

Unmet Needs Inflammatory Bowel Disease Survey Results

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Inflammatory bowel disease (IBD) is a term that refers to several diseases that are characterized by inflammation in the digestive tract. The most common of these are Crohn's disease and ulcerative colitis, but IBD also includes diseases such as microscopic colitis (lymphocytic colitis and collagenous colitis), diversion colitis, ischemic colitis, and radiation enteritis. IBD can cause many life-altering symptoms, including, but not limited to, severe abdominal pain, frequent diarrhea (sometimes up to dozens of times per day), rectal bleeding, fever, nutritional deficiencies, and weight loss. Treatment is complex and highly personalized, with most people requiring lifelong adherence to medications as well as dietary and lifestyle modifications, and some requiring surgery.

Methods

The Gastrointestinal Society, along with the Canadian Society of Intestinal Research, hosted a survey on its English (www.badgut.org) and French (www.mauxdeventre.org) websites from September 27, 2019 to September 13, 2020 about the unmet need of IBD, particularly in regard to communication between patients and their physicians. This was a follow-up to a survey we conducted in 2018. However, our original survey was only for Canadians. For this survey, we opened it up to global input. The only qualifying factor was an IBD diagnosis.

Results

Demographics

There were a total of 655 respondents, although not all questions were mandatory. The bulk of respondents were from Canada (50%) or the United States (30%). The remaining respondents were from Belgium, the United Kingdom, Australia, France, India, Ireland, Norway, Finland, Germany, Italy, Sweden, Austria, China, Czech Republic, Djibouti, Dominican Republic, Libya, Netherlands, New Zealand, Poland, Romania, Saudi Arabia,

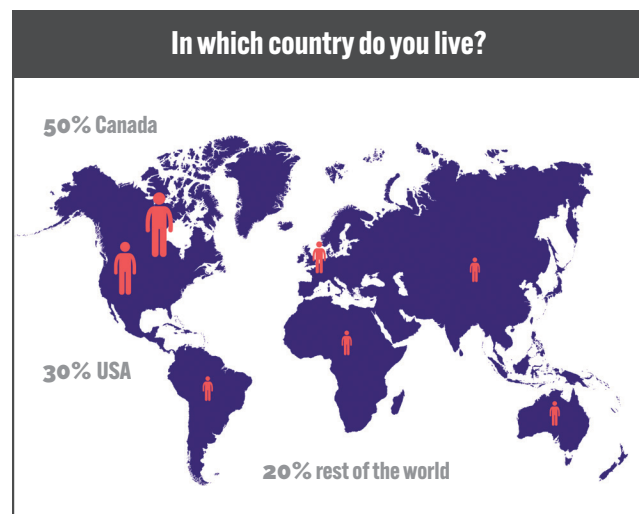
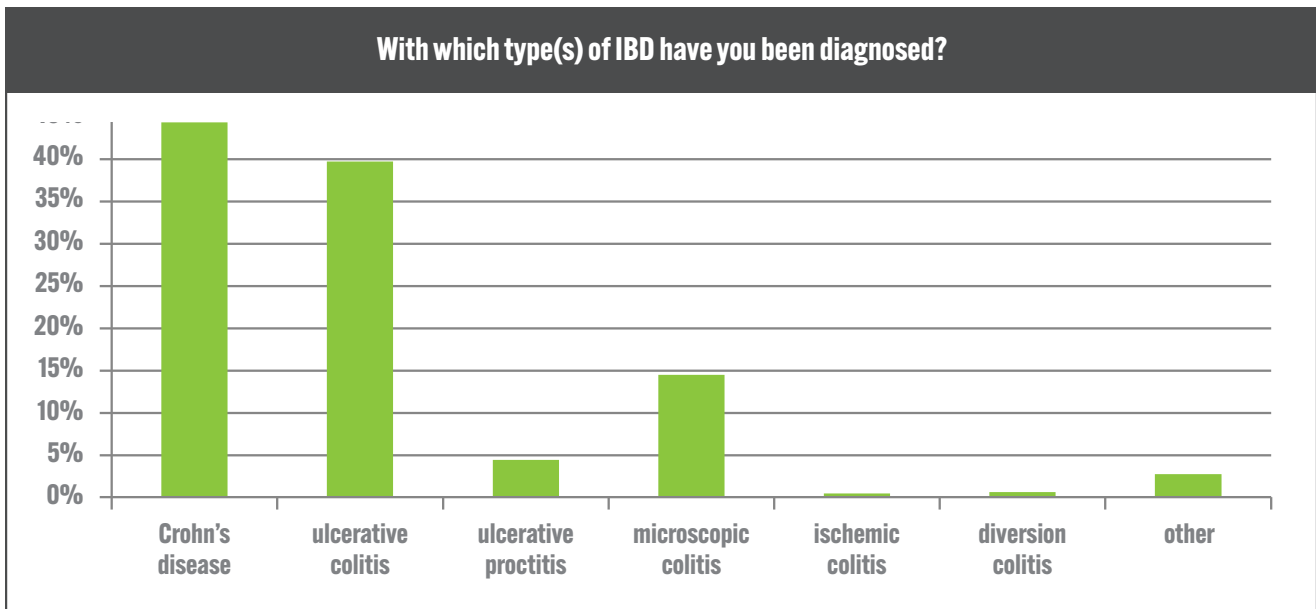


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South Africa, and United Arab Emirates.

Most respondents identified a diagnosis of Crohn's disease (46%) or ulcerative colitis (40%), but microscopic colitis was also quite common (15%), particularly in the US (35% of respondents from the US had microscopic colitis). Participants were across all age groups, and 74% were female. Most respondents received a diagnosis relatively soon after their symptoms developed, with 38% receiving a diagnosis in <1 year and 34% in 1-5 years, yet some participants waited a very long time, with 6% having symptoms for >20 years

before finally receiving an IBD diagnosis. There were respondents who were newly diagnosed, including 18% for <1 year and 27% for 1-5 years, along with respondents who have suffered with this disease for a long time, including 16% who had the condition for 5-10 years, 17% for 10-20 years, and 22% for >20 years.

Disease Severity

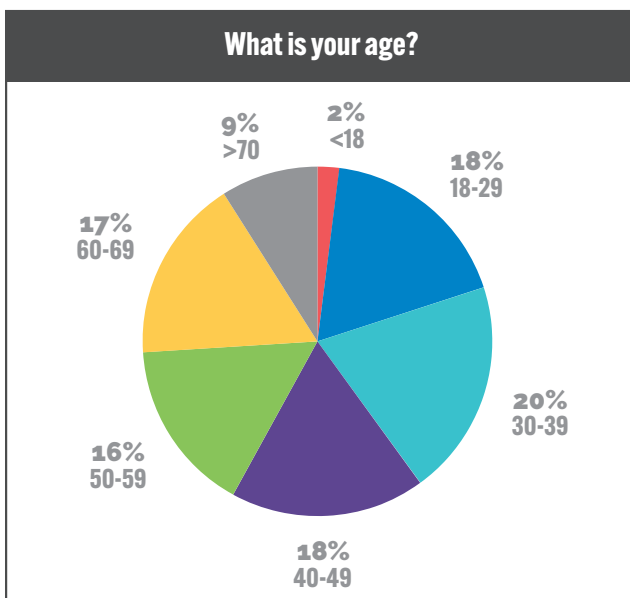
When it came to how severe their physician rated their disease, 9% had mild IBD, 37% had moderate IBD, 36% had severe IBD, and 18% were unsure. 65% of respondents agreed with their physician's assessment, but 6% did not and 29% were unsure.

When asked what symptoms were most important to them in deciding IBD severity:

- 27% listed quality of life
- 17% pointed to the daily number of bowel movements
- 16% thought that symptoms resulting from poor food absorption, such as weight loss, nutritional deficiencies, and delayed growth, were most important
- 11% reported that abdominal pain was most important
- 11% indicated rectal bleeding
- 6% said that manifestations outside the digestive tract were most important
- 3% thought that surgery was the most important factor

Symptoms

The most reported symptom was frequent (more than 3 per day) bowel movements; 32% experienced this almost



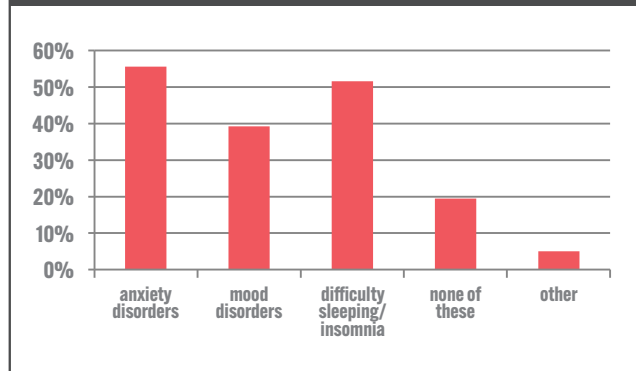
always, 26% frequently, and 20% occasionally. Abdominal pain was also very common; 30% occasionally, 29% frequently, and 15% almost always. Overall, when asked to rate how active their disease was over the past 6 months, 24% claimed that it was constantly active, 23% often active, 18% sometimes active, 11% occasionally active, and 10% rarely active. Interestingly, 14% were in remission and had no symptoms for the past 6 months. IBD also affects normal day-to-day life. Only 21% of respondents indicated that IBD does not affect their quality of life. 27% missed >20 days of work in the past year due to IBD, with a further 18% missing 6-20 days, and 23% missing 1-5 days.

Mental Health

We asked respondents to indicate if they currently experience, or have experienced in the past, any mental health conditions. Anxiety disorders were most common, affecting 56% of respondents, along with 52% having insomnia or difficulty sleeping, 39% having mood disorders, and 5% having other mental health conditions. Only 19% of respondents indicated that they did not have a mental health condition.

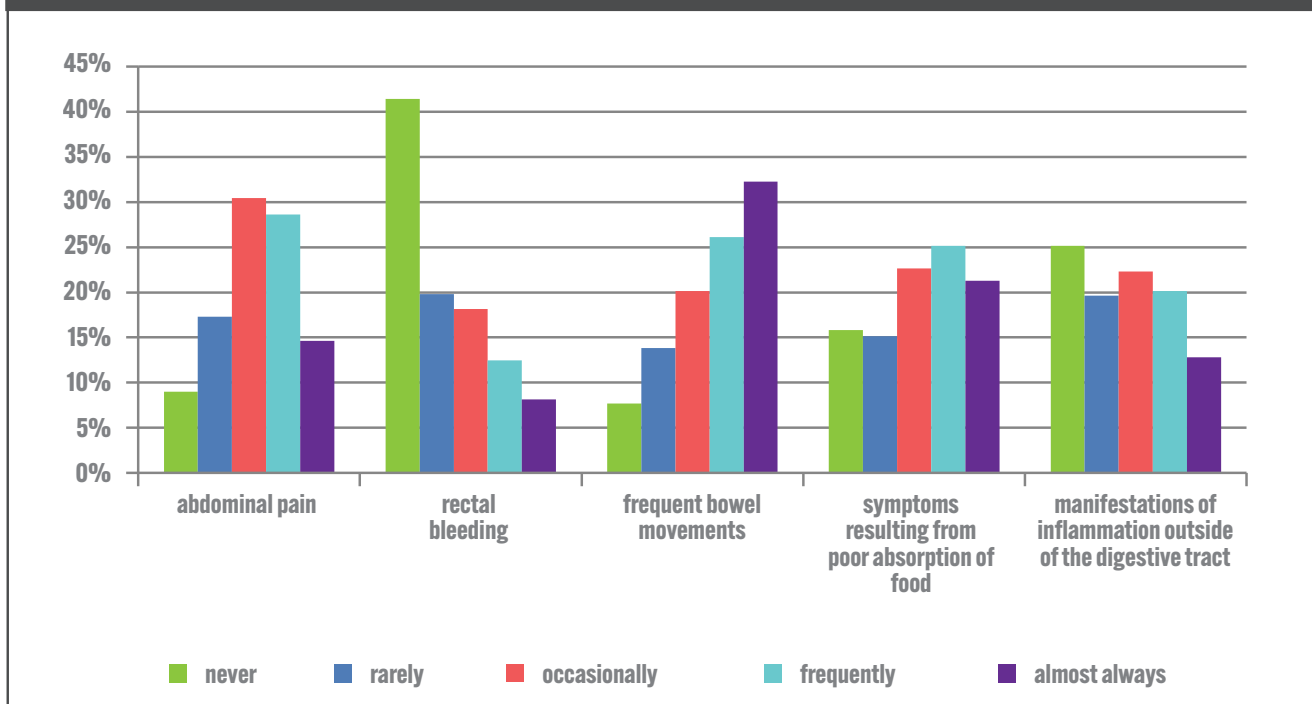
It is important for people who are struggling with chronic diseases, such as IBD, to make sure that they receive support

Do you experience any of the following mental health related conditions (currently or ever)?



for any comorbid mental health conditions, so we asked the respondents whether or not they discuss these with their healthcare team. Of those who have a mental health condition, 28% discuss it with their primary care physician, 12% with their gastroenterologist, and 18% with both, and 11% indicated that they speak with a psychologist, counsellor, or psychiatrist instead. However, some respondents were not receiving any healthcare support for their mental health conditions; 17% don't speak to a physician but would if they

To what degree have you experienced the following symptoms during the last year?



thought it would help, 5% do not speak with a healthcare expert and wouldn't want to, and 9% wouldn't know how to bring it up with their healthcare team.

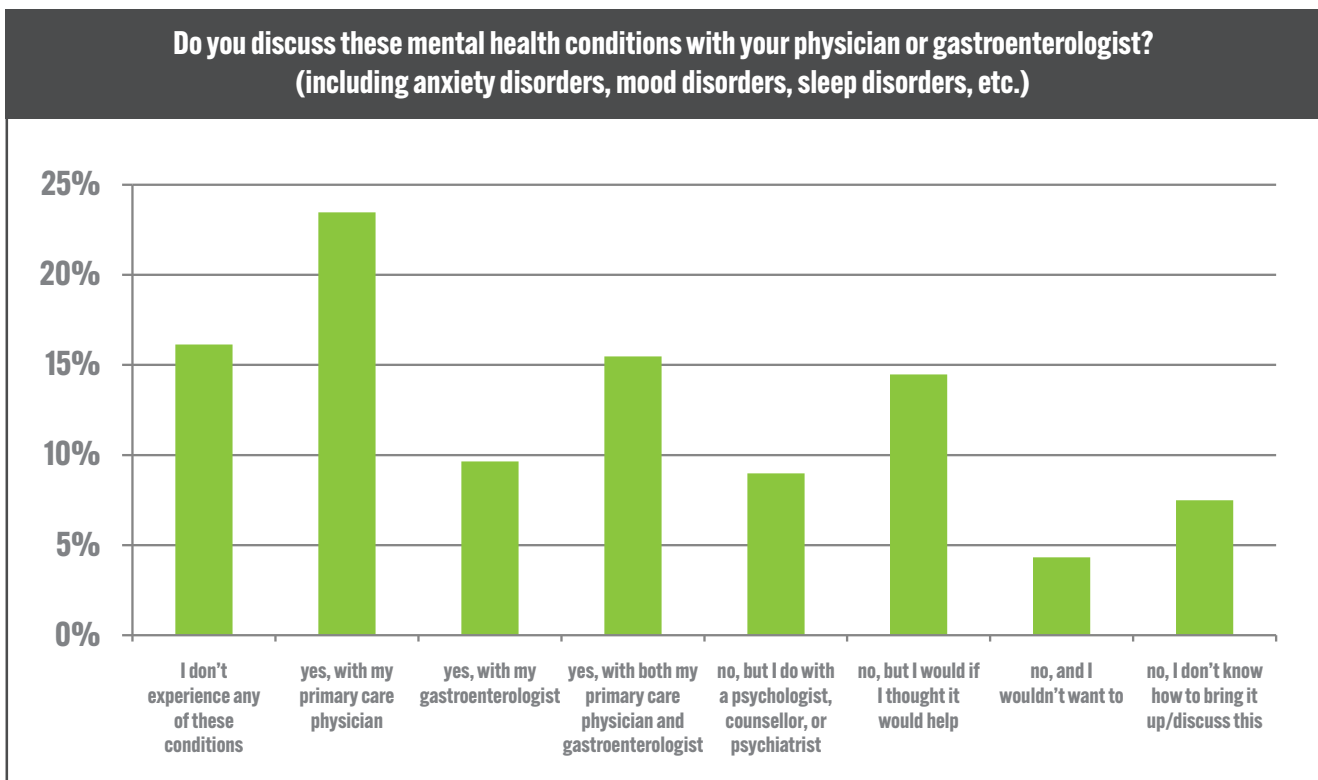
In an open-ended question asking respondents to explain what it feels like to have a flare, many further expressed how anxiety is a big part of their disease experience. Even in individuals who otherwise do not struggle with mental health conditions, the symptoms associated with bowel disease can increase worries, stress, and anxiety. For example, worrying about having accidents in public, fear over losing their jobs or being unable to leave home and maintain social relationships, the stress of wait times to see physicians, and the difficulty of not being able to eat. When feeling well, many individuals are anxious about when their next flare might occur, which can make it difficult to plan for the future. In the words of one respondent, "A flare is debilitating and a cause of anxiety for those with IBD – it can destroy our social [and] work lives and obliterate mental health by separating us from the normative acts: going out to lunch, taking a road trip, etc. Life is experienced differently for those with IBDs."

Healthcare

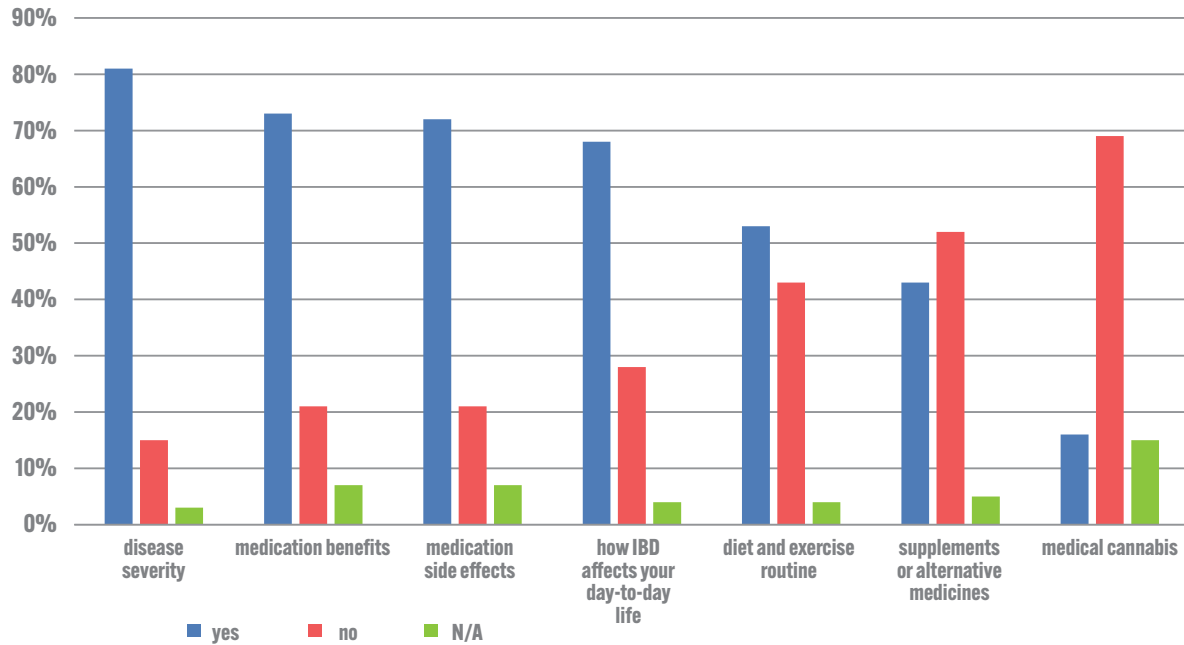
For individuals with chronic health conditions, having

a healthcare team they can count on is very important. However, many survey respondents indicated that they aren't getting the care they need. According to one respondent: "It's difficult to get in touch with my gastroenterologist in the past year. Left a message with a question – he didn't respond. Haven't seen him for 7 months. I have no family doctor as mine moved away. Don't feel taken care of." This is not uncommon. Respondents felt let down in many ways, including wait times that are far too long, lack of follow-up, and healthcare practitioners who are uninformed on IBD or are dismissive of patient symptoms and preferences. Many respondents also felt frustrated that their physician would put them on a medication and not offer any advice on diet, which is a crucial aspect of life for individuals affected by a disease that prevents them from being able to eat normally.

We also wanted to see what aspects of their disease patients choose to bring up in conversation with their physicians. Most respondents indicated that they discuss their disease severity (81%), medication benefits (73%), and side effects (72%), and how IBD affects their day-to-day life (68%). They also discuss diet and exercise (53%), supplements or alternative medicines (43%), and medical cannabis (16%).



Do you communicate with your physician or gastroenterologist about the following aspects of your IBD?



Treatment

Medications

The most used medications were corticosteroids and 5-ASA. However, respondents were more likely to have used these medications in the past than the present. Biologics were less commonly used, but with a much higher percentage of respondents taking them currently than previously. Alarming, 33% of respondents reported that the medications they were using did not adequately control their symptoms.

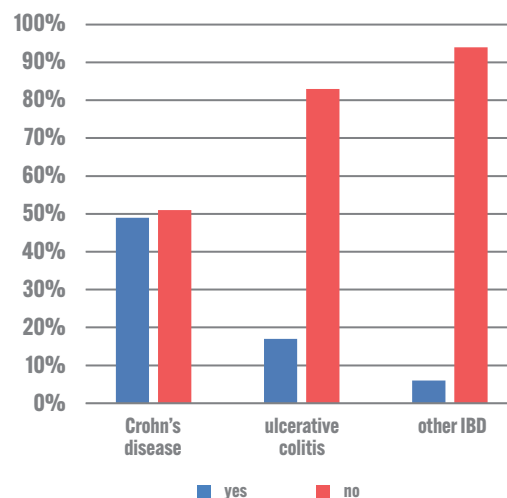
In open-ended comments, patients indicated concern over side effects from their medications. One respondent said, “My biggest concern is that I need to take budesonide, a corticosteroid that weakens my immune system – so I worry about my vulnerability to other diseases.” Another indicated that, “The side effects from the drugs have been socially devastating for me. The side effects from the drugs have been worse than the disease.” Other concerns include medication prices being too high and physicians not taking side effects seriously.

Biologics

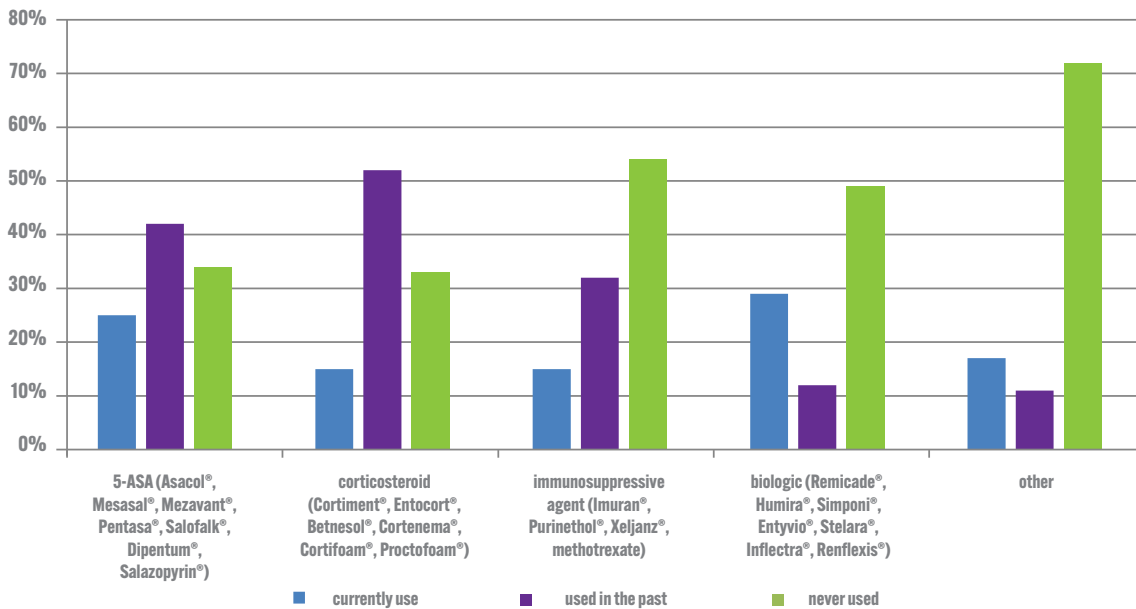
Biologics are powerful, effective medications that often control IBD when other medications do not. Unfortunately,

patients do not always respond well to biologics. We asked those who had previously taken a biologic why they discontinued treatment and found that for 42% it had stopped working, 29% developed a reaction, and 29%

Have you had surgery to treat your IBD?



Which medication(s) have you taken to treat your IBD?



gave another reason, such as that it didn't work well in the first place, their physician switched them to a different medication, or they had surgery. Some respondents also had to stop taking biologics due to the cost.

Many of these individuals had been taking biologics for a relatively brief time before discontinuing, with 22% having taken it for <3 months, 39% for 3-12 months, and 39% for >12 months.

When asked how important it is for their physician to have the sole authority in deciding which originator biologic or biosimilar they were prescribed, 60% indicated that it was very important, 17% somewhat important, 19% were unsure, and only 5% thought that it was not important.

Surgery

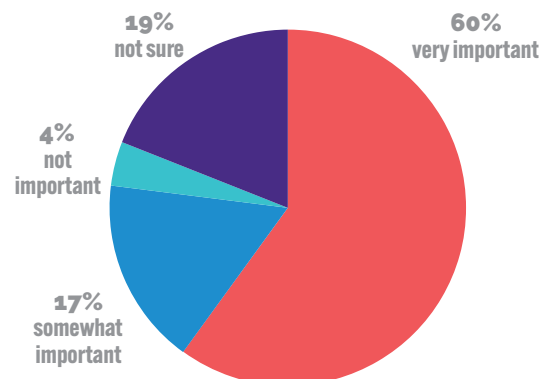
Surgery is another tool that physicians frequently use to help control IBD. In this survey, 28% of respondents indicated that they had some type of surgery to treat their IBD. Surgery was more common in those with Crohn's disease than other types of IBD; 49% of those with Crohn's disease had surgery compared to 17% of those with ulcerative colitis and 6% of those with other types of IBD.

Flares

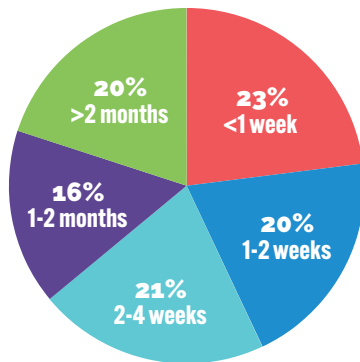
When treating IBD, the goal is to control inflammation and symptoms through various treatments that achieve

mucosal healing. This is known as remission. When someone experiences a sudden return of their symptoms, this is known as a flare. We asked respondents to explain what it felt like to experience a flare and what their biggest concerns were. Some of their experiences included

How important is it to you for your physician to have the sole authority to decide, together with you, the most suitable originator biologic or biosimilar medicine to treat your disease?



The last time you had an IBD flare, how long did it take from you first noticing your symptoms worsening until you saw a healthcare professional about it?



overwhelming fatigue and pain, anxiety and loss of freedom related to needing to use the toilet frequently, being unable to eat, and generally feeling like they can't live normally due to symptoms.

On top of these life-altering symptoms, many are unable to get healthcare quickly enough after the onset of a flare. In fact, 20% of respondents waited >2 months to see their doctor, 16% waited 1-2 months, and 21% waited 2-4 weeks. Some were able to see their physicians much sooner though, with 20% waiting 1-2 weeks and 23% seeing their doctor in <1 week. It is important to note that this survey was active during the first 7-8 months of the COVID-19 pandemic.

While 22% of respondents felt they were able to see their healthcare team soon enough, there were a variety of reasons for the delays that others experienced. Many respondents did not contact their healthcare team right away, including 36% who were hoping it would get better on its own, 19% who were unsure whether or not it was a flare at first, and 4% who were nervous about going to the doctor's office. For 23% of respondents, wait times were the problem; these individuals called their physician right away, but had to wait for an appointment.

It is especially important for patients to see their physician as soon as possible because it can take some time to get symptoms under control. While 11% of respondents had their symptoms under control <1 week after visiting their physician, for others it took much longer. 18% had their symptoms under control in 1-2 weeks, 14% in 2-4 weeks, 11% in 1-2 months, and 17% in >2 months. Of concern, 30% indicated that their symptoms were still not yet under control.

Conclusions

The results of this survey demonstrate a clear unmet need in timely and appropriate care as well as effective treatments for inflammatory bowel disease across the globe. There is no cure, nor is there a magic bullet or single solution for managing IBD. This is why it is so important for patients to have access to ongoing, timely medical care. However, respondents indicated that they are not receiving the care they require, and that their healthcare team is frequently dismissive of their complaints. Our global study also strengthens the need for mental health support, as anxiety is a common comorbidity for individuals suffering from the chronic effects of IBD. We need to do more to improve care at home and beyond our borders.

Crohn's disease and ulcerative colitis are chronic diseases and strong efforts must go toward finding a cure. With collaboration and meaningful engagement across stakeholders, including health charities, we can make significant steps toward increasing accessibility of effective therapies, timely care, and improve the quality of life for persons living with IBD.

About the GI Society

The Gastrointestinal Society and the Canadian Society of Intestinal Research represent inflammatory bowel disease (IBD) patients on a variety of healthcare fronts, including health policy. We have designed this survey to help us understand patient opinions and outlook regarding the unmet need in IBD. We will use this information anonymously and in aggregate to shape future programming and to inform community members, healthcare professionals, and health policy decision-makers.

Acknowledgement

We received unrestricted educational grants from AbbVie Canada and Janssen Canada to make this work possible and neither organization had input into this report.

The Gastrointestinal Society does not intend that this report replace the knowledge or diagnosis of your physician or healthcare team, and we advise seeking advice from a medical professional whenever a health problem arises.

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