

THE **Unmet** NEED OF **Inflammatory Bowel Disease** SURVEY RESULTS

Gastrointestinal Society

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Inflammatory bowel disease (IBD) is an umbrella term that primarily refers to Crohn's disease and ulcerative colitis. These diseases are characterized by inflammation in the digestive tract. In ulcerative colitis, this inflammation is limited to the inner mucosa of the colon. In Crohn's disease, inflammation can occur in any part of the digestive tract and through the entire thickness of the gut wall. IBD can cause

frequent diarrhea, abdominal pain, rectal bleeding, fever, malnutrition, and many other symptoms, and often leads to a decreased quality of life. Canada has among the highest prevalence of IBD in the world at 0.7% of the population. While new medications and treatments do become available, there are still some gaps in treatment options and disease knowledge, from the patient perspective.

Methods

The Gastrointestinal Society hosted a survey on its English (www.badgut.org) and French (www.mauxdeventre.org) websites from July 6 to September 4, 2018, asking patients about their views on the unmet need in IBD. Links to this survey were posted on social media and boosted via advertisements. To qualify, survey participants had to be living in Canada and have moderate to severe IBD or be the parent/guardian of a child with moderate to severe IBD. The survey contained questions pertaining to the treatment and management of IBD, including biologics and older medications, alternative treatments, and accessing health care.

Results

Demographics

Qualified respondents totalled 432 from all ten provinces, but no territories. Of these respondents, 56% had Crohn's disease, 42% had ulcerative colitis, and 7% had another type of IBD, including unspecified and microscopic IBD; some individuals listed more than one type of IBD. Many respondents had IBD for several years, with 46% having had IBD for at least 10 years. The majority of respondents were female (81%) and >40 years-of-age (69%).

Treatment Goals

We asked respondents what their ultimate goal in treating IBD is, aside from finding a cure. The most common responses were maintaining a good quality of life (37%) and achieving remission (32%). When it comes to flare-ups, 63% of respondents were concerned about losing the ability to function daily, 58% worried about symptom pain, 33% worried about the impact on work, 25% worried about the impact on their family, and 22% worried about potentially needing surgery. Respondents were interested in learning more about other aspects of IBD treatment, including diet (57%), medical cannabis (48%), and increasing support from their health care team (39%).

Health Care

Wait times to see health care professionals are a problem for many individuals in Canada, with 55% waiting more than a week to see their general practitioner. However, to see a gastroenterologist 27% reported waiting 3-12 months while 6% reported waiting longer than a year. 53% of respondents were only somewhat satisfied with their general practitioner's knowledge of IBD, but 23% were very satisfied. When asked which tools their gastroenterologist offers are most useful to them, 60% said tests and monitoring, 54% said medication selection and monitoring, 39% said

Fig 1. How Long Have You Had IBD?

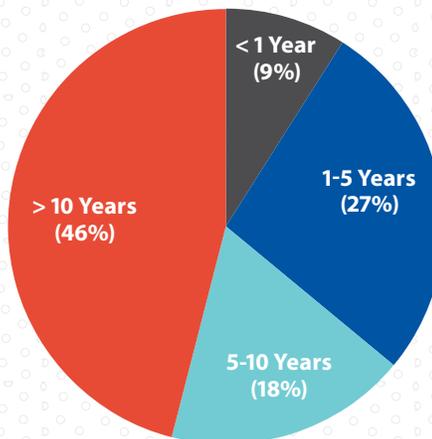


Fig 2. What is Your Ultimate Goal for Managing IBD, Aside from Finding a Cure?

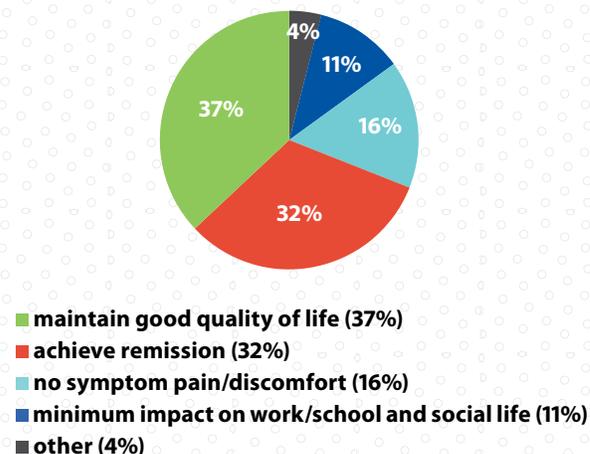


Fig 3. What do You Wish You Knew More About Regarding IBD?

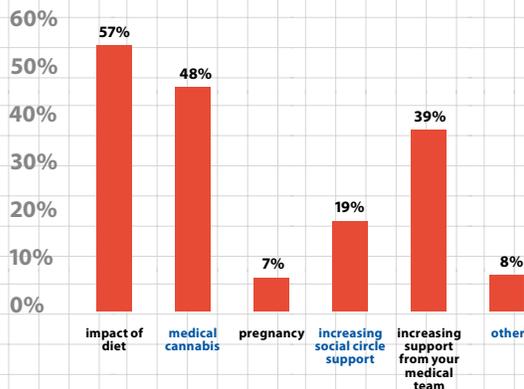


Fig 4. Wait Time to See GP

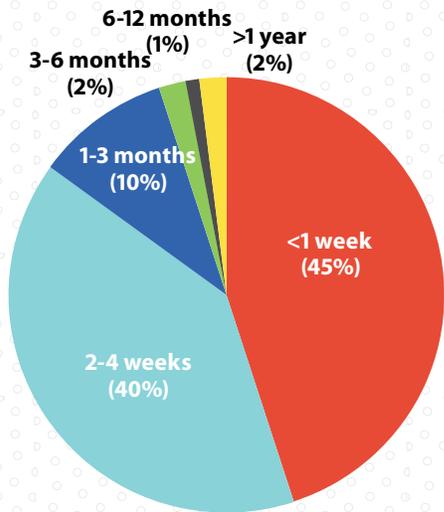


Fig 7. Do Current Medications Control Your Condition?

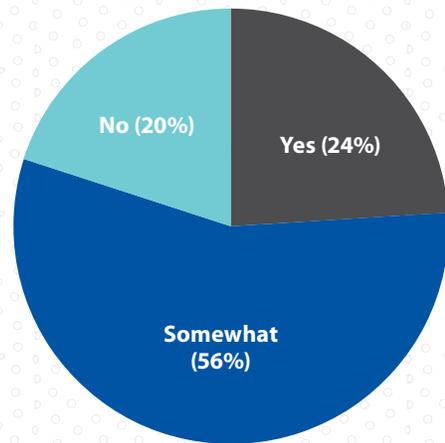


Fig 5. Wait Time to See a Gastroenterologist

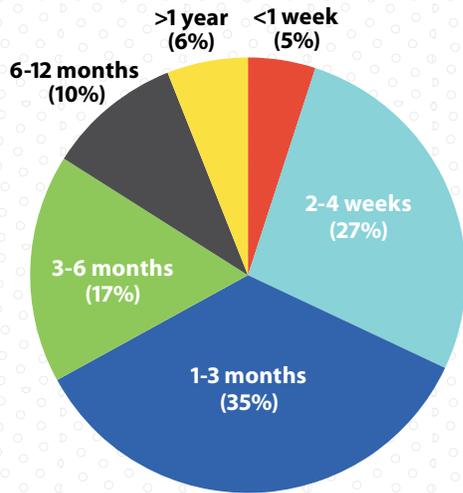


Fig 8. Concern About Non-Medical Switching from Innovator Biologic to Biosimilar

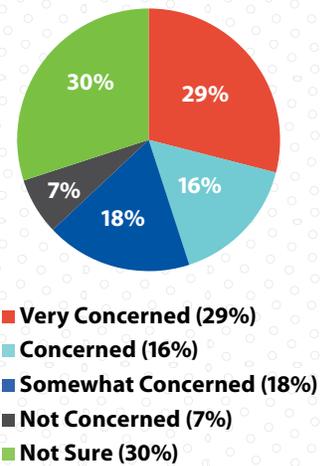


Fig 6. Out-of-Pocket Medication Costs

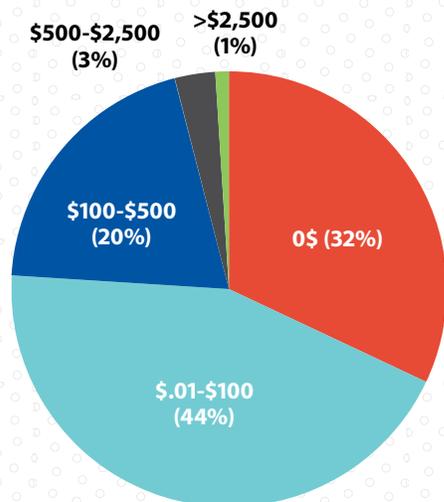
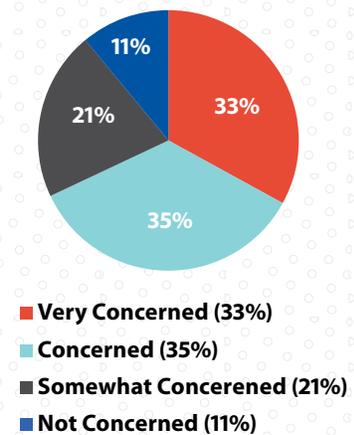


Fig 9. Concern Regarding IBD Having Fewer Biologic Choices than Other Diseases



information on treatment options, 34% said explanation of treatment goals, and 29% said discussions on quality of life.

Medications

56% of respondents claimed that medications currently available to treat IBD only somewhat control their condition and 24% said that they do control symptoms, whereas 20% said that they don't control symptoms at all. 38% of respondents had their medication covered under private insurance plans, 27% under public plans, 23% on mixed public and private plans, and 12% had no coverage. Many individuals had low monthly out-of-pocket medication costs (32% \$0, 44% \$0.01-100), but some had high costs, including 20% paying \$100-500, 3% paying \$500-2,500, and 1% paying >\$2,500 per month on medications. 43% of respondents were concerned about the risks of surgery to treat IBD.

Biologics and Biosimilars

The most commonly used biologics were Remicade® (29%) and Humira® (26%). Of the respondents who have taken biologics, 63% said the biggest improvement in their life from taking a biologic was symptom reduction. 23% of these individuals achieved remission from taking biologics. 63% of respondents were concerned, to some degree, with non-medical switching from an innovator biologic to a biosimilar. 89% of respondents were concerned, to some degree, about there being fewer biologic options available to treat IBD than there were for other inflammatory disease areas, such as rheumatoid arthritis.

70% of respondents consider patient support programs (PSPs) to be somewhat to very important. Approximately half of the respondents who were enrolled in a PSP said that the most beneficial aspects of PSPs are the helpful staff and assistance with filling out medication coverage paperwork.

Conclusions

Canadians with inflammatory bowel disease feel like their symptoms are not under control much of the time. They worry about the ramifications of flare-ups on their day-to-day lives and are concerned that IBD doesn't have as many biologic options as other diseases. They want more support from their health care team, and access to patient support programs. Many individuals want to learn more about how diet and medical cannabis can help them.

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