



# Impact of inflammatory bowel disease on quality of life: Results of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) patient survey

Subrata Ghosh<sup>a,\*</sup>, Rod Mitchell<sup>b</sup>

<sup>a</sup> Gastrointestinal Section, Imperial College London, Hammersmith Hospital, Du Cane Road, London W12 0NN, UK

<sup>b</sup> European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA), Bournemouth, UK

Received 2 May 2007; accepted 1 June 2007

## KEYWORDS

Inflammatory bowel disease;  
Crohn's disease;  
Ulcerative colitis;  
Quality of life;  
Drug therapy;  
Surgery;  
Physician–patient relations

## Abstract

**Background:** The predominant symptoms of inflammatory bowel disease (IBD) are diarrhoea, abdominal pain, gastrointestinal bleeding, weight loss, malnutrition and fatigue. These symptoms can have substantial psychosocial implications and cause sufferers to limit their lifestyles, with consequent impact on quality of life (QoL).

**Aims:** To survey the impact of IBD on peoples' lives as well as opinions of treatment and patient–doctor communication in a large European cohort of patients.

**Subjects and methods:** Seven organisations affiliated with the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) distributed questionnaires to 12,200 members between May and August 2005. In total, 5636 responses were received and analysed using descriptive statistics.

**Results:** Of 5576 patients with evaluable responses, 1000 (17.9%) were not currently receiving any treatment, and 3109 (55.8%) were currently receiving anti-inflammatory/5-aminosalicylic acid, 1143 (25.9%) receiving immunomodulators, and 1076 (19.3%) receiving steroids (biologics constituted 4%; however, at the time of this survey they were not approved for use in treating patients with UC). Three quarters were either very ( $n=2233$ , 40.0%) or somewhat ( $n=2010$ , 36.0%) satisfied with the results obtained from their current treatment medication. If given a choice, 4819 (86.4%) said they would rather try a new type of drug therapy than undergo surgery. However, only 2182 (39.1%) reported that their doctor talked to them about newly developed treatments. Three quarters (75.6%,  $n=4213$ ) reported that symptoms affect their ability to enjoy leisure activities, while over two thirds (68.9%,  $n=3841$ ) felt symptoms affected their ability to perform at work. However, nearly half ( $n=2666$ , 47.8%) reported that their doctor does not ask about the impact of symptoms on their QoL. For those patients who received immunomodulators, 72.7% reported QoL improvements (1462/2012) while 72.8% reported QoL improvements with

\* Corresponding author. Tel.: +44 208 3833266; fax: +44 208 7493436.

E-mail address: [s.ghosh@imperial.ac.uk](mailto:s.ghosh@imperial.ac.uk) (S. Ghosh).

steroids (2622/3601). 75% of patients with CD who received biologic therapy (6% of responders) stated that their QoL improved following biologic therapy.

**Conclusions:** IBD symptoms have a substantial impact on patients' lives, and QoL as well as new treatments should be an important feature of patient–physician discussions. The survey results may point to areas where support of IBD patients might be improved.

© 2007 European Crohn's and Colitis Organisation. Published by Elsevier B.V. All rights reserved.

## 1. Introduction

Inflammatory bowel disease (IBD) is characterised by chronic, relapsing inflammation of the intestinal mucosa<sup>1,2</sup> and an inability to down-regulate the inflammatory immune response once activated.<sup>1</sup> IBD encompasses ulcerative colitis (UC), Crohn's disease (CD) and 'indeterminate colitis,' which is not clearly diagnosed as UC or CD.<sup>1,3</sup> The peak age of onset of IBD is 15 to 30 years, with a second smaller peak occurring between 50 and 70 years of age.<sup>1,4</sup> While genetic factors are thought to play a role in the development of UC and CD, environmental triggers may account for the geographical distribution of IBD—it is most prevalent in northern developed regions, e.g., the US, UK and Scandinavia.<sup>1,4,5</sup>

The predominant symptoms of IBD are diarrhoea, abdominal pain, gastrointestinal bleeding, weight loss, malnutrition and fatigue which can substantially impact a patient's quality of life (QoL), largely due to the psychosocial impact of symptoms.<sup>6–8</sup> A survey of IBD outpatients found that concerns about loss of bowel control, producing unpleasant odours, achieving their full potential in the workplace, feeling dirty or smelly, and issues with sexual relationships, ranked highly for both UC and CD.<sup>9</sup>

Both UC and CD can be characterised as following a course of exacerbations followed by periods of remission; between 25% and 50% of patients will relapse within a year.<sup>7,8,10–12</sup> In mild disease, 5-aminosalicylate-based compounds (5-ASAs) are often used first line, and agent selection is based on disease location.<sup>3</sup> Corticosteroids are effective in inducing remission in both UC and CD; however, their use is restricted in the long term due to side effects and/or dependency.<sup>3</sup> Although corticosteroids (prednisolone 1 mg/kg for 7 weeks,  $n=131$ ) have been shown to induce clinical remission in 92% of patients with CD, only 29% of these patients achieved endoscopic remission.<sup>13</sup>

Immunosuppressive agents such as azathioprine and 6-mercaptopurine have shown efficacy in maintaining remission and are used as steroid-sparing agents.<sup>3,14,15</sup> Many patients undergo surgery if steroids and immunosuppressive agents do not provide sufficient symptom control. In patients failing conventional therapy, biologic therapy with the tumour necrosis factor- $\alpha$  (TNF $\alpha$ ) inhibitor infliximab, has provided a treatment that enables mucosal healing and disease remission in both UC and CD. The TNF $\alpha$  inhibitors work by rapidly controlling the inflammation driven by TNF $\alpha$  and are being explored for treating early disease.<sup>16,7–20</sup>

The European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) was established in 1993 and aims to improve the well-being of patients with IBD and their partners and families. EFCCA membership now includes 22 European national Crohn's and colitis patient associations. An important part of the mission of EFCCA is to campaign for improvement in the QoL and quality of care for those with IBD ([www.efcca.org](http://www.efcca.org)). In order to understand the patient

experience of IBD (symptoms, treatments, QoL and patient–doctor communication), EFCCA invited affiliated organisations to participate in a survey of their members. The objectives of this survey were to obtain information about personal experiences of patients with IBD, including the presence of painful and sometimes embarrassing symptoms, the impact of symptom flare-ups on patients' QoL, to determine how many felt need for effective treatment and the need for patient–physician dialogue about the impact of symptom flare-ups on QoL and need for effective treatments that offer long-term relief. The results of this largest European survey of patients with IBD are presented here.

## 2. Methods

European national IBD patient organisations affiliated with the EFCCA were invited to participate in a survey of their members. Seven organisations participated, representing Denmark, Italy, the Netherlands, Spain, Switzerland, the UK and Portugal. Between May and August 2005, survey questionnaires were distributed to 12,200 members of these organisations. A total of 5636 postal responses (46%) were tabulated and analysed by the FFG (Facts & Figures Group), an independent opinion research institute based in Germany who handled the data collection.

Survey questions were devised by EFCCA and concerned the patients, their history of IBD, treatments and the impact of their disease on QoL. In an effort to encourage a good response, the questions were simple to understand and restricted in number (30 total) (see Appendix A). The survey was translated from English into Danish, Flemish, French, German, Italian, Portuguese and Spanish via Mastermedia, Germany, who also dealt with the logistics. The accuracy of the translation was confirmed by the participating patient organisations before being distributed to members in the appropriate language with a cover letter from one of the authors, Rod Mitchell of EFCCA, also appropriately translated, and in some cases an additional supportive letter from the respective organisation.

Descriptive statistics were used to analyse the responses with sub-analyses of those with CD and UC also performed. Data were expressed as absolute number of respondents and percentage of total, or mean  $\pm$  standard deviation, where appropriate. No further statistical analysis was performed.

## 3. Results

### 3.1. Demographics

A total of 5636 surveys were returned in time to enter the analysis, with 5576 patients fulfilling the questionnaire requirements. Of those patients providing a definitive diagnosis of UC or CD ( $n=5358$ ), 3025 (56.5%) stated that they had been diagnosed with CD only and 2333 (43.5%) with

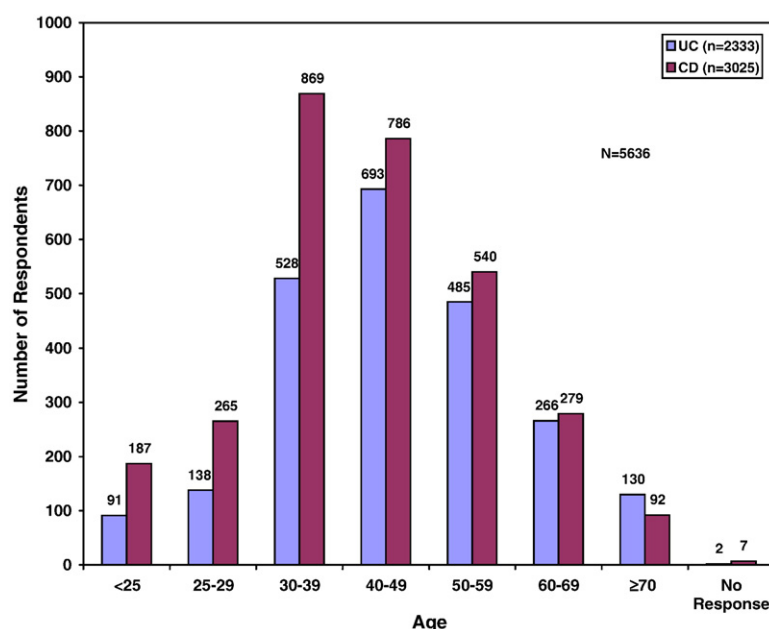


Figure 1 Age of UC and CD respondents to the EFCCA survey.

UC only. Another 204 patients ( $n=5576$ , 3.7%) stated that they had been diagnosed with both CD and UC, while 60/5636 (1.1%) did not complete any questions beyond stating age, gender and country and therefore were eliminated from further analysis (Figs. 1–3). Respondents who stated both CD and UC diagnoses ( $n=204$ ) were included in the total analysis but excluded from CD and UC subgroup analyses due to a possible lack of definitive diagnosis. In addition, 14 patients did not complete questions 4 and 5 pertaining to the status of their diagnosis but did continue to complete the questionnaire beyond this point. Their responses are included in the analysis since they indicated some level of suffering from their illness which was the intent of the survey.

The majority of respondents were female ( $n=3206/5636$ , 56.9%) in both CD ( $n=1806/3025$ , 59.7%) and UC ( $n=1252/$

2333, 53.7%) subgroups. The peak age group for respondents with a diagnosis of CD was 30 to 39 years, while for UC it was 40 to 49 years. Interestingly, the UK was the only country to demonstrate a greater proportion of respondents diagnosed with UC ( $n=281/580$ , 48.4%) than CD ( $n=264/580$ , 45.5%). Otherwise, there was no obvious pattern of difference between countries with regard to the results observed (Table 1).

### 3.2. Diagnosis and Setting of Care

The majority of respondents stated that it had been more than 5 years since they were first diagnosed ( $n=4176/5576$ , 74.9%), with similar proportions in both CD ( $n=2262/3025$ , 74.8%) and UC ( $n=1753/2333$ , 75.1%) subgroups. About three quarters of respondents were diagnosed by a gastroentero-

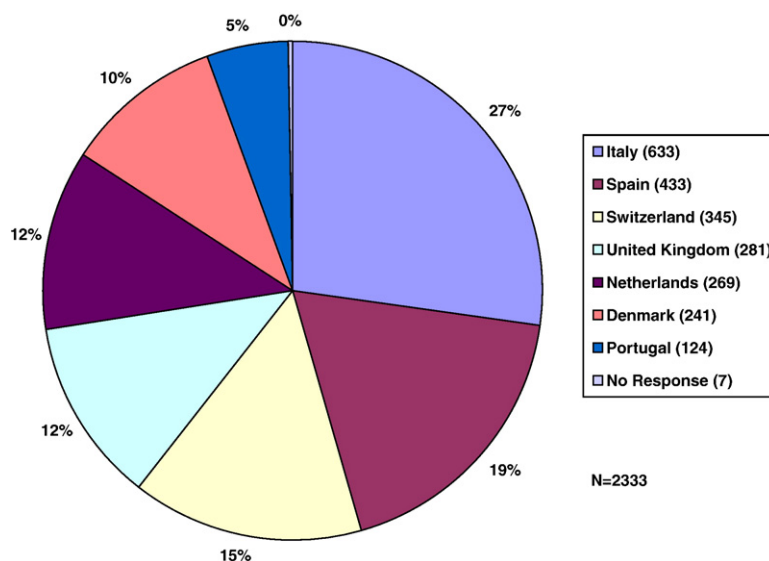
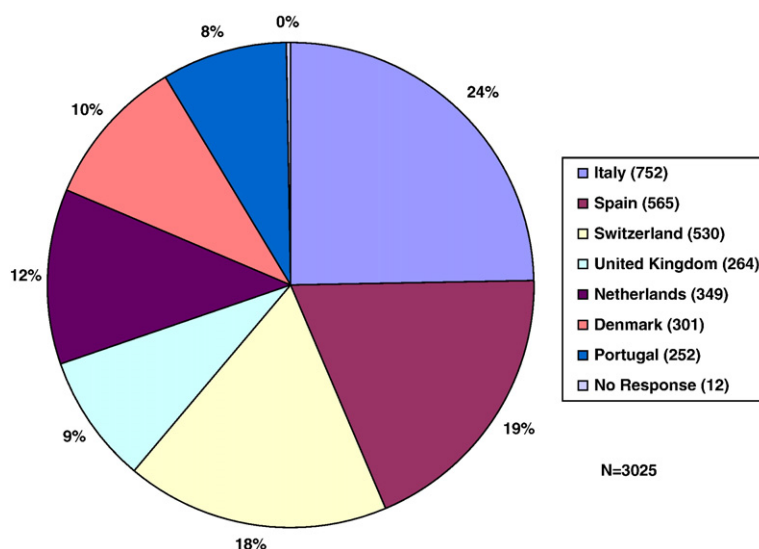


Figure 2 UC breakdown of respondents to the EFCCA survey by country.



**Figure 3** CD breakdown of respondents to the EFCCA survey by country.

logist ( $n=4144/5576$ , 74.3%), although the proportion of UC respondents ( $n=1836/2333$ , 78.7%) was higher than the proportion of CD respondents ( $n=2143/3025$ , 70.8%). The vast majority of patients reported being treated currently by a gastroenterologist ( $n=4855/5576$ , 87.1%; CD:  $n=2638/3025$ , 87.2%; UC:  $n=2022/2333$ , 86.7%) while only about a quarter reported some involvement of their family physician (1434/5576, 25.7%; CD:  $n=783/3025$ , 25.9%; UC:  $n=596/2333$ , 25.5%).

When the respondents being treated by a gastroenterologist were asked how many years they experienced symptoms before seeing a gastroenterologist, a slight majority had seen a gastroenterologist within a year ( $n=2546/4855$ , 52.4%; CD:  $n=1231/2638$ , 46.7%; UC:  $n=1222/2022$ , 60.4%; Fig. 4). However, a substantial proportion of respondents ( $n=1036/4855$ , 21.3%; CD:  $n=635/2638$ , 24.1%; UC:  $n=351/2022$ , 17.4%) experienced symptoms for more than 5 years before seeing a gastroenterologist.

**Table 1** Sex and age comparison of respondents to the EFCCA survey

	Total respondents ( $n=5636$ ), $n$ (%)	Crohn's disease ( $n=3025$ ), $n$ (%)	Ulcerative colitis ( $n=2333$ ), $n$ (%)
<b>Gender</b>			
Male	2410 (42.8)	1211 (40.0)	1073 (46.0)
Female	3206 (56.9)	1806 (59.7)	1252 (53.7)
No response	20 (0.4)	8 (0.3)	8 (0.3)
<b>Age</b>			
<25 years of age	286 (5.1)	187 (6.2)	91 (3.9)
25–29 years of age	417 (7.4)	265 (8.8)	138 (5.9)
30–39 years of age	1440 (25.6)	869 (28.7)	528 (22.6)
40–49 years of age	1530 (27.1)	786 (26.0)	693 (29.7)
50–59 years of age	1102 (19.6)	540 (17.9)	485 (20.8)
60–69 years of age	595 (10.6)	279 (9.2)	266 (11.4)
>70 years of age	254 (4.5)	92 (3.0)	130 (5.6)
No response	12 (0.2)	7 (0.2)	2 (0.1)

### 3.3. Symptoms and QoL

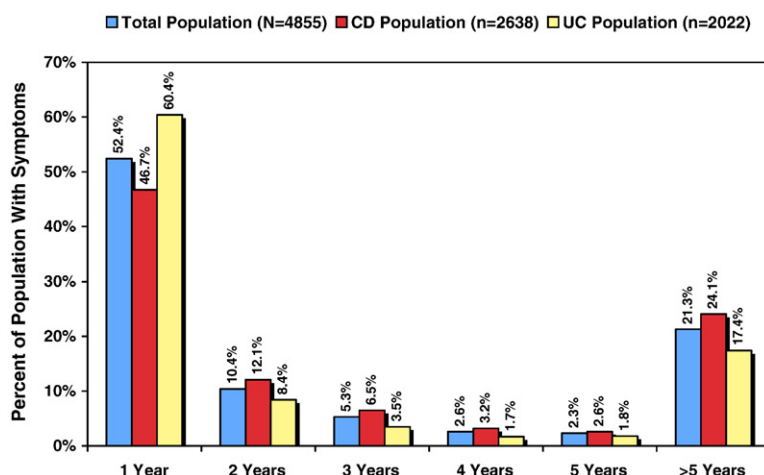
The proportions of respondents experiencing different symptoms of UC or CD are shown in Fig. 5. The proportion of CD respondents reporting fistulas was much greater than those with UC. Conversely, rectal bleeding was more common in UC respondents. The most common symptoms reported among CD respondents were persistent or recurrent diarrhoea, fatigue, weight loss and painful stomach cramps. In UC respondents, the most common reported symptoms were rectal bleeding, persistent or recurrent diarrhoea and fatigue. Survey results with regard to symptom flare-ups, the ability to enjoy leisure activities, the ability to perform at work, and the necessity to change jobs or altered responsibilities as a result of symptoms are provided in Table 2.

### 3.4. Family and Inflammatory Disease Associations

More than 1 in 10 respondents ( $n=660/5576$ , 11.8%) reported that a close family member (e.g., parent and/or sibling) had also been diagnosed with either CD or UC, and proportions were similar for respondents with a diagnosis of CD ( $n=379/3025$ , 12.5%) and UC ( $n=252/2333$ , 10.8%). The prevalence of other immune-mediated inflammatory disorders among respondents is reported in Fig. 6, and it is noticeable that comorbid conditions are more prevalent in CD respondents than in those with UC, albeit only slightly. Furthermore, over half of all respondents ( $n=3293/5576$ , 59.1%) reported experiencing joint pain as a symptom, again slightly more frequently in CD respondents ( $n=1905/3025$ , 63.0%) than UC respondents ( $n=1242/2333$ , 53.2%) (chi-squared=51.5;  $p<0.0001$ ).

### 3.5. Treatment

Of the 5576 respondents, 1000 (17.9%) stated they were not currently receiving any treatment (CD:  $n=572/3025$ , 18.9%; UC:  $n=385/2333$ , 16.5%). The proportions of patients receiving different forms of treatment are listed in Tables 3



**Figure 4** Distribution of responses to the question 'How many years did you experience symptoms before seeing a gastroenterologist?'

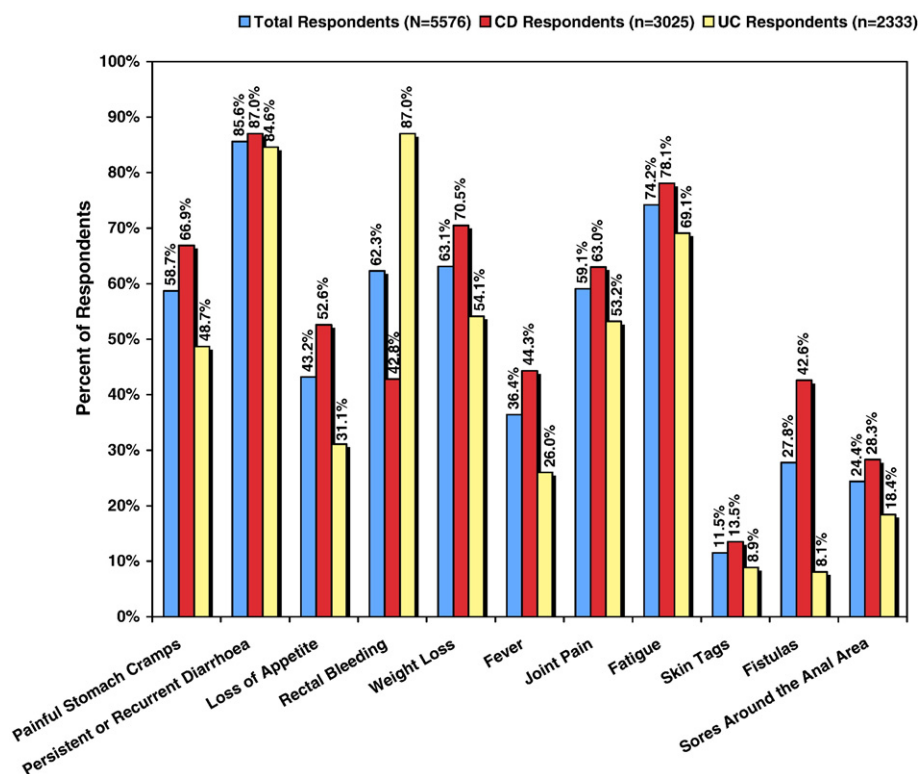
and 4. The most common therapy was anti-inflammatory drugs—5-aminosalicylic acid (5-ASA) in both CD ( $n=1460/3025$ , 48.3%) and UC ( $n=1539/2333$ , 66.0%) respondents followed by immunomodulators ( $n=937/3025$ , 31.0%) and steroids ( $n=570/3025$ , 18.8%) in CD respondents, and steroids ( $n=448/2333$ , 19.2%) and immunomodulators ( $n=446/2333$ , 19.1%) in UC respondents.

### 3.6. Treatment Impact

When respondents receiving biologic therapy, immunomodulators or steroids were asked to rate the impact on their QoL

in the months following treatment, the majority stated that it improved (biologic:  $n=288/387$ , 74.4%; immunomodulators:  $n=1462/2012$ , 72.7%; steroids:  $n=2622/3601$ , 72.8%; Fig. 7). Three quarters of respondents were either very ( $n=2233/5576$ , 40.0%) or somewhat ( $n=2010/5576$ , 36.0%) satisfied with the results obtained from their current treatment medication.

With regard to biologics, considered a newer class of therapy for CD and UC for the purposes of this survey, patients with CD (6% received biologic) had a higher reported improvement in QoL than those patients with UC (1.2% received biologic); 75% of those patients with CD stated that



**Figure 5** Symptoms reported by respondents.



**Table 2** Effect of symptoms on flare-ups and QoL including job performance

Current treatment	Overall (n=5576), n (%)	CD (n=3025), n (%)	UC (n=2333), n (%)
Symptom flare-ups every few months	3870 (69.4)	2148 (71.0)	1580 (67.7)
Symptom flare-ups monthly	611 (11.0)	383 (12.7)	201 (8.6)
Symptom flare-ups weekly	534 (9.6)	348 (11.5)	162 (6.9)
Symptoms affect ability to enjoy leisure activities	4213 (75.6)	2363 (78.1)	1693 (72.6)
Symptoms affect ability to perform job functions	3841 (68.9)	2168 (71.7)	1531 (65.6)
Symptoms caused a change in job or alter job responsibilities	1872 (33.6)	1137 (37.6)	643 (27.6)

their QoL improved following biologic therapy (versus 59% with UC). At the time of this survey, infliximab was the only approved biologic for CD. Therefore, the only data available indicated that 77% of surveyed patients with CD and treated with infliximab reported that their symptoms improved after treatment.

The survey did not inquire about the effect of 5-ASA therapies often combined with the other therapies.

When asked whether they had undergone surgery to treat their UC or CD, 1740/3025 (57.5%) of CD respondents answered 'yes' compared with only 321/2333 (13.8%) of UC respondents. When asked how they would rate their QoL following surgery, 87% (n=1869/2147) stated it was greatly (CD: n=1087/1740, 62.5%; UC: n=214/321, 66.7%) or somewhat (CD: n=427/1740, 24.5%; UC: n=67/321, 20.9%) improved. However, 1397/2147 (65.1%) reported experiencing a recurrence of symptoms after surgery (CD: n=1206/1740, 69.3%; UC: n=137/321, 42.7%). Furthermore, over a quarter (n=583/2147, 27.2%) reported experiencing serious complications after surgery (CD: n=449/1740, 25.8%; UC: n=102/321, 31.8%).

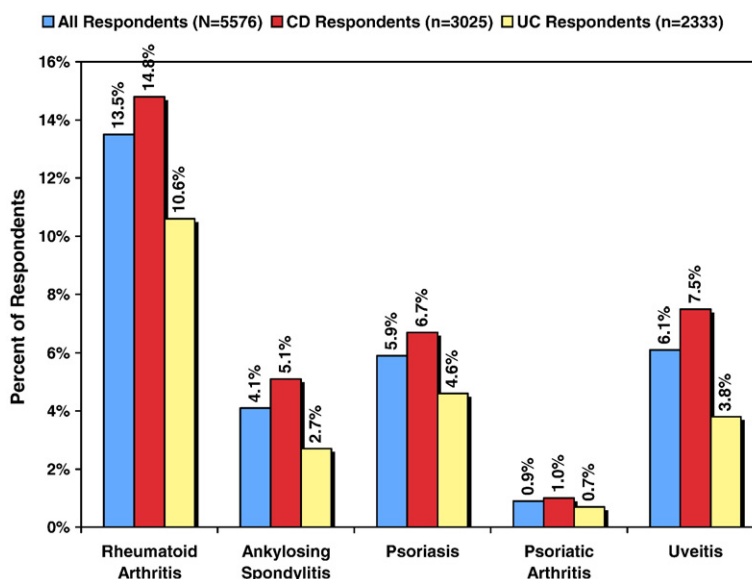
The entire respondent population was asked 'If faced with the need to undergo surgery for UC or CD, would you be willing to try a new type of drug therapy as an alternative?' A total of 4819/5576 (86.4%) said 'yes,' including 2620/3025

(86.6%) of CD respondents and 2020/2333 (86.6%) of UC respondents. However, only 2182/5576 (39.1%) of respondents reported that their doctor talked to them about newly developed treatments for CD or UC (CD: n=1371/3025, 45.3%; UC: n=740/2333, 31.7%).

### 3.7. Doctor–Patient Communication

Nearly half of the respondents (n=2666/5576, 47.8%) reported that their doctor does not ask about the impact of symptoms on their QoL; a similar proportion (n=2668/5576, 47.8%) reported that their doctor did. In CD respondents, 52.1% (n=1577/3025) reported being asked about QoL, while 43.8% (n=1326/3025) reported that they were not; in UC respondents, only 42.2% (n=985/2333) were asked while 53.3% (n=1243/2333) were not.

However, a majority of respondents (n=3119/5576, 55.9%) are prepared to initiate discussion about the impact of symptoms on QoL with their doctor. Indeed, 58.9% (n=1783/3025) of CD respondents and 51.7% (n=1205/2333) of UC respondents report having done so. Encouragingly, respondents report that once their doctor is aware of QoL issues, 79.6% (n=2125/2668) will take action (e.g., change treatment) to address the impact of symptoms. Action to lessen the impact of symptoms on QoL was slightly

**Figure 6** Prevalence of additional immune-mediated inflammatory disorders among respondents.

**Table 3** Previous therapies

Previous treatments	Overall (n=5576)		CD (n=3025)		UC (n=2333)	
	n (%)	Mean duration ± SD (years)	n (%)	Mean duration ± SD (years)	n (%)	Mean duration ± SD (years)
Immunomodulators	1338 (24.0)	3.56 ± 3.50	855 (28.3)	3.73 ± 3.57	421 (18.0)	3.15 ± 3.23
Steroids	3209 (57.6)	4.25 ± 5.60	1800 (59.5)	4.34 ± 5.61	1050 (45.0)	4.02 ± 5.51
5-aminosalicylic acid (5-ASA) therapies	3059 (54.9)	8.31 ± 6.85	1588 (52.5)	7.74 ± 6.50	1358 (58.2)	8.97 ± 7.20
Antibiotics	758 (13.6)	2.93 ± 4.63	541 (17.9)	3.00 ± 4.61	180 (7.7)	2.73 ± 4.95
Ciclosporin	212 (3.8)	1.15 ± 1.60	82 (2.7)	1.58 ± 1.95	116 (5.0)	0.85 ± 1.32
Biologics	286 (5.1)	1.68 ± 2.72	239 (7.9)	1.73 ± 2.79	34 (1.5)	0.94 ± 0.90
Surgery	1945 (34.9)		1572 (52.0)		290 (12.4)	
Don't know	211 (3.8)		86 (2.8)		114 (4.9)	
Have never been treated	426 (7.6)		210 (6.9)		207 (8.9)	

more likely in CD respondents (n=1289/1577, 81.7%) than in UC respondents (n=751/985, 76.2%).

#### 4. Discussion

Large-scale patient surveys such as this provide useful data to compare with clinical study data and epidemiological studies with a unique patient perspective. The numbers of respondents reporting comorbid conditions were higher than might be expected from published general population prevalences: rheumatoid arthritis was 15 times more common, ankylosing spondylitis 20 to 40 times more prevalent and psoriasis occurrence more than 10 times greater in the population surveyed than in the general population.<sup>21</sup> While these diagnoses are self-reported and have not been confirmed, this finding adds weight to the hypothesis that these conditions represent a common inflammatory mechanism affecting different bodily systems/organs. Furthermore, addressing the underlying inflammatory mechanism, rather than just symptoms, is likely to provide additional benefits to patients with comorbidities such as psoriatic arthritis which is a common comorbid condition in patients with inflammatory diseases like IBD.

**Table 4** Current therapies

Current treatment	Overall (n=5576), n (%)	CD (n=3025), n (%)	UC (n=2333), n (%)
Immunomodulators	1443 (25.9)	937 (31.0)	446 (19.1)
Steroids	1076 (19.3)	570 (18.8)	448 (19.2)
Anti-inflammatories/ 5-aminosalicylic acid (5-ASA) therapies	3109 (55.8)	1460 (48.3)	1539 (66.0)
Antibiotics	290 (5.2)	224 (7.4)	56 (2.4)
Ciclosporin	31 (0.6)	16 (0.5)	13 (0.6)
Biologics	211 (3.8)	178 (5.9)	27 (1.2)
Don't know	88 (1.6)	47 (1.6)	30 (1.3)
Not currently on treatment	1000 (17.9)	572 (18.9)	385 (16.5)

Self-reported treatment regimens suggest that a high proportion of patients with CD are receiving anti-inflammatory drugs including 5-ASA (48%); however, the recently published *European Crohn's and Colitis Organisation (ECCO) Consensus on the Management of Crohn's Disease* suggests a very limited role for 5-ASA in CD. They state that '5-ASA should be considered clinically no more effective than placebo for active ileal or colonic CD'.<sup>18</sup> Encouragingly, however, it appears that the majority of patients who received 'stepped up' therapy reported improvement of QoL in the following months, including over 50% (n=163/320) of CD patients who received the relatively new biologic therapy reporting that their QoL was greatly improved and a further 26.3% (n=84/320) somewhat improved. These data may also encourage the use of the 'top down' approach (the utilisation of more aggressive therapy at an early stage of the disease) in certain patient populations who may be predisposed to a more progressive disease state and potentially debilitating comorbid conditions that has been confirmed both clinically and biologically with the use of biomarkers for rapidly progressing disease.<sup>18,20</sup>

A high level of symptoms was reported with 69% reporting symptom flare-ups at least every few months. Yet, over three quarters (76.0%) of respondents reported that they were satisfied with the results obtained from their current medication, despite a similar proportion (75.6%) reporting that symptoms affect their ability to enjoy leisure activities. This suggests that many patients expect to adapt their lifestyles to allow for IBD. Furthermore, it suggests that patients may have low expectations of treatment for their condition. In this population, as in many clinical studies, patients had symptoms for a significant period of time.

Over half of respondents with CD (57.5%) had undergone surgical treatment. Although most of these respondents (87%) reported that their QoL improved following surgery, 69.3% experienced a recurrence of symptoms and 25.8% experienced serious complications. These complications include abdominal discomfort and pain, pelvic sepsis, hemorrhage and intestinal obstruction. In patients with UC, the median postoperative bowel frequency is five stools per day and one at night and at least 10% of patients need one or more additional surgical procedures for treatment of

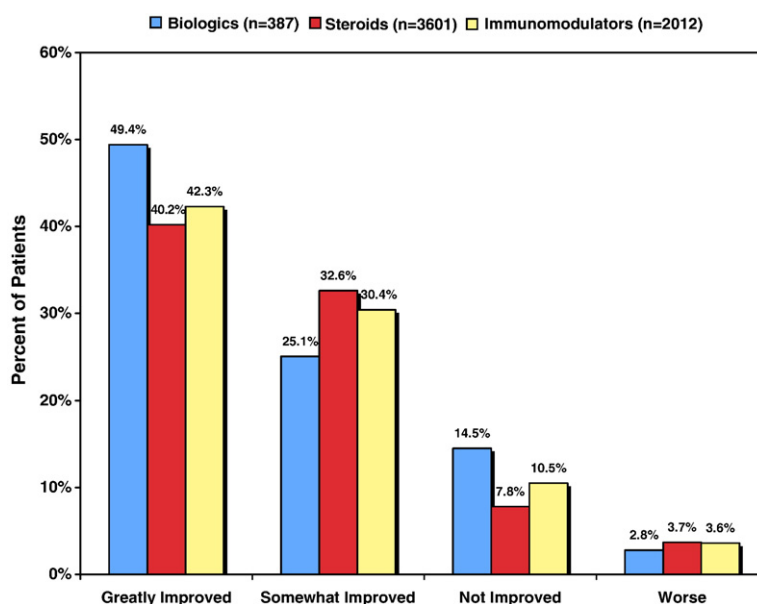


Figure 7 Impact on QoL afforded by different treatment options.

complications.<sup>22</sup> In addition, a 38.1% infertility rate has been reported for women with pelvic pouch surgery.<sup>23</sup> In addition, pouchitis can occur in 45% of patients<sup>24</sup> and seepage occurs in over 30% of patients.<sup>25</sup> With regard to CD, upwards of 50% of patients who underwent an initial surgery required additional surgeries.<sup>26</sup>

Therefore, recent advances in medical management indicate that the use of surgery as a means of relieving symptoms should be positioned only after available medical options have been exhausted.<sup>18</sup> It is therefore interesting that over 86% of respondents would prefer to try a new drug therapy rather than undergo surgery. As, historically, surgery was considered inevitable in CD patients, this response may surprise some; however, it clearly establishes that the majority of CD patients wish to avoid surgery and its associated risks and complications, if possible.<sup>18</sup>

According to this survey, discussion of disease-related issues impacting patient QoL is more likely to be initiated by the patient than their treating doctor. Intriguingly, QoL was less likely to be discussed, by either party, if UC was diagnosed rather than CD. The lack of discussion about QoL could reflect a general acceptance by both patients and physicians that IBD will inevitably negatively impact patients' lives. More encouraging is the suggestion that once physicians are aware of the impact of symptoms on a patient's QoL, the majority will take some action to address this.

It should be noted that the methods used in this survey create an inherent selection bias. First, as members of patient self-help organisations were approached, it is likely that they are aware of the issues associated with IBD and wish to generate more awareness of QoL issues. Second, those who chose to complete and return the survey may also experience a greater impact of symptoms on their everyday lives than those who did not respond. However, as nearly a fifth of respondents reported that they were not currently receiving any treatment for IBD, this suggests that

patients with milder symptoms were also represented in this sample. In addition, due to the number of responses (46% of surveys completed and returned), it can be concluded that a substantial proportion of the IBD community in the participant countries was represented. Therefore, even if the respondents represent a group with more severe symptoms/QoL impact, this group of patients is still sizeable and their views need to be considered. It cannot be determined from this survey whether non-responders were similar in demographic and disease characteristics to those who responded.

The responses to this survey suggest that QoL is not occupying a central role when the care of patients with UC or CD is considered. It has been proposed that the two most significant interventions to dramatically improve QoL and patient–physician relationships are proper patient education and appropriate treatment of concurrent depression and anxiety.<sup>8</sup> The goals of treatment should include the control of inflammation, mucosal healing and long-term remission. Physicians should also inquire as to the impact of IBD symptoms on patients' lives and discuss newer treatment options with them. In all dealings with IBD patients, physicians should remain aware of, and sensitive to, the detrimental effects of symptoms on patients' lives and seek to improve QoL using all the tools at their disposal.

## Acknowledgement

Responses were analysed by Fact and Figures Group (FFG), Germany—an independent opinion research institute.

Competing Interests: Professor S Ghosh has lectured in educational meetings sponsored by Schering-Plough and Centocor and has been a member of advisory boards to advise Schering Plough and Centocor about inflammatory Bowel Disease. In addition Schering Plough has supported research in Prof. Ghosh's department

Funding: Financial support for this survey was provided by Schering-Plough Corporation.



## Appendix A



### EFCCA Survey Questionnaire

*Thank you in advance for taking the time to answer the following questions. Please circle your selected answer or answers to each question.*

#### DEMOGRAPHICS/HISTORY

1. Please provide the following information:
  - a. Sex
    - i. Male
    - ii. Female
  - b. Age
    - i. Younger than 25 years old
    - ii. 25–29 years old
    - iii. 30–39 years old
    - iv. 40–49 years old
    - v. 50–59 years old
    - vi. 60–69 years old
    - vii. 70+ years old
2. Have you been diagnosed with Crohn's disease (CD)?
  - a. Yes
  - b. No
3. Have you been diagnosed with ulcerative colitis (UC)?
  - a. Yes
  - b. No

*(If answer to both 2 and 3 above is No, do not continue)*
4. How long has it been since your diagnosis?
  - a. 0 up to 1 years
  - b. 1 up to 2 years
  - c. 2 up to 3 years
  - d. 3 up to 4 years
  - e. 4 up to 5 years
  - f. More than 5 years
5. Has a close family member (e.g., parent and/or sibling) been also diagnosed with CD/UC?
  - a. Yes
  - b. No
6. What type of doctor diagnosed your UC/CD?
  - a. Family physician
  - b. Gastroenterologist
  - c. Other
7. What type of doctor is treating your UC/CD? Check all that apply.
  - a. Family physician
  - b. Gastroenterologist
  - c. Other
8. If yes to gastroenterologist, how many years did you experience symptoms before seeing a gastroenterologist?
  - a. 0 up to 1 years
  - b. 1 up to 2 years
  - c. 2 up to 3 years
  - d. 3 up to 4 years

- e. 4 up to 5 years
  - f. More than 5 years
9. Have you been diagnosed with any of the following?
    - a. Rheumatoid arthritis
    - b. Ankylosing spondylitis
    - c. Psoriasis
    - d. Psoriatic arthritis
    - e. Uveitis (inflammation of the middle layer of the eye)

#### TREATMENT

10. Prior to your current therapy, have you in the past been treated with any of the following medications; if so, how long? Please circle all that apply and indicate length of treatment as appropriate.

a. Immunomodulators (e.g., antimetabolite 6-mercaptopurine, azathioprine, methotrexate)	_____ years
b. Steroids (e.g., prednisone, prednisolone)	_____ years
c. 5-aminosalicylic acid (5-ASA) therapies (e.g., mesalamine, osalazine, sulfasalazine)	_____ years
d. Antibiotics (e.g., ciprofloxacin, clarithromycin, ampicillin)	_____ years
e. Cyclosporine	_____ years
f. Biologics (e.g., infliximab)	_____ years
g. Surgery	
h. Don't know	
i. Have never been treated	

11. Which of the following therapies are you currently receiving for CD/UC? Circle all that apply.
  - a. Immunomodulators (e.g., antimetabolite 6-mercaptopurine, azathioprine, methotrexate)
  - b. Steroids (e.g., prednisone, prednisolone)
  - c. Anti-inflammatories/5-aminosalicylic acid (5-ASA) therapies (e.g., mesalamine, osalazine, sulfasalazine)
  - d. Antibiotics (e.g., metronidazole, ciprofloxacin, clarithromycin, ampicillin)
  - e. Cyclosporine
  - f. Biologics (e.g., infliximab)
  - g. Don't know
  - h. Not currently on treatment
12. If yes to treatment with biologics in question 10 or 11, how would you rate the impact on your quality of life in the months following treatment?
  - a. Greatly improved
  - b. Somewhat improved
  - c. Not improved
  - d. Worse
13. If yes to treatment with steroids in question 10 or 11, how would you rate the impact on your quality of life in the months following treatment?
  - a. Greatly improved
  - b. Somewhat improved
  - c. Not improved
  - d. Worse

14. If yes to treatment with immunomodulators in question 10 or 11, how would you rate the impact on your quality of life in the months following treatment?
  - a. Greatly improved
  - b. Somewhat improved
  - c. Not improved
  - d. Worse
15. Are you satisfied with the results obtained from your current treatment medication?
  - a. Very satisfied
  - b. Somewhat satisfied
  - c. Somewhat dissatisfied
  - d. Very dissatisfied
16. Have you undergone surgery to treat your UC/CD?
  - a. Yes
  - b. No
17. If yes to question 16, how would you rate your overall quality of life following surgery?
  - a. Greatly improved
  - b. Somewhat improved
  - c. Not improved
  - d. Worse
18. If yes to question 16, have you had a recurrence of CD/UC symptoms after surgery?
  - a. Yes
  - b. No
19. If yes to question 16, have you had serious complications after your surgery?
  - a. Yes
  - b. No
20. If faced with the need to undergo surgery for UC/CD, would you be willing to try a new type of drug therapy as an alternative?
  - a. Yes
  - b. No
21. Does your doctor talk to you about newly developed treatments for CD/UC?
  - a. Yes
  - b. No
- b. Somewhat affect
- c. Do not affect
25. How do these symptoms affect your ability to perform in the job?
  - a. Greatly affect
  - b. Somewhat affect
  - c. Do not affect
26. Have you had to change jobs or alter your responsibilities because of your symptoms?
  - a. Yes
  - b. No
27. Do you initiate a discussion with your doctor about the impact of these symptoms on your quality of life?
  - a. Yes
  - b. No
28. Does your doctor ask you about the impact of these symptoms on your quality of life?
  - a. Yes
  - b. No
29. If yes to question 28, has your doctor taken action (e.g., changed treatment) to reduce the impact of your symptoms on your quality of life?
  - a. Yes
  - b. No

#### IMPACT OF SYMPTOMS ON QUALITY OF LIFE

22. Which of the following symptoms of CD/UC have you experienced? Please circle all that apply.
  - a. Painful stomach cramps
  - b. Persistent or recurrent diarrhea
  - c. Loss of appetite
  - d. Rectal bleeding
  - e. Weight loss
  - f. Fever
  - g. Joint pain
  - h. Fatigue
  - i. Skin tags
  - j. Fistulas
  - k. Sores around the anal area
23. How often do you experience symptom "flare-ups?"
  - a. Weekly
  - b. Monthly
  - c. Every few months
24. How do your symptoms affect your ability to enjoy leisure activities (e.g., travel, dining, sports)?
  - a. Greatly affect

#### References

1. Hanauer SB. Inflammatory bowel disease: epidemiology, pathogenesis, and therapeutic opportunities. *Inflamm Bowel Dis* 2006;**12**(Suppl 1):S3–9.
2. Papadakis KA, Targan SR. Role of cytokines in the pathogenesis of inflammatory bowel diseases. *Annu Rev Med* 2000;**51**:289–98.
3. Podolsky DK. Inflammatory bowel disease. *N Engl J Med* 2002;**347**:417–29.
4. Andres PG, Friedman LS. Epidemiology and natural course of inflammatory bowel disease. *Gastroenterol Clin North Am* 1999;**28**:255–81.
5. Loftus Jr EV, Sandborn WJ. Epidemiology of inflammatory bowel disease. *Gastroenterol Clin North Am* 2003;**31**:1–20.
6. Casati J, Toner BB. Psychosocial aspects of inflammatory bowel disease. *Biomed Pharmacother* 2000;**54**:388–93.
7. Sewitch MJ, Abrahamowicz M, Bitton A, et al. Psychological distress, social support, and disease activity in patients with inflammatory bowel disease. *Am J Gastroenterol* 2001;**96**: 1470–9.
8. Husain A, Triadafilopoulos G. Communicating with patients with inflammatory bowel disease. *Inflamm Bowel Dis* 2004;**10**: 444–50.
9. De Rooy EC, Toner BB, Maunder RG, et al. Concerns of patients with inflammatory bowel disease: results from a clinical population. *Am J Gastroenterol* 2001;**96**:1816–21.
10. Prantera C, Andreoli A. Prevention of relapse and recurrence. In: Prantera C, Korelitz BI, editors. *Crohn's disease*. New York: Marcel Dekker; 1996. p. 291–310.
11. Summers RW, Switz DM, Sessions Jr JT, et al. National Cooperative Crohn's Disease Study: results of drug treatment. *Gastroenterology* 1979;**77**:847–69.
12. Riley SA, Mani V, Goodman MJ, et al. Why do patients with ulcerative colitis relapse? *Gut* 1990;**31**:179–83.
13. Modigliani R, Mary JY, Simon JF, et al. Clinical, biological, and endoscopic picture of attacks of Crohn's disease. Evolution on prednisolone. *Gastroenterology* 1990 Apr;**98**(4):811–8.
14. Present DH, Korelitz BI, Wisch N, et al. Treatment of Crohn's disease with 6-mercaptopurine. A long-term, randomized, double-blind study. *N Engl J Med* 1980;**302**:981–7.

15. Bouhnik Y, Lemann M, Mary JY, et al. Long-term follow-up of patients with Crohn's disease treated with azathioprine or 6-mercaptopurine. *Lancet* 1996;**347**:215–9.
16. Rutgeerts P, Sandborn WJ, Feagan BG, et al. Infliximab for induction and maintenance therapy for ulcerative colitis. *N Engl J Med* 2005;**353**:2462–76.
17. D'Haens GR, Baert F, Assche G, et al. Better outcomes with potent top-down induction therapy in recent onset Crohn's disease. *Gut* 2005;**54**(Suppl VII):A17.
18. Travis SPL, Strange EF, Lémann M, et al. European evidence based consensus on the diagnosis and management of Crohn's disease: current management. *Gut* 2006;**55**(Suppl I):i16–35.
19. Hanauer SB. Crohn's disease: step up or top down therapy. *Best Pract Res Clin Gastroenterol* 2003;**17**:131–7.
20. Hommes DW, Baert F, Van Assche G, et al., Management of recent onset Crohn's disease: a controlled randomized trial comparing step-up and top-down therapy. *Gastroenterology* in press.
21. Williams JP, Meyers JA. Immune-mediated inflammatory disorders (I.M.I.D.s): the economic and clinical costs. *Am J Manag Care* 2002;**8**:S664–81.
22. Daperno M, Sostegni R, Scaglione N, et al. Outcome of a conservative approach in severe ulcerative colitis. *Dig Liver Dis* 2004;**36**:21–8.
23. Johnson P, Richard C, Ravid A, et al. Female infertility after ileal pouch-anal anastomosis for ulcerative colitis. *Dis Colon Rectum* 2004 (Jul);**47**(7):1119–26.
24. Carter MJ, Lobo AJ, Travis SPL. Guidelines for the management of inflammatory bowel disease in adults. *Gut* 2004;**53**(Suppl V):v1–16.
25. Delaney CP, Fazio VW, Remzi FH, et al. Prospective age-related analysis of surgical results, functional outcome and quality of life after ileal pouch-anal anastomosis. *Ann Surg* 2003;**238**: 221–8.
26. Brown CJ, Maclean AR, Cohen Z, Macrae HM, O'Connor BI, McLeod RS. Crohn's disease and indeterminate colitis and the ileal pouch-anal anastomosis: outcomes and patterns of failure. *Dis Colon Rectum* 2005;**48**:1542–9.