/UC-related symptoms been in the past 12 months? All sample sizes: CD, $N = 177$; UC, $N = 125$. Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

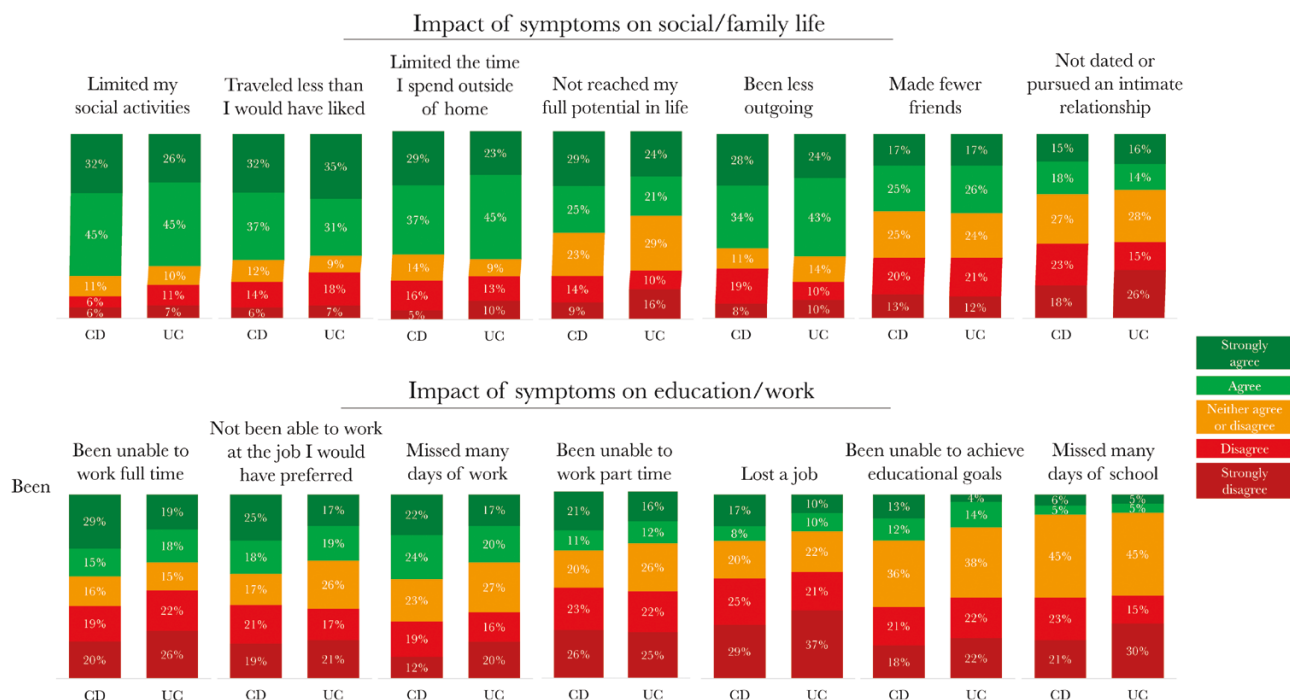


Figure 7. Impact of symptoms on social life, family life, education, and work. Please indicate how much you agree or disagree with the following statements about the impact Crohn's disease/ulcerative colitis has had on your life up to now. "Because of my Crohn's disease/ulcerative colitis, I have ..." All sample sizes: CD, $N = 177$; UC, $N = 125$. Abbreviations: CD, Crohn's disease; UC, ulcerative colitis.

indicated that their symptoms negatively impacted interpersonal relationships (eg, made fewer friends [agree or strongly agree, 42% CD, 43% UC]; did not date or pursue an intimate relationship [agree or strongly agree, 33% CD, 30% UC]).

A negative impact of symptoms on work was reported by less than half of respondents (eg, missed many days of work [agree or strongly agree, 46% CD, 37% UC], unable to work full time [agree or strongly agree, 44% CD, 37% UC] or part time [agree or strongly agree, 32% CD, 28% UC], unable to work at preferred job [agree or strongly agree, 43% CD, 36% UC], and lost a job [agree or strongly agree, 25% CD, 20% UC]). A quarter or less of respondents indicated that IBD symptoms impacted their education (eg, achieving educational goals [agree or strongly agree, 25% CD, 18% UC] or missed many days of school [agree or strongly agree, 11% CD, 10% UC]).

Anxiety, depression, and/or embarrassment experienced as a result of IBD was reported by 70% or more of respondents, and about half reported experiencing insecurity and low self-esteem (Figure 8). Less than 1 quarter of respondents reported experiencing positive emotions, such as determination, hopefulness, and strength resulting from their IBD.

Discussion

The long-term goal of IBD treatment is to prevent disease progression and associated complications to prevent long-term disability and preserve quality of life. The current treat-to-target approach to IBD therapy includes both endoscopic healing and symptom control. Recent clinical management guidelines position biologics as first-line therapies to induce and maintain remission in moderate to severe IBD, which has led to the increased use of biologics in this population.⁹ Our Treatment Experience survey found that biologic/

JAKi therapies were reported by the highest proportion of respondents to (1) be very to extremely effective and (2) provide better or much better symptom improvement compared to conventional IBD therapies. Interestingly, however, despite most respondents also reporting symptom improvement with 5-ASAs or immunomodulators, a numerically lower proportion of respondents reported them to be very or extremely effective relative to biologics. While this finding was not explored in depth, it may be attributable to conventional therapies in some patients leading more often to partial, rather than complete, symptom improvement or to the expectation that conventional therapies are less effective than biologics. Another notable finding included the numerically lower proportion of respondents with UC (47%) that indicated having taken/currently taking a biologic versus respondents with CD (74%), despite the fact that a numerically greater proportion of respondents with UC (60%) reported their biologic to be very to extremely effective than respondents with CD (35%). In fact, respondents with UC reported symptom relief, decreased symptom severity, decreased urgency to use the restroom, and prevention of symptom recurrence on biologics/JAKi in numerically greater proportions than did users with CD. These data may suggest that, despite evolving management strategies in moderate to severe UC, biologics/JAKi therapies remain underutilized in this population, perhaps due to a perception by HCPs that UC is less aggressive or progressive than CD and/or an adherence to the traditional step-up approach to treatment, reserving biologic/JAKi therapy for the most severe UC disease.^{10–16} Further exploration to better understand this finding is warranted. The prevalent use of 5-ASA agents reported by respondents with CD also bears mentioning, with more than half reporting taking or having taken sulfasalazine or a 5-ASA. This was a surprising finding given the demonstrated lack of benefit of this class of drugs for inducing or maintaining remission in CD.^{17–19} While sulfasalazine can be effective to improve symptoms in mild to moderate CD limited to the colon, it has not been shown to be more effective than placebo in achieving mucosal healing.^{20–22} Therefore, although the use of 5-ASA agents in the CD population is not justified by clinical evidence, these results suggest their use persists in real-life treatment of CD.

Perhaps one of the most important findings from the Treatment Experience survey was the strong influence that the quantity and quality of interaction and time spent between the patient and physician had in determining satisfaction with care. “Recommends regular check-ups,” “listens and understands,” and “spends enough time with me” were the top positive descriptors of HCP/patient discussions that differentiated satisfaction versus dissatisfaction with care. This held true for both the majority (≥85%) of respondents who indicated their HCP to be a gastroenterologist, as well as for the minority of respondents who indicated that their IBD was treated by non-GI HCP. Respondents to this survey, overall, felt cared for and were satisfied with their IBD care. These survey findings highlight the importance patients place on having regular follow-ups and on having an HCP who actively listens and provides adequate face to face time as a determinant of satisfaction with IBD care. Communication and personalization of care are key to improving outcomes and fostering resiliency, which better enables the successful navigation of adverse life experiences, such as coping with a chronic health condition.²³

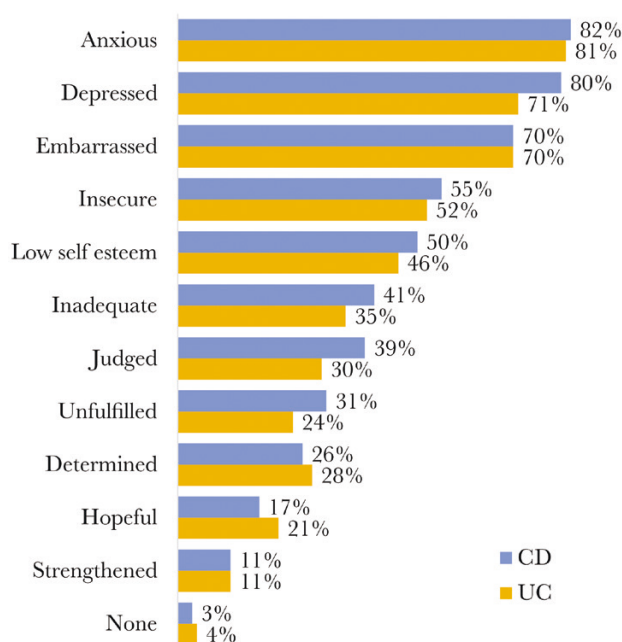


Figure 8. Emotional impact of IBD. Which, if any, of these emotions have you experienced as a result of Crohn's disease/ulcerative colitis? Sample size: CD, N = 177; UC, N = 125. Abbreviations: CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

The Quality of Life survey revealed that the majority of respondents agreed or strongly agreed that IBD symptoms affected their overall quality of life. Despite receiving different therapies, a significant proportion of respondents reported their symptoms to be moderate to severe with frequent episodes of exacerbation, with nearly half reporting a bowel movement frequency of ≥ 4 times per day, and over 3 quarters reporting fecal urgency to be immediate to uncontrollable. These findings suggest that many respondents remain undertreated and do not achieve clinical remission despite regular follow-up with their HCP, or that other noninflammatory causes of their GI symptoms are left unexplored and unassessed. Not surprisingly, the resulting emotional manifestations of IBD symptoms were unequivocal, with the greatest proportion of respondents experiencing depression, anxiety, and embarrassment, as well as limitations in their social and work life. These findings highlight another unmet need in patients care, which is that persistently active GI symptoms affect every aspect of daily and emotional life and need to be assessed and treated in conjunction with medical care. Indeed, it has been established that physical and emotional symptoms of IBD often elicit or exacerbate each other (eg, stress leads to a flare, the flare causes additional stress) resulting in a vicious cycle culminating in a greater impact of each symptom on overall health.

While these surveys were designed to provide a comprehensive overview of the treatment experiences of people with IBD and the impact of IBD on quality of life, there are limitations that should be noted. The survey designs were intended to provide a greater understanding of the perceptions and experiences of the respondent, rather than a quantitative assessment of differences between groups or treatments. A number of questionnaires, such as the Inflammatory Bowel Disease Questionnaire (IBDQ), Symptoms and Impacts Questionnaire, Short-Form 36 questionnaire, Work Productivity Activity Impairment questionnaire, and scales, such as Functional Assessment Chronic Illness Therapy-Fatigue and Hospital Anxiety Depression, have been developed to assess patient reported outcomes and are commonly used in clinical trials; however, these instruments are typically used in a study population with active disease and relate to symptom severity. In contrast, the questionnaires described herein were developed based on the most common issues and challenges shared in organic conversations in one of the largest IBD social networks; in doing so, these questionnaires have the added value of being centered around what is important to people with IBD, bringing into focus their voice. In addition, the number of responses for questions was low in some instances, limiting the utility of the responses that were provided. Most respondents to these surveys were female, reflecting the gender makeup of patients belonging to the MyCrohnsAndColitisTeam network, and survey results may reflect potential gender bias in perception of disease and symptom severity and impact on quality of life. Also, because respondents sought support from the MyCrohnsAndColitisTeam network, survey responses may be reflective of a population with more problematic experiences with IBD, and/or may be reflective of a population with greater IBD-related literacy. Most respondents were diagnosed 1–3 decades ago, and their historical experiences with treatment may also bias survey findings. Finally, because these surveys were accessed at www.mycrohnsandcolitisteam.com, respondents likely did not include persons with limited

online acumen or access, such as those that are older and/or socioeconomically marginalized.

Taken together, these survey findings underscore the importance of the HCP/patient relationship in satisfaction with IBD care. These results also suggest that, for many, IBD remain undertreated, resulting in persistent and significant gastrointestinal symptoms that negatively affect physical and emotional health and decrease overall quality of life by impacting different sociopsychological and economic aspects of daily life. In order to devise a better and more comprehensive treatment strategies in IBD, we need to close the awareness gap between the patients and HCPs of the deeply negative and disruptive effect that uncontrolled IBD symptoms have on patients physical and emotional health. Closing this gap amidst a growing demand on specialist health services and prioritization of cost containment and time efficiency remains a significant challenge, requiring a new approach to meet the needs of the patient. A comprehensive approach requires the implementation of an integrated care model, enlisting the services of general practitioners, nurse educators, GI psychologists, and nutritionists. Clinical interaction formats can include multidisciplinary visits, one-on-one in-person or virtual clinical visits, as well as patient education and self-management sessions, with the aim of optimizing medical management and properly addressing the multifaceted impact of IBD.

Conclusion

To achieve disease control in IBD, it is crucial to select a therapy that is appropriate for the disease and for the severity of symptoms, and the therapeutic effect of the drug must then be periodically reassessed and the treatment plan adjusted accordingly until sustained remission is achieved. Additionally, IBD management must also take into consideration the wider impact of the disease on daily life. Addressing both the physical and emotional needs of the patient with the intent to improve overall quality of life is as critical to the treatment process as improving clinical and endoscopic disease parameters. Effective patient/HCP communication is essential to optimizing IBD outcomes and ensuring delivery of the best possible treatment. This requires an investment of effort and time, as well as the willingness of the HCP to make appropriate therapeutic plan changes during the course of these chronic and often progressive inflammatory illnesses.

Supplementary Data

Supplementary data is available at *Crohn's and Colitis* 360 online.

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Authors' Contributions

A.C. and L.K. contributed to study concept and design, analysis and interpretation of data, and critical revision of the

manuscript for important intellectual content. J.A.Z. contributed to study concept and design, analysis and interpretation of data, critical revision of the manuscript for important intellectual content, material support, and study supervision. B.S. contributed to study concept and design, data acquisition, analysis and interpretation of data, critical revision of the manuscript for important intellectual content, data analysis, and study supervision.

Conflicts of Interest

A. Charabaty: consulting fees from AbbVie, Takeda, Janssen, Pfizer, and BMS. Founder of @MondayNightIBD. L. Keefer: research grant from AbbVie; consultant for Eli Lilly, Takeda, Pfizer, and AbbVie. Co-founder Trellus Health. B. Schneider: research grant from AbbVie. J.A. Zambrano is an AbbVie employee and may own AbbVie stock and/or options.

Data Availability

All data referenced are available in tables and figures within the manuscript.

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