



# IBD and health-related quality of life — Discovering the true impact ☆

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## KEYWORDS

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## Abstract

**Background and aims:** Although inflammatory bowel diseases (IBD) significantly impact the patient's quality of life, no European-level data exists on patients' perspectives. The primary objective of this survey was to obtain an international perspective of the impact of IBD on patients' lives. Secondary objectives included obtaining a better understanding of the quality of care, access to care, and differences between countries, age groups, and sub-groups of IBD.

**Methods:** The survey questionnaire consisted of 52 questions in six categories. The survey was translated into ten languages, tested on volunteers, and promoted across 25 national IBD associations. Data was collected anonymously online, and participation was optional.

**Results:** 4670 patients completed the survey. Most respondents received a final diagnosis within a year from noticing first symptoms, but 67% had to visit emergency clinic at least once before diagnosis. 85% had been hospitalized in the last five years. 64% felt that gastroenterologists should ask more probing questions and 54% that they did not get to tell something potentially important to their physician. Most respondents experienced symptoms weekly also in remission. Most had been absent from work due to IBD and 24% had received unfair comments about their work performance. 45% felt that IBD had negatively affected their performance in educational settings.

**Abbreviations:** EFCCA, European Federation of Crohn's and Ulcerative Colitis Associations; IBD, Inflammatory bowel diseases; HRQoL, Health-related quality of life.

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**Conclusions:** The results of this survey can be used in defining strategic priorities and planning projects and awareness raising activities. The unmet needs of IBD patients can be better demonstrated and communicated to the public, health service managers and politicians.

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## 1. Introduction

Inflammatory bowel diseases (IBD) significantly impact and impair the patient's quality of life.<sup>1–4</sup> These impairments are usually related to periods of active disease and increased disease severity.<sup>5</sup> IBD patients also worry about disease complications and other issues related to their illness.<sup>6,7</sup>

To the authors' knowledge, no current European-level data on the perspectives of people with IBD and the impact of IBD on their quality of life is available. The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) has repeatedly received requests from national IBD associations across Europe to share and translate examples of best practice in survey and questionnaire design.

On this note, a pan-European survey, larger and of a higher quality than anything produced before, was carried out. It was designed to cover a holistic view of IBD, including the impact of IBD on quality of life as well as on additional aspects such as access to health care, education, employment, and relationships.

## 2. Materials and methods

### 2.1. Objectives

The primary objective of the survey was to obtain an international perspective of the impact of IBD on patients' lives. Secondary objectives included obtaining a better understanding of the quality of care offered, access to health care and support facilities in various countries, and the differences between countries, age groups, and different groups of IBD.

### 2.2. The impact questionnaire

The questionnaire was developed by EFCCA in cooperation with Abbott, prepared by a survey company and reviewed prior to use by health informaticians. Many of the questions were sourced from validated, published and peer-reviewed academic surveys or from national IBD association surveys conducted in the past. The survey questionnaire consisted of 52 questions divided in six categories: 1) your experience with IBD, 2) health care, 3) the impact that IBD has on your life, 4) overall work impact, 5) overall life impact, and 6) the role of patient organizations.

The survey was made available in English, Dutch, French, German, Hebrew, Italian, Portuguese, Slovenian, Spanish, and Swedish and tested on six volunteers from six EFCCA member associations. From 29th November 2010 to 5th August 2011, the survey was offered and promoted across 25 national IBD associations in Europe, most of which were responsible for the

launch and communication to their own members by providing the members with an online link to the survey. Data was collected anonymously online, and participation was entirely optional. National associations were encouraged to promote the survey online among their members, in many countries in their own language. To achieve a wide international overview, the aim was to receive at least 100 responses from at least 10 countries.

In most questions, participants were allowed to tick one applicable option. In some questions, such as those concerning the incidence of extraintestinal manifestations, several options could be chosen. In others, such as questions concerning the frequency of symptoms, participants were given options "always (100% of the time)", "most of the time (75–99% of the time)", "much of the time (50–74% of the time)", "sometimes (25–49% of the time)", and "hardly ever/never (less than 25% of the time)".

## 3. Results

### 3.1. Respondents

A total of 4670 IBD patients from 25 countries who completed the survey online were included in this analysis. The goal of getting at least 100 responses from at least 10 countries each was reached in 15 countries in total. 62% of respondents had Crohn's disease, 33% ulcerative colitis, and the rest another form of IBD or an unconfirmed diagnosis. 66% of respondents were women, 33% men; the rest did not state their gender. The majority of respondents were between the ages of 25 and 44.

### 3.2. Your experience with IBD

54% of respondents received a final diagnosis within a year from noticing first symptoms (32% in the first six months, 22% 6–12 months after the first symptoms). For 45%, however, it took longer than a year, for 17% longer than five years (see Fig. 1). Access to specialist care was good; most respondents (70%) saw a specialist within a year from the onset of symptoms. 67% of respondents reported having had to go to an emergency clinic once or more before receiving their final diagnosis (7% more than ten times).

Many respondents had experienced co-morbidities or complications of IBD. 49% had experienced joint involvement and 34% skin involvement associated with IBD. 28% regularly used pain pills to relieve IBD symptoms, and 15% had had surgery complications such as adhesions, wound infections or pain. 52% had used corticosteroids, 42% had experienced side effects from them, and 49% were concerned about the long-term effects of corticosteroids.

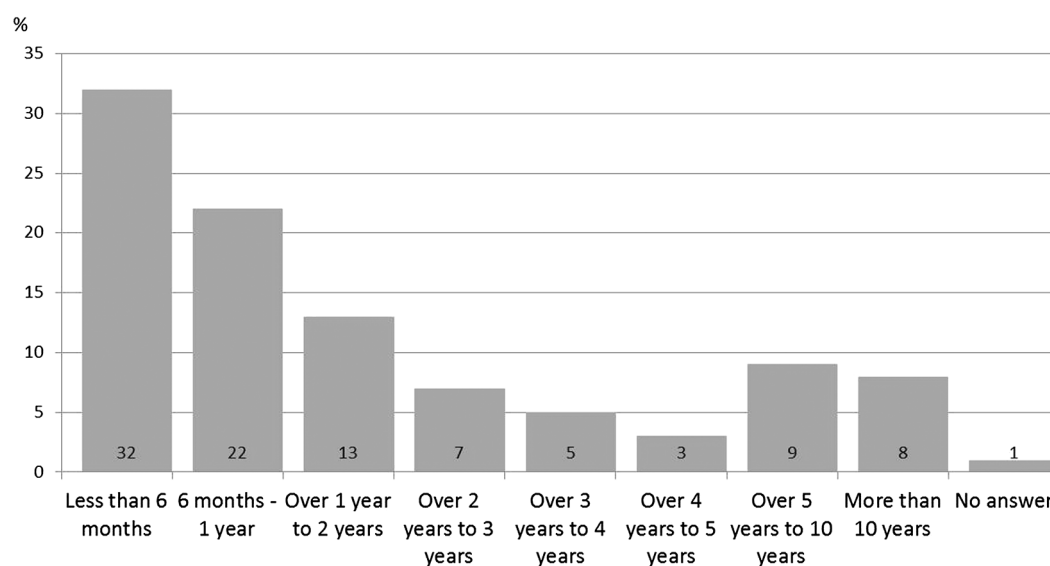


Figure 1 Time from noticing first symptoms to receiving final diagnosis.

### 3.3. Health care

60% of respondents had not been operated due to IBD. 16%, however, had had one surgery, 17% 2–4 surgeries, 5% 5–10 surgeries and 2% more than 10 surgeries. 73% of the operated respondents were very or somewhat satisfied with the surgery outcomes. Only 15% of the respondents had not been hospitalized at all in the last five years. 38% had spent 1–5 days in the hospital within the last five years and 47% more than six days.

The most commonly taken drug among the respondents was 5-aminosalicylates (48% currently taking at the time of the survey, 37% taken in the past). 58% had taken corticosteroids and 20% were taking them at the time of the survey, and 30%

had taken immunosuppressives and 33% were taking them at the time of the survey. 27% were currently being treated with biological drugs and 13% had been in the past. More Crohn's disease patients than ulcerative colitis patients were currently being treated with biologicals (36% and 12%, respectively). Only 7% of respondents were not taking any medication at the time of the survey. Most respondents reported they were very (25%) or somewhat (31%) satisfied with their treatment plan, and 88% had access to a specialist gastroenterologist at the clinic where they were treated. Only 69%, however, felt that access to their IBD professional was adequate.

54% of the respondents felt that they were not able to tell their physician something potentially important about their illness; 6% felt always this way, 23% most or much of the time

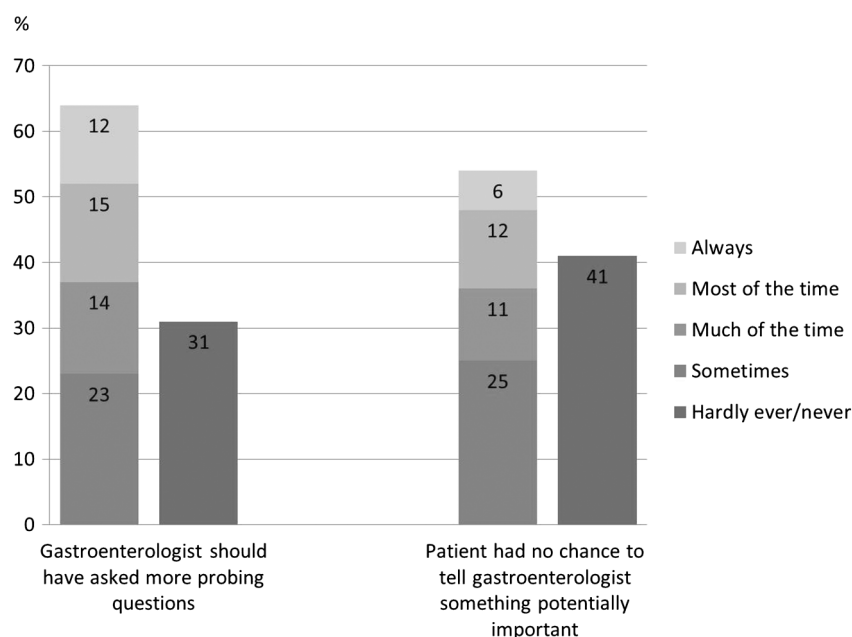


Figure 2 Communication with gastroenterologist.

and 25% sometimes. Furthermore, 64% of the respondents felt that their gastroenterologist should have asked more probing questions to better understand their disease status (see Fig. 2).

### 3.4. Impact that IBD has on your life

At the time of the survey, 50% of respondents were in remission, 22% were having active periodic flare-ups, and 25% had a chronically active disease. 30% of respondents experienced their last remission over 12 months ago (before the current one if they were experiencing one), but most respondents had their last flare-up more recently (18% less than a month ago, 17% 1–3 months ago, 14% 3–6 months ago, 16% 6–12 months ago). 13% had experienced no flare-ups in the last 2 years, whereas 42% had experienced 1–3 flares. 15% of respondents had a chronically flaring condition.

During a flare-up, 22% had hardly ever or never had to cancel or reschedule appointments. However, 34% had had to cancel or reschedule always or most of the time (12% and 22%, respectively) and 41% much of the time or sometimes (20% and 21%, respectively). During remission 37% still had to cancel or reschedule appointments due to IBD at least sometimes.

62% of respondents experienced gastrointestinal bleeding at least once a week during their last or current flare-up, 20% daily, and 28% at least one day a week also between flares. 87% of the respondents experienced abdominal pain at least one day a week during their last or current flare-up, 34% daily, and 62% at least once a week also between flares. 50% of the respondents felt tired every day of the week during their last or current flare-up, and 95% at least one day a week. Between flares, 83% of respondents felt tired at least one day a week, 20% daily. 89% had uncontrollable, sudden bowel movements during their current or recent flare-up at least one day a week, 36% daily. Between flares, 65% experienced sudden bowel movements at least one day a week. On a typical day during a flare, 91% of respondents had runny stools or diarrhea at least once per day and 20% more than 10 times per day. Between

flares, 58% of respondents had diarrhea at least once on a typical day. The frequency of symptoms during and in between flare-ups can be seen in Fig. 3.

48% of respondents felt that their life was significantly or somewhat affected by IBD symptoms even between flare-ups in remission, as compared to people without IBD. Most respondents (71%) worried at least sometimes about when the next flare-up will be; 16% of the respondents worried about it all the time.

### 3.5. Work impact

60% of respondents felt stressed or pressured about taking sick time from work due to IBD. 40% of respondents had made adjustments in their working life, such as working from home (10%), working part-time (15%), and/or working flexible hours (15%). Only 25% of the respondents had not been absent from work due to IBD in the last year; 29% had been absent 1–10 days, 16% 11–25 days, and 25% more than 25 days in the last year. Younger respondents tended to have had more sick days due to IBD. Most common reasons for being absent from work due to IBD were fatigue and/or not enough energy to get through the day (51% of the respondents), doctor appointment (49% of the respondents), hospital or emergency department visit (44% of the respondents) and cramping or painful abdomen (46% of the respondents; participants could tick all that applied to them). Respondents were also absent due to worrying about symptoms instead of actually having symptoms: 26% feared that toilet frequency will interfere with work, 15% that toilet frequency will bring colleagues' attention to the illness, and 19% worries about gas or discomfort and 15% of potential embarrassment. Only 7% of the respondents had never been absent due to IBD.

24% of respondents had received or heard unfair comments from superiors and/or colleagues about their performance at work in relation to their illness, and 20% felt they had been discriminated at the workplace due to IBD. IBD affected the respondents' work behavior in many ways: 29% of the

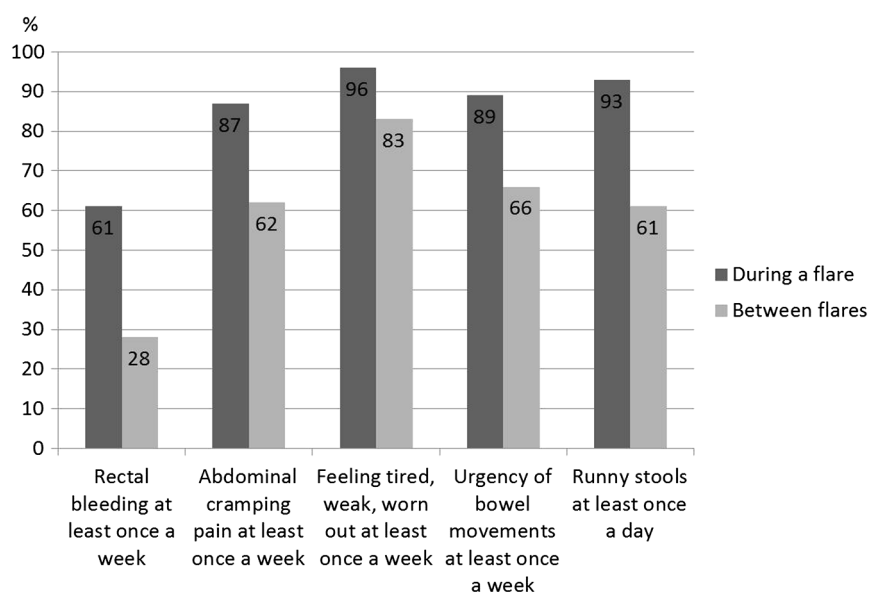


Figure 3 Symptoms during and in between flare-ups.

respondents felt they were less motivated due to IBD, 25% did not participate in work social activities, 23% were quieter during meetings, and 22% were irritable at work (participants could tick all that applied to them); only 28% of the respondents felt their work performance was unaffected by IBD. 56% of respondents felt that IBD had affected their career path, and 31% reported having had lost or had to quit a job due to IBD. 45% of the respondents felt that IBD has negatively affected their ability to perform to their full potential in an educational setting.

### 3.6. Overall life impact

35% of the respondents felt that IBD had prevented them from pursuing an intimate relationship. 17% of the respondents felt that IBD had caused their relationship to end, and 26% felt that IBD had prevented them from making and/or keeping friends.

67% of respondents frequently considered the availability of toilets when planning to attend an event, and 66% worried about the availability of toilets when going someplace new. 29% kept either a written or a mental list of clean, accessible toilets when leaving home and 20% had had to be rude to others in order to get to a toilet. 40% frequently woke up from sleeping as a result from IBD pain, and 27% had been joked about concerning their need to go to the toilet often.

43% of respondents had participated in some way the activities of one of the EFCCA member associations, and 63% of those engaged in the patient associations felt that it had improved their life in general as someone with IBD.

## 4. Discussion

Although more than half of respondents received a diagnosis within a year from first symptoms and access to specialist care was generally good, almost one third of the respondents had to wait longer than a year, and almost two thirds go to an emergency clinic at least once before receiving a final diagnosis. These pre-diagnosis hospital admissions present a burden on health services, and as some of them could possibly be avoided with a timely diagnosis and treatment, good access to IBD specialists should be maintained and diagnostic protocols reviewed to reduce the time of waiting for a final diagnosis. As many IBD patients had had to present themselves in emergency care prior to final diagnosis, IBD awareness should be raised among emergency care staff.

Most respondents were satisfied with their treatment plan and/or surgery outcome. Still, the majority of respondents had spent time in hospital in the last five years, reflecting great potential for improvement in the treatment of IBD patients. Reducing this burden on health services by reviewing the treatment of IBD patients and keeping in line with published evidence-based guidelines<sup>8–11</sup> may counter-balance the cost of new, costly IBD treatments.

Although access to biological therapy is becoming more established, the majority had used corticosteroids and had concerns about their long-term effects. The use of corticosteroids should be in line with published guidelines,<sup>10,11</sup> and the full range of treatment options should be offered and considered to IBD patients, according to comparative risk–benefit profiles.

Most respondents had access to specialist care, but a third felt the access was not adequate. The majority of respondents also felt that they did not get to ask all the questions they wanted to at the consultation and wished they had been asked more probing questions. Access to specialist care and communication at consultations as well as duration and frequency of specialist consultations should be improved to ensure coverage of all relevant issues. It has also been previously documented that quality of care (including competence, courtesy, accessibility, information, continuity of care, accommodation, autonomy, and costs) has an impact on IBD patients' health-related quality of life.<sup>12</sup> The reason for not being able to ask questions should be clarified in future research.

In addition to the clinical symptomatic, IBD management should include assessment of the wider impact of IBD on the patients' everyday life, focusing on three key areas: fatigue, urgency and pain. As most respondents experienced these symptoms also between flare-ups, this should be considered in treatment plans and the patients should not be left alone when they are in remission. The findings on the impact of fatigue independent of disease activity are in line with some previous studies.<sup>1,13</sup> As a better HRQoL in IBD patients has been reported among those who had been diagnosed a longer time ago,<sup>14,15</sup> it could be that IBD patients with a longer disease history "get used" to living with the illness. It may be that the newly diagnosed patients would need more and different kinds of support. This should also be clarified in future research.

Most respondents had taken time off work in the last year due to IBD, a quarter even over 25 days, which is in line with previous findings.<sup>16</sup> Sick leave being more common in IBD patients than general population has also been previously documented,<sup>16</sup> and in this survey, young respondents had had more sick days. Not surprisingly, disease severity and ability to work seemed to correlate in this survey. The majority of respondents felt stressed or pressured about taking time off, and many had experienced unfair complaints or discrimination at work; such comments could perhaps be prevented with improved IBD awareness. As almost half of respondents felt they were not able to perform to their full ability in their studies, interventions for offering support to students with IBD should be developed.

Considering the impact of IBD on the daily life of the patients in terms of issues such as having to worry about finding available toilets and stress in and/or lack of intimate relationships, health care professionals should be aware and sensitive of these issues which may bring additional psychological burden on IBD patients. In a study that compared people with ulcerative colitis to people with other chronic illnesses, the people with ulcerative colitis reported significantly more worrying over disease complications, depression and embarrassment than patients with rheumatoid arthritis, asthma and migraine headaches.<sup>7</sup> According to a study carried out in Sweden, Crohn's disease patients worried more about complications and achievement than intimacy and stigmatization.<sup>6</sup> The main worries and concerns of IBD patients should be clarified in future studies in order to design more effective interventions and management plans to support the patients in their daily life.

As many respondents who engaged in a patient association experienced it as beneficial, health care professionals should actively direct patients to the national IBD associations. As IBD and its symptoms may sometimes be considered less "socially

acceptable",<sup>17</sup> speaking about the illness with peers rather than people not familiar with IBD may be easier.

Although this survey provides a wide overview on the impact on different life situations of IBD patients in Europe, there were limitations. The participation in the survey was self-selecting and as the survey was done online, it was limited to those with internet access. Respondents were from all age groups, but most respondents were between 19 and 54 years of age. It is possible that there are less internet users and therefore respondents in older age groups. Furthermore, the economic status and ethnicity of the respondents, which may have an effect on their internet usage, were not recorded. Although the survey was available in ten languages, it was not translated into all languages of EFCCA member associations, which also may have limited participation. The respondents may therefore not fully represent the entire population of IBD patients in Europe. Furthermore, the participants self-assessed their disease activity, and the possibility of recall bias cannot be entirely excluded in e.g. exact medication history or amount of emergency clinic visits, if these occurred a long time ago.

Despite the limitations, the results of this survey present a large, up-to-date, high-quality data set. The results can be used by national IBD associations in defining strategic priorities and planning projects and awareness raising activities and on the European level in designing lobbying activities and media and publicity articles. With this data, the unmet needs of people with IBD can be better demonstrated and communicated to the public, health service managers and politicians.

## Conflict of interest

S. Vermeire has received honoraria/grants from Centocor, MSD, Abbvie, UCB, Pfizer, Takeda and Genentech. D. Hommes has served as an advisor and/or received honoraria/grants from AbbVie and Janssen. The other authors declare no other conflicts of interest.

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All authors participated in the design and/or analysis of the survey and writing/editing/critically reviewing the manuscript. All authors read and approved the final manuscript.

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