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## A national survey on the patterns of treatment of inflammatory bowel disease in Canada

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### Abstract

**Background:** There is a general lack of information on the care of inflammatory bowel disease (IBD) in a broad, geographically diverse, non-clinic population. The purposes of this study were (1) to compare a sample drawn from the membership of a national Crohn's and Colitis Foundation to published clinic-based and population-based IBD samples, (2) to describe current patterns of health care use, and (3) to determine if unexpected variations exist in how and by whom IBD is treated.

**Methods:** Mailed survey of 4453 members of the Crohn's and Colitis Foundation of Canada. The questionnaire, in members stated language of preference, included items on demographic and disease characteristics, general health behaviors and current and past IBD treatment. Each member received an initial and one reminder mailing.

**Results:** Questionnaires were returned by 1787, 913, and 128 people with Crohn's disease, ulcerative colitis and indeterminate colitis, respectively. At least one operation had been performed on 1159 Crohn's disease patients, with risk increasing with duration of disease. Regional variation in surgical rates in ulcerative colitis patients was identified. 6-Mercaptopurine/Azathioprine was used by 24% of patients with Crohn's disease and 12% of patients with ulcerative colitis (95% CI for the difference: 8.9% – 15%). In patients with Crohn's disease, use was not associated with gender, income or region of residence but was associated with age and markers of disease activity. Infliximab was used by 112 respondents (4%), the majority of whom had Crohn's disease. Variations in infliximab use based on region of residence and income were not seen. Sixty-eight percent of respondents indicated that they depended most on a gastroenterologist for their IBD care. There was significant regional variation in this. However, satisfaction with primary physician did not depend on physician type (for example, gastroenterologist versus general practitioner).

**Conclusion:** This study achieved the goal of obtaining a large, geographically diverse sample that is more representative of the general IBD population than a clinic sample would have been. We could find no evidence of significant regional variation in medical treatments due to gender, region of residence or income level. Differences were noted between different age groups, which deserves further attention.

## Background

In 2001, we conducted a national survey of the members of the Crohn's and Colitis Foundation of Canada. The primary objective of the survey was to examine the use of complementary and alternative medicine by people with inflammatory bowel disease (IBD) (Am J Gastro in press). The secondary objectives were (1) to compare responding members to published clinic-based and population-based IBD samples, (2) to describe current patterns of health care and behaviors of IBD patients and (3) to determine if unexpected variations exist in how and by whom IBD is treated in Canada.

There is a general lack of information on the care of IBD in a broad, geographically diverse, non-clinic-based population of patients. In the absence of defined population-based cohorts of IBD patients, investigators tend to rely on clinic samples when conducting surveys on a variety of issues. Often these published patient cohorts are derived from specialty centers. Clinic samples are clearly limited in that they would be expected to include the sickest patients and those who seek care through conventional medical providers. For our study of complementary and alternative medicine use, we believed that such a sample was inappropriate. In North America identifying a population-based IBD sample is difficult, if not impossible, in most jurisdictions. Therefore, we approached the Crohn's and Colitis Foundation of Canada to conduct a survey of their membership. We believed that this would be a reasonable approach to obtaining a sample, that although not truly population-based, would be large and geographically diverse and that would include patients that might be missed or underrepresented in clinic-based samples.

Medical and surgical care should depend predominantly on the health care needs of the patient. However, there are many examples where variations in health care cannot be explained by the health care needs of the population, but instead are associated with characteristics of the patients, such as age, gender, income level or place of residence.[1] Canada has a predominantly publicly-financed, privately-delivered health care system. The public health care insurance program provides access to universal, comprehensive coverage for medically necessary hospital, in-patient and outpatient physician services. However, this program does not cover the costs of outpatient medications. Outpatient medications are paid for out of pocket and by separate public and private insurance programs.

When examining the predictors of and variations in the treatment of IBD, we have focused on surgery, 6-Mercaptopurine/azathioprine (6 MP/Aza) and infliximab use in patients with Crohn's disease and the type of physician providing primary IBD care. It is unlikely that anyone would dispute that corticosteroids are appropriate and

effective drugs for treating patients with moderate-severe disease activity. In contrast, despite the fact that 6 MP/Aza is one of the oldest treatments for Crohn's disease and was included in the National Cooperative Crohn's Disease Study [2], concern about the potential for long-term side effects, prolonged time to therapeutic onset and true effectiveness may result in less consensus as to its role and, therefore, greater variation in its use for the treatment of Crohn's disease patients. The use of 6 MP/Aza in ulcerative colitis is less established than in Crohn's disease. Infliximab is a new therapeutic agent that was progressing through clinical trials and just entering clinical practice at the time of this survey.

## Methods

### Study Sample

All members of the Crohn's and Colitis Foundation of Canada (CCFC) were eligible to participate. The CCFC sent a letter to each of the 5146 members on its mailing list asking them to respond if they did not wish their name and address to be provided on a one-time basis to University affiliated researchers conducting a survey. Approximately 458 people declined to be contacted, of whom it is believed approximately 20% were physician or corporate members. The CCFC then provided to us a mailing list that excluded these individuals. Our mailing list included 4688 individuals (language preference: English 4074, French 614). A random sample of 235 people was selected for two pilot studies and the remaining 4453 were included in the main postal survey.

Membership in the CCFC requires a \$30 annual membership fee.[3] The primary purpose of the CCFC is to "Find the Cure" through fund-raising and supporting research. Local educational events are held, but the CCFC does not organize support groups as part of its mandate. Members are sent regular mailings by the CCFC about recent research and local educational events.

### Survey Methodology

The package mailed to the main study sample was in the member's stated language preference. It included a cover letter from the investigators, a self-addressed, stamped return envelope and adult and pediatric versions of the questionnaire. The cover letter indicated that the questionnaire was to be completed by the addressee (the CCFC member) unless that person did not have IBD. If that person did not have IBD but one of their children less than age 16 did, they were asked to complete the pediatric questionnaire. They were asked to indicate on the questionnaire that they did not have IBD if neither of these conditions were met and to return the questionnaire otherwise uncompleted. The first set of questionnaires was mailed in September and October 2001. A second

questionnaire was sent to non-respondents approximately 8 weeks later.

In a pilot study we contacted by telephone 159 CCFC members of whom 152 (96%) agreed to participate in an interview. Twenty-eight (18%) of the contacted members did not have inflammatory bowel disease. Of these, 22 (79%) had a family member with IBD, of which 3 indicated that the family member was under age 16 and residing in the same household. Based on these results, we would have expected that 16% of the membership selected for the mailed survey would not have been eligible and should have returned their questionnaires uncompleted and marked as "do not have IBD".

#### **Instrument design and testing**

A draft questionnaire was created based on our previous surveys and other published surveys of complementary medicine use.[4–8] Versions for adults (age 16 and above) and children were created. Only the results from the adult questionnaire are provided in this paper. The adult version included items on the nature of the member's IBD, past and current medical treatments, disease-related concerns, complementary medicine use, reasons for complementary medicine use or non-use, other general health attitudes and behaviors, and demographic characteristics. We have previously found substantial agreement between patients self-report and GI clinic chart reviews for medications such as azathioprine and oral corticosteroids.[9]

Current IBD disease activity was measured using a single item on self-assessed global activity (How would you rate the activity of your IBD today?) with a 7-point Likert scale that ranged from "totally inactive" to "terrible, worse than it has ever been". For this analysis activity was collapsed into four categories (Inactive = Inactive, Slight = Mild, Some/Moderate=Moderate and Quite/Extreme/Terrible=Severe).

A patient's preferred role in the treatment of their IBD was with a single 5-item question, that ranged from "I prefer to make the final selection about which treatment I will receive" to "I prefer to leave all decisions regarding my treatment to my doctor."

Prior to pilot testing, the draft questionnaire was reviewed by several IBD experts. Pilot testing of the adult English version of the questionnaire was conducted in two cities (Vancouver, Calgary) on a total sample of 74 patients recruited through gastroenterology clinics. One translator translated the original English questionnaire into French. The French translation was pilot tested in Montreal on 31 French-speaking patients recruited through an IBD clinic. The questions were then revised and checked a second time for meaning and grammar by a second translator.

#### **Analysis**

Each variable was initially described using descriptive statistics (means, standard deviations, proportions) and graphs. The strength of association between two variables was measured using odds ratios and 95% confidence intervals. Demonstrating statistical significance was based on 95% confidence intervals that did not cross unity or a P value  $\leq 0.05$ . P values were calculated by t tests or chi square tests as appropriate. Logistic regression was used to estimate confidence intervals and P values for factors that had more than two levels and to examine for potential confounding and interaction.

#### **Ethical Considerations**

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

#### **Results**

##### **Respondents**

Questionnaire packages were mailed to 4453 CCFC members. Packages were returned due to wrong addresses for 101 members. Questionnaires were returned by 3284 members (response rate 75.5%). We excluded 437 responses from the final analysis sample because the member did not have IBD (n = 310, 9% of returned questionnaires), the majority of the questionnaire was not completed (n = 24), member deceased (n = 8), residence out of Canada (n = 17) or type of IBD not given (n = 6). The demographic characteristics of the analysis sample are shown in Table 1.

##### **Disease Characteristics**

The number (%) of patients who classified themselves as having Crohn's disease, ulcerative colitis or indeterminate colitis/unclear disease type were 1787 (63%), 913 (32%) and 128 (5%), respectively. Because of the small number in the indeterminate colitis/unclear group, subsequent subgroup analyses based on disease type are performed only on those with Crohn's disease or ulcerative colitis. Disease characteristics of those with Crohn's disease and ulcerative colitis are shown in Table 2.

Disease activity was rated as inactive by 19% of CD patients and 27% of UC patients (P < 0.001). In those with CD, no statistically significant difference in disease activity was seen among men or women or among the different age groups. Among those with ulcerative colitis, inactive disease was much more likely to be reported among those who had previously undergone surgery than those who had not (55% vs. 22%, P < 0.001). Although we did not specifically ask patients what kind of surgery they had undergone, we presume that the procedure in the majority of patients with ulcerative colitis was total proctocolectomy with or without ileal pouch formation. After considering whether or not the UC patient had

**Table 1: Demographic characteristics of IBD sample**

Characteristic	
Age, mean (range)	47 years (16 – 88)
Females, n (%)	1729 (61%)
Region, n (%)	
Maritime Provinces	155 (6%)
Quebec	464 (16%)
Ontario	1307 (46%)
Prairies (Alberta, Saskatchewan, Manitoba)	636 (23%)
West Coast (British Columbia, Territories)	266 (9%)
Education, n (%)	
Less than high school diploma	268 (10%)
High school diploma	482 (17%)
Technical college or some university course	990 (35%)
University degree	1046 (38%)
Employment status, n (%)	
Employed	1814 (64%)
Student	148 (5%)
Homemaker	266 (9%)
Unable to be employed due to illness	220 (8%)
Retired	481 (17%)
Other unemployed†	62 (2%)
Combined family pre-tax income, n (%)	
<\$20 K	174 (6%)
21–40 K	444 (16%)
41–60 K	474 (17%)
61–80 K	423 (15%)
>80 K	759 (27%)
Did not answer	552 (19%)
Born in Canada, n (%)	2548 (91%)

†For employment status, other unemployed includes never employed and unemployed not due to IBD

undergone surgery, age and sex were not associated with the likelihood of having inactive disease.

### Surgical Therapy

At least one operation had been performed on 1159 (64.9%) patients with Crohn's disease and 142 (15.6%) patients with ulcerative colitis. For patients with Crohn's disease and ulcerative colitis, the probability of having undergone at least one surgery was associated with the number of years since their diagnosis (Table 3). A non-linear trend was seen in those with UC between the likelihood of having undergone surgery and age. Twelve percent of those in the 16 – 24 year age group had undergone surgery, compared with 17% in the two age groups 25 – 40 and 41 – 55. However, those over age 55 had a similar 12% surgery rate as those in the youngest age group. However, these differences were not statistically significant.

Overall, 16% of ulcerative colitis patients had undergone an operation for their disease. Although we did not specif-

ically ask patients what kind of surgery they had undergone, we presume that the majority of patients had undergone total proctocolectomy with or without ileal pouch formation. There was evidence that the probability of having had surgery varied with the geographic region that the patient lived ( $P = 0.001$ ). Table 4 shows factors associated with prior surgery in UC patients. Only duration of disease and geographic region were significant predictors of prior surgery.

### Medical Treatment

The medical treatments received by patients with Crohn's disease and ulcerative colitis over the preceding twelve months are shown in Table 5.

6 MP/Aza was used by 24% of patients with Crohn's disease and 12% of patients with ulcerative colitis (95% CI for the difference: 8.9–15%,  $p < 0.001$ ). Table 6 shows factors associated with 6 MP/Aza use in Crohn's disease patients. In those with CD, gender, income and region of residence were not associated with the use of 6 MP/Aza. However, their use was associated with age and markers of more active disease (use of either oral or intravenous steroids in the past 12 months, surgery within the past 2 years and number of hospitalizations in the past 5 years). The association between older age and less use of 6 MP/Aza persisted after adjustment for disease activity.

Because of the relatively small number of UC patients who had used 6 MP/Aza in the past 12 months, we did not attempt to examine multiple predictors of its use. However, in those patients who had not had previous surgery, we could find no evidence that 6 MP/Aza use varied by gender or region of residence. As with Crohn's disease, younger patients were more likely to report its use (e.g. 30% of those 16 – 24 and 10% of those over age 55,  $P = 0.011$ ).

Infliximab had been used by 112 (4.0%) respondents. The majority of patients who had received Infliximab were in the Crohn's disease group, but 7 (1.0%) with ulcerative colitis and 6 (4.7%) with indeterminate colitis also reported its use. Associations between the use of Infliximab and specific patient, disease and treatment characteristics are shown in Table 7. Significant differences in the proportion of patients who had received Infliximab were not seen across income levels or across the five geographic regions.

### General IBD Health Care

Sixty eight percent of respondents with Crohn's disease or ulcerative colitis indicated that they depended most on a gastroenterologist for their IBD. There was significant regional variation in this, in that 74% of patient in Ontario or Quebec depended most on a gastroenterolo-

**Table 2: Disease and treatment characteristics of respondents with Crohn's disease and Ulcerative colitis**

Characteristic	Crohn's disease	Ulcerative colitis	95% CI for difference (P value)
Disease duration, mean (± SD)	18.4 years (10.7)	14.8 years (9.8)	2.8 to 4.4 (<0.001)
Ever hospitalized, n (%)	1494 (83.6%)	464 (50.8%)	29.1 to 36.5% (<0.001)
Number of hospitalizations past 5 years, mean (± SD)	2.7 (3.0)	1.9 (1.9)	0.5 to 1.1 (<0.001)
Ever surgery, n (%)	1159 (64.9%)	142 (15.6%)	46.1 to 52.5% (<0.001)
Surgery within the past 2 years	255 (14.3%)	44 (4.8%)	7.3 to 11.6% (<0.001)
Disease Activity, n (%)			
Inactive	329 (18.4%)	241 (26.4%)	-11.4 to -0.6% (<0.001)
Mild	607 (34.0%)	299 (32.8%)	-2.5 to 5.0% (0.547)
Moderate	616 (34.5%)	268 (29.4%)	1.4 to 8.8% (0.007)
Severe	204 (11.4%)	82 (8.9%)	0.1 to 4.8% (0.055)

**Table 3: Percentage of patients with Crohn's disease and ulcerative colitis that reported having had at least one surgery by time since diagnosis**

Years since diagnosis	Crohn's disease n (%)	Ulcerative Colitis n (%)
0 – 2	6 (22%)	2 (8%)
3 – 5	76 (39%)	11 (9%)
6 – 10	170 (51%)	35 (17%)
11 – 20	398 (65%)	47 (14%)
21 – 30	350 (83%)	31 (19%)
>30	157 (84%)	16 (25%)

gist compared with 55–61% of patients in the rest of the country.

Seventy-two percent of respondents indicated they were "a lot" or "completely" satisfied with the care they received when they last saw the doctor they depended on most. There was no significant difference in degree of satisfaction between those who relied most on a gastroenterologist and those who did not.

Patients were asked what role they wished to play in the treatment of their IBD. The largest proportion (44%) preferred that they shared responsibility with their physician for treatment decisions. This was the case for all age groups except among patients 16–24 years, the largest proportion (42%) of this age group preferred to make their own final treatment decision after seriously considering their doctor's opinion. In contrast, patients in the older age groups relied more upon their physicians to make their treatment decisions for them. Of those over age 55, 33.0% indicated that they preferred their doctor to make treatment decisions compared with only 13% – 17% in the other age groups.

**Discussion**

In this paper, we have reported on one of the largest published surveys of patients with inflammatory bowel disease. The sample was drawn from the membership of the Crohn's and Colitis Foundation of Canada. The primary strengths of our sample are that it is (1) very large, (2) geographically diverse, (3) diverse in terms of patient and disease characteristics and (4) non-clinic based. However, it is not a true population-based sample, which would be most desirable for obtaining unbiased results. How representative our sample is of the general IBD population (freedom from bias) will be affected by who chooses to join the CCFC and who chose to complete the questionnaire. We would have expected from our pilot study that 16% of respondents would have indicated that they did not have IBD. However, only 9% of questionnaires were returned with this indicated. This suggests that those who did not have IBD were less likely to respond to the questionnaire than those with IBD.

In our study we did not validate the respondents' diagnosis of IBD. We did exclude anyone who did not classify themselves into one of our three categories of IBD (We also excluded anyone who wrote in another form of colitis, such as collagenous colitis). A study of Crohn's and

**Table 4: Associations between the previous surgery and patient characteristics for patients with ulcerative colitis**

Characteristics	% Reporting Surgery	Odds ratio†	95% CI†
Sex			
Male	15.2	Referent	
Female	15.8	1.0	0.7 – 1.5
Age			
16–24	11.8	Referent	
25–40	17.5	1.2	0.4 – 3.9
41–55	16.8	1.0	0.3 – 3.0
>55	15.0	0.6	0.2 – 1.9
Region			
Maritimes	8.3	Referent	
Quebec	11.3	1.5	0.5 – 4.6
Ontario	16.0	2.1	0.7 – 6.0
Prairies	24.4	3.5	1.2 – 10.4
West Coast	7.6	0.9	0.2 – 3.3

† Adjusted for duration of disease

Colitis Foundation of America members in North Carolina found that 98% of members who self-reported IBD were judged to have definite or probable disease based on clinical assessment of x-ray, endoscopy or pathology reports.[10] Examining the drug and health care experiences provides some further validation of our sample. Only 637 (23%) had not used at least one IBD drug therapy in the past 12 months (excluding antidiarrheals, antibiotics and narcotics). Of these, only 199 (7% of total sample) had not undergone at least one surgery for their IBD. Finally, 94 of the 199 (3% of total sample) had never been hospitalized because of their disease. Therefore, we are confident that our sample is not significantly contaminated by people who do not have IBD. We have also previously found that there was a high degree of agreement between patient self-classification as to disease type and that recorded in their medical charts.[9]

To better understand how our sample relates to both the larger IBD population and to clinic-based samples, we compared demographic and disease characteristics of this sample to two other published samples.

First, we have previously published on the CAM use of a gastroenterology-clinic based IBD sample.[4] In comparison to that sample, our current sample is slightly older (mean age 46 vs. 40 years), contains fewer females (61% vs. 68%) and is better educated (73% vs. 64% with education beyond high-school degree). However, as expected, the current sample also contains more people with less severe Crohn's disease as shown by lower rate of hospitalizations (83% vs. 92%) and surgery (65% vs. 79%) and, although measured in different ways in the two studies, probably less use of oral and iv corticosteroids. In con-

trast, the ulcerative colitis sample includes a larger proportion of patients who have undergone surgery (presumably proctocolectomy 16% vs. 6%).

The second comparison is the population-based sample from the University of Manitoba IBD Database.[11–13] Our current sample is also older than this population and is especially underrepresented by patients in the 20 – 29 year old age group. Our sample also has a larger proportion of females and a higher education level than the Manitoba sample, although employment levels appear roughly similar. The higher socioeconomic status of our sample could reflect that this group is more interested in membership and/or could also be the result of the very modest annual membership fee limiting access to those of lesser means. Finally, the Manitoba sample classified patients as Crohn's disease or ulcerative colitis only, with a ratio of 1.17 Crohn's disease patients to ulcerative colitis patients. In our sample, we had nearly twice the number of people identifying themselves as having Crohn's disease versus ulcerative colitis.

Therefore, there are important differences between our sample and two other IBD populations. First, as desired, our current sample does appear to include a broader range of patients, especially in terms of patients with less severe disease or UC patients who have previously undergone surgery, than our clinic-based sample. However, in contrast to a population-based sample, our current sample is older, contains a greater proportion of females and those with Crohn's disease, and is better educated. These differences probably are the result of self-selection into the CCFC membership rather than due to who chose to respond to our questionnaire. The proportion of non-respondents who had a female title (i.e. Mrs. Ms.) in the CCFC mailing list was similar to the proportion of females in our analysis sample.

Based on these comparisons, we believe that this sample achieved our goal of obtaining a large, geographically diverse sample, which although not necessarily fully representative of the general IBD population, is likely more so than more readily available clinic samples. Creating a national sample for a mailed survey using the methodology of the Manitoba IBD cohort clearly would have been a daunting, if not impossible, task. Biased prevalence estimates of parameters of interest could be derived from our sample if they were associated with sex, age or educational achievement. However, these limitations can be acknowledged and potentially minimized through stratified analysis or standardization.

One aspect of quality of medical care is access to appropriate treatments. Most previous studies of physician practice

**Table 5: Treatment characteristics of respondents with Crohn's disease and Ulcerative colitis.**

Treatments	CD n (%)	UC n (%)	95% CI for difference (P value)
PO 5ASA	956 (54%)	672 (74%)	-23.7 to -16.4 (<0.001)
Topical Steroids/5ASA	183 (10%)	391 (43%)	-36.1 to -29.1 (<0.001)
PO Steroids	623 (35%)	259 (28%)	2.8 to 10.2 (0.001)
6 MP/Azathioprine	424 (24%)	109 (12%)	8.9 to 14.7 (<0.001)
IV Steroids	90 (5%)	41 (5%)	-1.1 to 2.2 (0.571)
Infliximab	99 (6%)	7 (1%)	3.6 to 6.0 (<0.001)

PO: Per os 5ASA: 5-Aminosalicylates 6MP: 6-Mercaptopurine IV: Intravenous

**Table 6: Associations between the use of Azathioprine or 6-mercaptopurine and patient and treatment characteristics for patients with Crohn's disease**

Characteristics	% reporting Aza/6 MP	Odds ratio	95% CI
Sex			
Male	23.5	Referent	
Female	23.8	1.0	0.8 to 1.3
Age			
16-24	45.3	Referent	
25-40	29.0	0.5	0.3 to 0.8
41-55	22.3	0.4	0.2 to 0.6
>55	15.0	0.2	0.1 to 0.4
Disease activity			
Inactive	19.2	Referent	
Mild	18.5	1.0	0.7 to 1.3
Moderate	26.6	1.5	1.1 to 2.1
Severe	38.2	2.6	1.7 to 3.9
Hospitalizations Past 5 Years			
None	17.4	Referent	
1 - 2	26.1	1.7	1.3 to 2.2
> 2	38.8	3.0	2.2 to 4.1
Surgery within the past 2 years			
No	21.3	Referent	
Yes	38.0	2.3	1.7 to 3.0
IV Steroids in past 12 months			
No	22.8	Referent	
Yes	41.1	2.4	1.5 to 3.7
PO Steroids in past 12 months			
No	16.6	Referent	
Yes	37.1	3.0	2.4 to 3.7
Combined family income before taxes (\$)			
< 20,000	27.6	Referent	
21,000-40,000	18.8	0.6	0.4 to 1.0
41,000-60,000	24.7	0.9	0.5 to 1.4
61,000-80,000	26.9	0.9	0.6 to 1.6
> 80,000	25.5	0.9	0.6 to 1.4
Prefer not to answer	21.4	0.7	0.4 to 1.2
Region			
Maritimes	21.0	Referent	
Quebec	28.2	1.5	0.9 to 2.5
Ontario	23.6	1.2	0.7 to 1.9
Prairies	22.0	1.1	0.6 to 1.8
West Coast	22.6	1.1	0.6 to 2.0

**Table 7: Associations between the use of infliximab and patient, disease and treatment characteristics for patients with Crohn's disease (n = 1787)**

Characteristics	% Reporting Infliximab	Odds ratio	95% CI
Sex			
Male	5.5	Referent	
Female	5.6	1.0	0.7 to 1.6
Age			
16–24	11.6	Referent	
25–40	7.7	0.6	0.3 to 1.3
41–55	4.8	0.4	0.2 to 0.8
>55	2.7	0.2	0.1 to 0.5
Disease activity			
Inactive	1.8	Referent	
Mild	2.3	1.3	0.5 to 3.3
Moderate	5.4	3.0	1.3 to 7.4
Severe	21.1	14.4	5.7 to 36.3
Prior hospitalization			
No	1.7	Referent	
Yes	6.3	3.9	1.6 to 9.6
Surgery within the past 2 years			
No	4.6	Referent	
Yes	11.4	2.7	1.7 to 4.2
IV Steroids in past 12 months			
No	4.8	Referent	
Yes	18.9	4.6	2.6 to 8.2
PO Steroids in past 12 months			
No	2.5	Referent	
Yes	11.2	5.0	3.2 to 7.8
PO 6 MP/Azathioprine in past 12 months			
No	3.6	Referent	
Yes	11.8	3.6	2.4 to 5.4

patterns in IBD have been of members of specialty societies or IBD organizations and have relied on physician self-report.[14–16]

In general we could find no evidence of significant variations in medical treatments due to gender, region of residence or income level. We did see differences associated with age. In general older patients were less likely to have received common IBD medical treatments in the preceding 12 months although they reported similar levels of disease activity.

Immunosuppressive drugs, predominantly the purine analogs, have become increasingly emphasized in the treatment of Crohn's disease as a way to reduce corticosteroid exposure, maintain remission and alter the natural history of the disease.[17] We found that 24% of Crohn's disease patients reported the use of azathioprine or 6-mercaptopurine in the previous 12 months. There is limited data on immunosuppressive use in IBD populations. Feagan et al. reported that 5% of patients with a Crohn's-related medical claim in several United States employee health plans had used 6 MP/Aza over a 1-year period from

1994–1995.[18] Metge et al. reported that 9% of the patients in the University of Manitoba IBD database who received at least one pharmaceutical prescription in 1997 filled a prescription for an immunosuppressive agent.[12] Although the populations and measures of 6 MP/Aza use differ between the studies, our data combined with these published studies does support a growing use of immunosuppressive drugs in Crohn's disease. Consistent with the generally accepted indications for immunosuppressive use, we found greater 6 MP/Azathioprine use by those who had used intravenous or oral corticosteroids in the past 12 months, those with multiple hospitalizations in the past five years and those who had undergone surgery within the past two years. Metge et al. reported that men were more likely to receive immunosuppressives than women.[12] However, we found no difference, even when examining the age groups that would include women of child-bearing age.

Infliximab entered clinical trials in Canada in mid-1999. A compassionate release program was instituted in the fourth quarter of 1999 and ran until the drug was given approval by the Health Protection Branch in June 2001.



Despite this survey being conducted only in late 2001, nearly 6% of Crohn's disease patients reported having used infliximab. We cannot tell what proportion of these received the drug initially as part of a clinical trial. Patients with markers of more severe disease (hospitalizations, surgery, steroid use) were those most likely to have received infliximab. Although a survey is clearly not the appropriate way to measure the effectiveness of an agent, it is interesting to note that only 20% of those who had received infliximab rated the current activity of their disease as inactive or mild and 43% rated it as at least quite active.

We did find regional variations in prior surgery among UC patients. It is not possible to exclude selection bias. This could occur if the probability of remaining a member of the CCFC after undergoing surgery depended on place of residence. This is unlikely. It is also possible, though seemingly unlikely, that regional variations in surgery could be due to regional variations in post-surgical UC patients responding to our questionnaire. We did initially have difficulty in having some patients with prior proctocolectomy respond to our questionnaire because they considered themselves to no longer have IBD. We received many phone calls after the first questionnaire was mailed out. We contacted each caller to indicate that they should complete the questionnaire and when we mailed the second questionnaire to non-responders we specifically indicated that those UC patients who had previous surgery should still complete the questionnaire. In the absence of these two unlikely scenarios, how can one explain the differences in the proportion of patients who underwent surgery in different areas of the country? One explanation could be regional variations in the use of cyclosporine for acute severe disease and azathioprine for chronically active disease. However, we could find no evidence of regional variation in 6 MP/Aza use among UC patients that had not undergone prior surgery. The number of patients reporting IV cyclosporine use in the past 12 months (5) precluded any meaningful analysis. Regional availability of colorectal surgeons could also affect surgical rates, but this could not be answered with our data.

In conclusion, we have conducted a national survey of IBD patients. Our sample includes a broader range of patients than those typical of clinic samples, especially in terms of patients with less severe disease and UC patients who have undergone surgery. We have found variations in the treatment of inflammatory bowel disease in Canada. Reassuringly, we have not been able to demonstrate significant variations in medical treatment based on place of residence, gender or income levels. Unexplained variations based on age were seen and should be evaluated further in future studies.

## Competing interests

None declared.

## Authors' contributions

Dr. Best conceived of the study. Drs. Hilsden, Verhoef and Best designed the study. Dr. Hilsden oversaw the conduct of the study and wrote the initial draft of the manuscript. Ms. Pocobelli conducted the analysis and contributed to the initial draft of the manuscript. Drs. Best and Verhoef participated in the revision of the manuscript to its final form.

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