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Mapping patient journey in inflammatory bowel disease in Brazil: a cross-sectional descriptive study based on an online survey

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ABSTRACT

Objective: This study maps the journey of patients with inflammatory bowel disease (IBD) in Brazil, highlighting challenges in diagnosis, treatment, and follow-up. **Methods:** An online survey was carried out with patients over 18 years old, diagnosed with IBD. A questionnaire was applied, covering aspects of IBD like daily routine, treatments, and its impact on patients' lives.

Results: The study included 3,566 patients, mostly women (71.7%) aged 35-54 (39.8%). Crohn's Disease was the most prevalent diagnosis (55.9%). Most patients (58.8%) were diagnosed within a year of symptom onset, while 20.3% faced delays of over three years. Over a third of patients (33.9%) had more than five emergency visits before diagnosis, and 54% were hospitalized due to IBD. After diagnosis, 82.4% changed their diet, though only 31.4% had access to a nutritionist. Aminosalicylates were the most common treatment (45.2%), and 31.6% underwent surgery. Over 70% feared disease flares during remission.

Conclusions: The IBD Patient Journey provides a comprehensive view of how IBD profoundly impacts patients' daily lives, even in remission. The study highlights significant challenges, such as delays in diagnosis and limited access to specialists, which negatively affect patients` quality of life.

Keywords: patient experience, inflammatory bowel disease, diagnosis, treatment.

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INTRODUCTION

Inflammatory bowel diseases (IBD), including Crohn's Disease (CD) and Ulcerative Colitis (UC), are chronic conditions with significant impacts on patients' quality of life, including persistent symptoms, frequent hospitalizations, and the need for long-term medical management. Despite their growing prevalence, the epidemiological profile of IBD patients in Brazil remains poorly described, with few published studies and limited sample sizes (1-5). This lack of specific information about the clinical and epidemiological characteristics of IBD patients in Brazil poses challenges for healthcare planning and public policies aimed at improving care for these patients. International data underscore the negative impact of IBD on quality of life and productivity, further highlighting the need for better understanding of patient experiences (6-8).

Jayasooriya et al., in a recent systematic review and meta-analysis, highlighted the consequences of late diagnosis on clinical outcomes in IBD. Delays in diagnosis were associated with higher rates of complications and increased need for surgery, emphasizing the importance of early detection and intervention (9). Bernstein et al. highlight that mental health comorbidities are common in patients with IBD, but are not always recognized and managed. Reinforcing the need for multidisciplinary care, the British Dietetic Association points out that nutritional assessment is essential in patients with IBD, since suboptimal nutritional intake contributes to poorer nutritional status (10). These findings are particularly pertinent to Brazil, where access to specialized care remains limited, further complicating timely treatment of IBD. Understanding the Brazilian patient journey, including time to diagnosis, treatment patterns, and barriers to treatment, is essential to improving overall IBD care in the country.

To address this gap, the Brazilian Association of Ulcerative Colitis and Crohn Disease (ABCD), in collaboration with the National Association of People Living with IBD (DII Brasil), conducted the "Patient Journey in IBD" survey. This internet-based study aimed to map the patient journey, a concept in healthcare research that focuses on understanding patient experiences to improve care. By exploring patient perceptions, needs, and barriers in accessing care, the survey sought to identify unmet needs and opportunities to enhance health services for IBD patients in Brazil.

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The European Federation of Crohn’s and Ulcerative Colitis Associations (EFCCA) had previously launched the IMPACT survey in 2010, which involved 4,760 patients across 25 countries (7). The Brazilian study applied similar methods, adapting the survey to the Brazilian context. To our knowledge, this is the first large-scale study in Brazil to capture patient-reported data on IBD using a standardized instrument that has been employed in international studies.

Therefore, this study aims to provide a comprehensive overview of the patient experience with IBD in Brazil, focusing on the impact of delayed diagnosis, treatment patterns, and unmet healthcare needs, thereby contributing to the broader efforts to improve care for IBD patients both nationally and globally.

MATERIALS AND METHODS

Online survey with patients aged 18 years or older, with a convenience sample of individuals with a confirmed diagnosis of IBD living in Brazil.

The questionnaire, administered through the SurveyMonkey platform, was translated and adapted from the "IMPACT" study conducted by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) in 2010, involving 4,760 patients with Crohn's Disease (CD) and Ulcerative Colitis (UC) from 25 European countries. The instrument consisted of 44 open and closed questions. The first five questions aimed to identify the eligibility criteria and prevent ineligible patients from answering the following questions. The following 39 questions were segmented into 7 stages, each assessing different aspects of IBD: “You and your routine”, “Your IBD”, “Treatments”, “Healthcare providers in your life”, “The impact of IBD on your life”, “The impact of patient associations on your life” and “The impact of IBD on your work and school activities”. Four questions about patient nutrition and weight were added to the original IMPACT survey questionnaire (7).

Between May 4 and June 26, 2017, the questionnaire was made available to patients on the ABCD website (*https://www.abcd.org.br/jornada-2017/*). During this period, campaigns to promote the study among healthcare providers and patient associations were carried out to encourage participation.

Participants

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Patients aged 18 years or older, residing in Brazil and previously diagnosed with any type of IBD by a healthcare professional (even if not specified) were considered eligible. To establish the diagnosis of IBD for the purposes of this research, two questions were used: "What type of IBD have you been diagnosed with?" and "Has a healthcare professional ever confirmed that you have any type of IBD?". The answers "I do not have any type of IBD" to the first question or "No" to the second question led to the exclusion of the subject, who was unable to answer any other questions. Patients who did not complete the questions considered mandatory were also excluded from the analysis set.

Statistical analysis

Descriptive analyses of the variables studied were conducted, with categorical variables described using absolute (n) and relative (%) frequencies. Data was organized and analyzed using Microsoft Excel.

Ethical aspects

All subjects answered an online Informed Consent Form available through the survey platform, created specifically for this study by the study organizing committee. Patients were unable to proceed to the questionnaire without providing informed consent. All answers were collected anonymously and no data allowing patient identification was collected. This study was approved by the Research Ethics Committee of the Faculty of Medicine at the Federal University of Pelotas (CAAE 86000324.0.0000.5317).

RESULTS

The online questionnaire was accessed by 4,428 individuals. Among them, 261 were excluded due to eligibility issues. Another 601 were excluded from the analysis set because they did not complete the questionnaire. The final analysis included 3,566 enrolled patients. The results will be presented in 4 sections: 1) Patient characteristics; 2) Diagnosis and definition of care; 3) Treatment patterns and satisfaction with treatment; and 4) Impact of IBD on patients' lives.

Patient characteristics

Most patients were female (71.7%), were between 35 and 54 years old (39.8%), and lived in the southeast region of the country (58%). Considering the

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diagnosis of the patients, the majority reported having Crohn's disease (55.9%), followed by Ulcerative Colitis (39.6%), and unspecified colitis (4.5%). Regarding the type of health care coverage, only 28.5% (1015) reported receiving care through the *SUS - Sistema Único de Saúde* (Brazil's public healthcare system, offering free, universal access to medical care for all citizens, funded by the government) **(Table I).**

Diagnosis and definition of care

Regarding the onset of symptoms and establishment of the diagnosis, **Figure 1** (A and B) illustrates the time to an established diagnosis and the time to attend an appointment with a specialist physician after the onset of IBD symptoms. The time to a definitive diagnosis was less than 1 year for the majority of patients (58.8%), but was more than 3 years for 20.3% of patients, despite the fact that almost half of the patients (47.3%) attended their first appointment with an IBD specialist physician within 6 months of the onset of symptoms.

According to **Figure 1C** 71.1% of patients had at least 1 visit to the emergency unit due to IBD symptoms before the definitive diagnosis. The most frequently reported number of visits to the emergency department prior to diagnosis was 5 or more times (33.9% of the total sample). **Table I** presents data on self-reported access to specialists related to IBD and multidisciplinary care. Most patients reported having access to an IBD specialist (75.3%) and attending regular appointments with their IBD specialist (76.4%). However, with regard to multidisciplinary care, although 84.5% of patients reported a desire to have access to a multidisciplinary team, few patients reported having had follow-up with a nutritionist (31.4%) or psychologist (21.1%).

Treatment patterns and satisfaction with treatment

About the results on treatment patterns and patient satisfaction. Dietary modifications due to IBD were reported by 82.4% of patients, with 79.2% of them reporting exclusion of specific foods or ingredients from their diets, although only 31.4% had access to a consultation with a nutritionist as mentioned above **(Table I).**

At least one day of hospitalization due to IBD was reported by 54.0% of patients, and 31.6% of patients had at least one surgery related to the disease.

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Among the 1,128 patients with a history of IBD surgery, 42.1% were completely satisfied, while only 5.1% were completely dissatisfied **(Table I)**.

The most frequently used class of medications currently used by IBD patients in our sample was aminosalicylates (45.2%), followed by biologics (40.6%). The use of immunomodulators at some point during treatment was reported by 64.5% of patients **(Table II).**

Table II also presents data on the frequency of use of each medication class, according to diagnosis, only for individuals with Crohn's disease and ulcerative colitis. Significant differences in terms of absolute frequency were observed for all medication classes. Current use of biologics was reported by 59.0% of patients with CD but by only 16.7% of patients with UC.

Approximately one third of the sample reported being completely satisfied with their current treatment.

Impact of IBD in patients' lives

Table III presents the patients' responses to the questions about the impact of IBD on their personal and professional lives. Almost half of the sample (46.6%) reported having to cancel or postpone appointments due to IBD always or most of the time. According to 25.6% of patients, IBD has a severe impact on their lives even during periods of remission, and more than half of patients (51.6%) worry always or most of the time about future flare-ups of the disease.

Regarding interpersonal relationships and productivity, 14.8% of patients strongly agreed that IBD prevented them from having intimate relationships and 10.1% strongly agreed that IBD had caused the end of a relationship. Regarding the ability to make and keep friends, 40.1% of patients reported some degree of negative impact due to IBD.

Regarding career, patients strongly agreed that IBD had caused them to be fired or resign from work (23.9%), that the disease had a negative impact on their careers and income (27.6%), and that it had prevented them from developing their full potential at work or in school (29.4%).

DISCUSSION

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This study provided valuable data for better understanding the characteristics, treatment patterns, and patient journey of IBD patients in Brazil, with significant voluntary participation compared to previous national surveys (11-13). Most patients in our sample were female, a finding consistent with other studies using similar methodologies (14,15). Interestingly, IBD diagnosis is typically equally distributed between men and women, but men tend to be underrepresented in surveys like ours (16). Cultural factors may influence this trend, as women are often more inclined to participate in online surveys about their health.

In the present study sample, private healthcare coverage was the most common method of accessing medical services. This differs from the general Brazilian population, where less than 30% of individuals aged 14 and older have private health insurance (17). This discrepancy may limit the generalizability of our findings to other populations, particularly those relying exclusively on the public healthcare system (SUS). Given the characteristics of the Brazilian healthcare system, it can be inferred that patients using public services likely experience reduced access to specialists and the resources necessary for a timely and accurate diagnosis (18).

Barriers to accessing gastroenterological care appear to be less significant in our sample, as more than 75% of patients reported frequent consultations with gastroenterologists, and more than 45% had their first consultation with a specialist within six months of symptom onset. However, only 8.0% of the sample reported receiving multidisciplinary care.

Dietary modifications due to the diagnosis of IBD were reported by more than 80% of our sample, with most patients adopting more restrictive diets (excluding foods or ingredients) without formal guidance from a nutritionist or dietitian. It is reasonable to assume that these dietary modifications are being carried out independently by the patient or guided only by a gastroenterologist. These findings are markedly significant since patients with IBD may present alterations in nutritional status due to malabsorption of micronutrients, even among patients with normal BMI or overweight/obesity, and this characteristic may be underdiagnosed in the absence of multidisciplinary care (19).

Similarly, it was observed that only one fifth of the sample had access to psychological support. Studies indicate that depression and anxiety disorders are at

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least twice as common in people with IBD than in the general population and can precede the onset of IBD by years (20-22).

A recurring concern is the fear of new flare-ups during remission, reported by more than 70% of patients, with 32% stating that this fear is always present. This reinforces the need for psychological and psychosocial support for these patients. According to Bernstein et al, in their study describing the complex interaction between IBD and extra-intestinal diseases, they highlight the need to increase mental health screening and access to mental health care in the management of patients with IBD (10).

The drug treatment of Inflammatory Bowel Disease (IBD) often involves the use of several classes of drugs, with aminosalicylates being the most common continuous therapy, used by 45.2% of patients in this sample, and being more indicated for mild to moderate cases of IBD, especially in patients with ulcerative colitis (UC). Biological therapies, used by 40.6% of patients, also play an essential role in the treatment of more severe forms of IBD, both in Crohn's disease and UC.

However, 50.8% of patients have never received biological treatment, which is even more evident among patients with ulcerative colitis (UC), with 74.6% reporting never having used biologicals, suggesting difficulties in accessing this class of drugs. The difficulty in accessing biological therapies can be explained, in part, by the lack of reimbursement for this class of drugs in the SUS for UC, which mainly impacts patients without private health insurance. Even among those with access to private insurance, other factors, such as high drug costs and bureaucracy, may hinder the widespread use of these more advanced treatments (23). It is worth noting that this questionnaire was carried out in 2017, and biological medicines for ulcerative colitis were only approved by the SUS in March 2020, which may have impacted access to these treatments since then.

Despite these challenges, most patients were satisfied with their treatment, including IBD-related surgeries. However, even with adequate access to doctors and treatments, patients still experience significant impacts from IBD on their daily lives. Our results indicate that IBD negatively affects quality of life, even during periods of remission, influencing personal relationships, productivity and overall well-being.

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These findings corroborate previous studies showing a reduced quality of life among IBD patients (7,12,24).

The IBD patient journey in Brazil appears to consist of three distinct stages. The first stage begins with the onset of symptoms, followed by several months of "trial and error" experiences, including visits to various doctors and emergency units, until the patient meets a specialist familiar with IBD who can provide an accurate diagnosis. This leads to the second stage: diagnosis. In IBD, an early diagnosis, often defined as one made within the first two months after symptom onset, is crucial, as delays in diagnosis and treatment are well-documented in the literature to be associated with a higher risk of complications (25). The third stage is treatment and disease management, during which patients frequently encounter challenges such as limited access to specific medication classes and multidisciplinary care.

The results of this study are important because, according to the scientific literature, a clear and accurate understanding of the patient experience benefits the healthcare sector and society by enabling personalized care, guiding future research, improving the quality of medical care, and informing health policies (26).

The main limitations of this study are related to its design and the use of an online platform, which may have led to the selection of patients belonging to population strata with higher income and education levels than the average Brazilian population, since internet access in the country is not universal. This makes our sample susceptible to selection bias, since participation was voluntary and non-probabilistic. However, despite these limitations, the study provided valuable descriptive information for a better understanding of the self-perceived impact of inflammatory bowel disease (IBD) on patients' lives and journeys, offering a relevant overview for improving medical care and health policies.

Conclusion

This study provides a comprehensive overview of the experiences of patients with inflammatory bowel disease (IBD) in Brazil, highlighting the significant impact of late diagnosis on the quality of care and patients' lives. The findings highlight not only the negative impact of IBD on quality of life, but also the identification of unmet health needs affecting this population. By highlighting these gaps, the study contributes to a deeper understanding that can guide improvements in care at both

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national and global levels. Thus, this information is essential for the development of more effective and targeted health policies to better meet the demands of patients with IBD.

Author Contributions

All authors contributed to the conceptualization, design, data collection, formal analysis, preparation of the original draft, and critical review of the final manuscript.

Declaração de Conflito de Interesse

The authors have declared no conflicts of interest.

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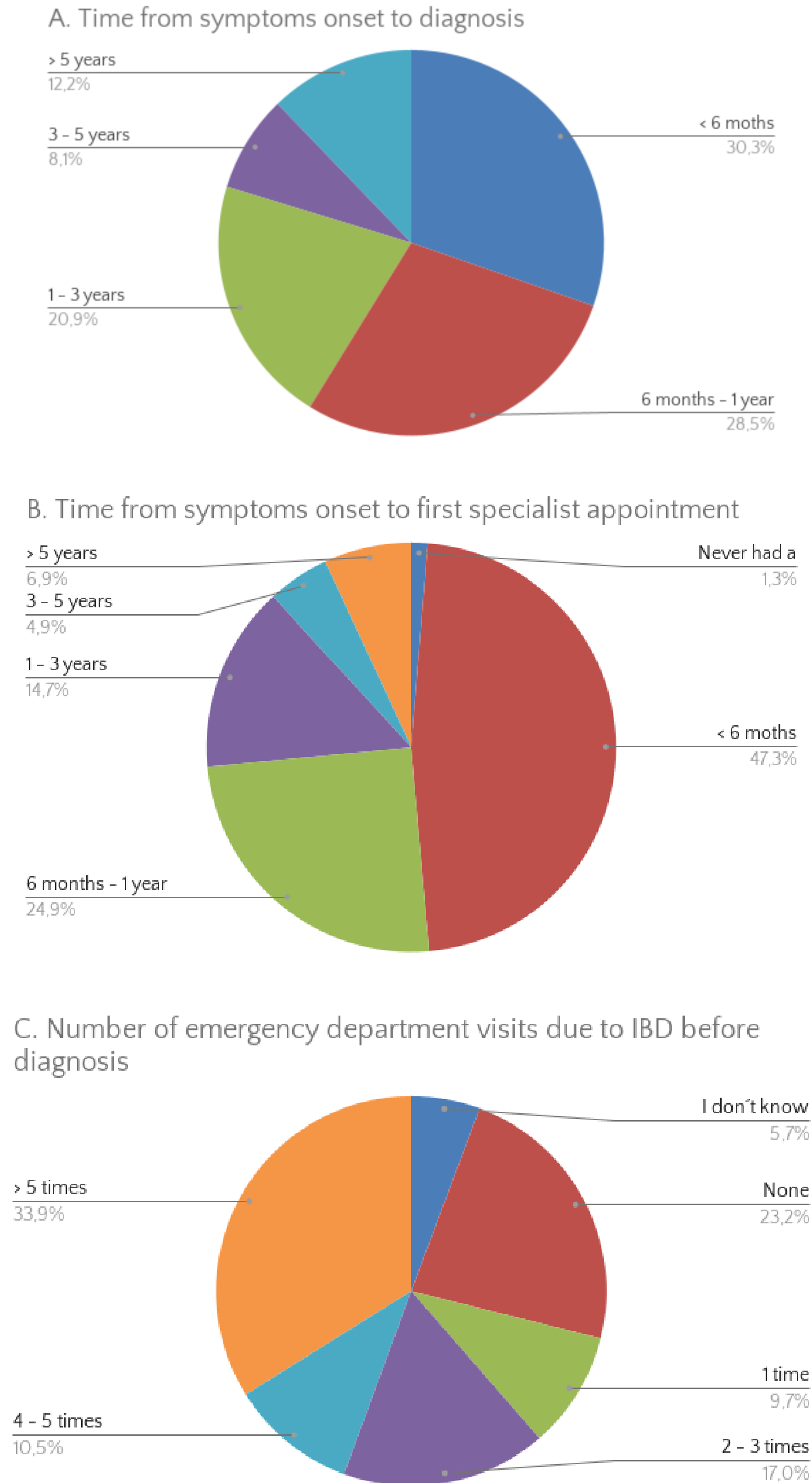

Figure 1. Time to diagnose and specialist care.
*IBD: Inflammatory bowel disease

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Table I. Characteristics of Patients, Access to Health Services and Treatment Patterns. N=3566

Characteristic	***N(%)***
Age, years	
18-24	520 (14.6)
25-34	1308 (36.7)
35-54	1421 (39.8)
55+	317 (8,9)
Type of coverage for health services	
Insurance/private health plan only	2207 (61.9)
Public healthcare system only (SUS)*	1015 (28.5)
Private/Out-of-pocket only	229 (6.4)
Other/undetermined	115 (3.2)
Primary diagnosis	
Crohn Disease	1992 (55.9)
Ulcerative Colitis	1413 (39.6)
Unspecified Colitis	161 (4.5)
Difficult to schedule an appoint with **IBD-specialist	
I face difficulties	880 (24.7)
I do not face difficulties	2686 (75.3)
Frequency of appointments with IBD-specialist physician	
Frequent appointments	2726 (76.4)
Once a year appointment	657 (18.5)
I never go to a IBD-specialist	183 (5.1)
Access to a IBD-experienced to	N=3115
Nurse	302 (8.5)
Psychologist	752 (21.1)
Family physician or general practitioner	940 (26.4)
Nutritionist	1121 (31.4)
Access to a multidisciplinary team/clinic	
Yes, I have access	287 (8.0)
No, but I would like to have access	3012 (84.5)
No, but I do not want to have access	267 (7.5)
Diet modifications due to the IBD diagnosis	
I modified my diet, excluding specific foods	2826 (79.2)
I modified my diet, including specific foods	112 (3.2)
I did not modify my diet	628 (17.6)
IBD-related hospitalization days in the previous 5 years	

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0 (None)	1565 (43.9)
1-5 days	788 (22.1)
6-10 days	296 (8.3)
More than 10 days	840 (23.6)
I do not know	77 (2.2)
Number of IBD-related surgeries (lifetime)	
0	2438 (68.4)
1-3	868 (24.3)
4+	260 (7.3)
Satisfaction with IBD-related surgery (n=1128)	
1 totally dissatisfied	58 (5.1)
2-4 moderately satisfied	595 (52.8)
5 totally satisfied	475 (42.1)

*SUS: Brazilian Unified Health System
**IBD: Inflammatory bowel disease

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Table II. Characteristics of Drug Treatment Patterns of inflammatory bowel disease Brazilian patients.

Variable	All Sample N(%)	Crohn's Disease N(%)	Ulcerative Colitis N(%)
Aminosalicylates (5-ASA)	N=3490	N=1927	N=1404
Current use	1578 (45.2)	501 (26.0)	996 (70.9)
Previous use	1617 (46.3)	1177 (61.1)	384 (27.4)
Never used	295 (8.5)	249 (12.9)	24 (1.7)
Immunomodulators	N=3332	N=1909	N=1277
Current use	1262 (37.9)	906 (47.5)	344 (26.9)
Previous use	885 (26.6)	625 (32.7)	248 (19.4)
Never used	1185 (35.6)	378 (19.8)	685 (53.6)
Biologics	N=3315	N=1906	N=1262
Current use	1347 (40.6)	1124 (59.0)	211 (16.7)
Previous use	284 (8.6)	170 (8.9)	110 (8.7)
Never used	1684 (50.8)	612 (32.1)	941 (74.6)
Corticosteroids	N=3411	N=1925	N=1334
Current use	576 (16.9)	307 (15.9)	245 (18.4)
Previous use	2330 (68.3)	1398 (72.6)	859 (64.4)
Never used	505 (14.8)	220 (11.4)	230 (17.2)
Antibiotics	N=3306	N=1879	N=1278
Current use	182 (5.5)	119 (6.3)	51 (4.0)
Previous use	2067 (62.5)	1300 (69.2)	689 (53.9)
Never used	1057 (32.0)	460 (24.5)	538 (42.1)

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Table III. Impact of inflammatory bowel disease in patients' lives. N=3566

Characteristic	N(%)
How often do you have to cancel or postpone appointments due to your IBD?	
Never	268 (7.5)
Almost never	512 (14.4)
Sometimes	1124 (31.5)
Most of the time	1077 (30.2)
Always	585 (16.4)
IBD affects your daily life even when you are in remission (as compared to a person without IBD)	
No	713 (20.0)
IBD slightly affects my life in remission periods	1941 (54.4)
IBD severely affects my life in remission periods	912 (25.6)
When in remission, how often do you worry about a future crisis?	
Never	265 (7.4)
Almost never	569 (16.0)
Sometimes	891 (25.0)
Most of the time	693 (19.4)
Always	1148 (32.2)
IBD prevents me from having intimate relationships (N=3551)	
1 totally disagree	1637 (46.2)
2-4 moderately disagree	1389 (39.0)
5 totally agree	525 (14.8)
IBD caused the end of an intimate relationship (N=3551)	
1 totally disagree	2242 (63.1)
2-4 moderately disagree	951 (26.8)
5 totally agree	358 (10.1)
IBD prevents me from making or keep friends (N=3551)	
1 totally disagree	2133 (59.9)
2-4 moderately disagree	1119 (31.5)
5 totally agree	306 (8.6)
IBD made me being fired or resign (n=3552)	
1 totally disagree	1801 (50.7)
2-4 moderately disagree	901 (25.3)
5 totally agree	850 (23.9)
IBD negatively impacts my career and/or income (N=3559)	

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1 totally disagree	1112 (31.2)
2-4 moderately disagree	2447 (41.2)
5 totally agree	982 (27.6)
IBD prevents me from developing my full potential at work or studies (N=3554)	
1 totally disagree	832 (23.4)
2-4 moderately disagree	1677 (47.2)
5 totally agree	1045 (29.4)

*IBD: Inflammatory bowel disease

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