

## Inflammatory Bowel Disease: A Patient's and Caregiver's Perspective

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**Abstract** The purpose of this study was to conduct a survey examining the impact of inflammatory bowel disease (IBD) on patients' and their caregivers' daily activities. Questionnaires were distributed to patients registered in the APDI (Portuguese Association for IBD) database and their respective caregivers in 2007. Of 422 patient respondents, 251 had Crohn's disease (CD) and 171 had ulcerative colitis (UC), with the majority of patients being women (58.1%) and aged over 40 years (37.4%). The number of disease flares experienced by IBD patients was slightly higher for patients with CD than for patients with UC (2.64 vs. 2.34), and surgery was more often required in CD patients as compared to UC patients (42.4 vs. 7%). Sixty percent (60%) of patients reported having no problems with mobility, daily activities, or personal hygiene; however, over half of all patients experienced some pain and anxiety. Adult patients and children and adolescents respectively experienced time off work or school due to their disease but caregivers were not affected in this regard. The caregivers life ( $N = 324$ ) was affected by anxiety, with the major concern reported as the risk of the patient developing cancer. Both IBD patients and caregivers thought that the provision of information on new drugs and contact time with a doctor would have the biggest impact on improving care. The symptoms and

complications of IBD have a considerable impact on the lives of patients and their caregivers, and several actions could be taken to improve their care.

**Keywords** Inflammatory bowel disease · Crohn's disease · Ulcerative colitis · Patient's perspective of life · Caregiver's perspective of life · Quality of life

### Introduction

Inflammatory bowel disease (IBD) encompasses both ulcerative colitis (UC) and Crohn's disease (CD). The clinical course of IBD is characterized by flares followed by periods of remission. The treatments for IBD have been proven to be effective in controlling disease symptoms; however, only the new drugs, namely, anti-TNF antibodies have demonstrated an ability to change the natural history of disease [1]. It has been recognized that understanding the impact on quality of life of IBD is important in determining which aspects of the disease could be improved to meet patients' needs [2] and to optimize healthcare for both patients and caregivers. Previous studies have already revealed that physicians frequently underestimate the physical [3] and functional [4] impairment in CD.

Health-related quality of life (HRQoL) is a global concept that incorporates the patients' perceptions, attributions, and daily level of function in response to an illness. It is influenced by social, cultural, psychological, and disease-related factors [5, 6]. In Portugal, data in this area are generally lacking. Thus, the aims of this study were to characterize the clinical aspects of the disease as experienced by patients, such as symptoms, complications, and treatment; to examine how the day-to-day lives of patients and their caregivers have been affected; and to

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identify which actions could be taken to improve the QoL of patients and their caregivers.

## Methods

In total we estimate that there are approximately 12,500 patients with IBD in Portugal. A questionnaire was distributed to patients registered in the APDI database (national database) and their respective caregivers (defined as the person who spends the most time caring for the patient, providing necessary assistance and supervision) by mailing in May 2007 and the survey was closed to respondents in August 2007. The decision of who is the caregiver was made by the patient (the definition of caregiver was supplied and explained to the patient). The survey to the patients consisted of 32 questions and captured information on age of disease onset, duration of disease, symptom profile, treatments, and impact on daily activities and living. Quality of life was evaluated using a visual analogue scale (VAS). Survey questions were structured into two categories—dichotomous and multiple choice. In addition to this clinical evaluation, patients were surveyed on which types of information or initiatives could improve their lives and also how their condition had affected their work and productivity. In this last instance, the work productivity and activity impairment questionnaire was used: inflammatory bowel disease (WPAI: IBD). This consists of six sub-questions and was translated into Portuguese and locally validated as fit for purpose. The survey to the caregivers consisted of 13 questions structured into two categories—dichotomous and multiple choice. For caregivers, in addition to age, gender, and caregiver–patient relationship, they were surveyed on which types of information or initiatives could improve their lives and also how their condition had affected their work and productivity. In patients and caregivers questionnaires the auto-filling method was applied. Descriptive statistics were used to evaluate the response. The Chi-squared test and Fisher's exact test were used when testing the hypothesis regarding categorical variables. All aspects of survey distribution and analysis were conducted by an independent organization in Portugal specializing in patient-level surveys.

## Results

### Demographics

A total of 422 patients (23% of replay) took part in the survey and completed questionnaires with the majority being women (58.1 vs. 36.3%, respectively, gender was not

recorded in 5.7% of cases). Of the 422 respondents, 251 had CD (6.1% sample precision for a confidence interval of 95%) and 171 UC (7.4% sample precision, 95% CI), and 37.4% of patients were older than 40 years. The median age at diagnosis was 28 years for CD patients and 31 years for UC patients, with a relatively even distribution of duration of disease across the 1–4, 5–9, and 10–15 year groupings (Table 1).

### Symptoms

Diarrhea, abdominal pain, and weight loss were the most commonly reported symptoms by all patients. Loss of appetite, fever, skin lesions, and acute episodes requiring surgery were reported by more CD patients than UC patients (Fig. 1a). The dominant complaint by CD patients was abdominal pain, with 56.6% reporting this as the main symptom of their disease. Rectal bleeding was the dominant complaint of UC patients, with 71.3% of patients reporting this as the main symptom (Fig. 1b).

### Flares

The number of disease flares experienced by IBD patients was slightly higher for patients with CD than for patients with

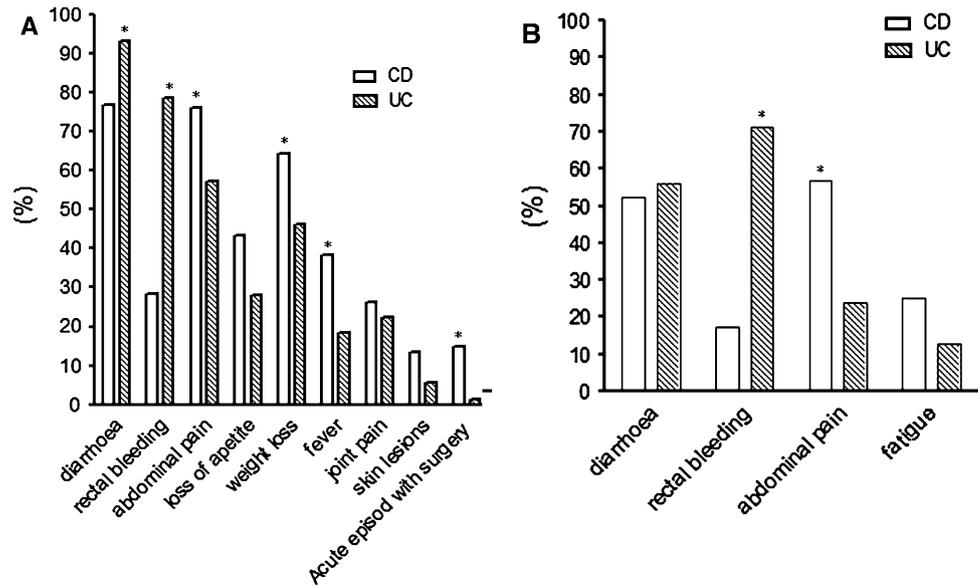
**Table 1** Baseline population characteristics

Characteristic	CD ( <i>n</i> = 251) <i>n</i> (%)	UC ( <i>n</i> = 171) <i>n</i> (%)	Total ( <i>n</i> = 422) <i>n</i> (%)
Gender			
Male	87 (34)	66 (38)	153 (36)
Female	155 (62)	90 (53)	245 (58)
No response	9 (4)	15 (9)	24 (5.7)
Age of patients			
<20 years	4 (1.5)	6 (3.5)	10 (2.4)
20–25 years	22 (8.7)	11 (6.4)	33 (7.8)
26–30 years	13 (12.7)	18 (10.5)	50 (11.8)
31–35 years	63 (25)	25 (11.6)	88 (20.9)
36–40 years	30 (11.9)	29 (16.9)	59 (14.0)
≥40 years	91 (36.2)	67 (39.1)	158 (37.4)
No response	9 (3.5)	15 (8.7)	24 (5.7)
Years at diagnosis*	28.1 ± 10.8	30.8 ± 12.6	29.2 ± 11.7
Years of disease			
<1	9 (3.6)	7 (4.1)	16 (3.8)
1–4	71 (28.3)	56 (32.7)	127 (30.1)
5–9	59 (23.5)	28 (16.4)	87 (20.6)
10–15	62 (24.7)	55 (32.2)	117 (27.7)
>15	49 (19.5)	25 (14.6)	74 (17.5)
No response	1 (0.4)	0	1 (0.2)

\* Median ± SD (years)

CD Crohn's disease, UC ulcerative colitis

**Fig. 1 a** Most common reported symptoms by patients. **b** Predominant symptoms experienced by responders. \* $P < 0.005$



UC, but this difference was not significant (2.64 vs. 2.34,  $P = 0.441$ ) (Fig. 2a). Flares were reported most often in the spring, especially by CD patients, with the lowest number of flares occurring in the summer. A stressful episode in a patient's life appeared to have a greater impact on the number of flares experienced than did the time of year, with almost a third of patients reporting that flares were more frequent during stressful times (Fig. 2b). The number of medical visits (mean), nursing care, ambulatory hospital care, and visits to hospital due to flares reported by year are represented in Fig. 2c. It is interesting to note that CD patients needed more nursing care than UC patients ( $P < 0.05$ ).

### Medical Treatment

IBD patients responding to the survey were using a variety of treatments routinely to control their disease. When patients experienced flares, steroids, and 5-aminosalicylic acid were the most commonly reported interventions. Antibiotics and immunomodulators were taken more often by CD patients, and the newer biological drugs were used in both patient groups but much less frequently than the other treatments (Fig. 2d). 5-Aminosalicylic acid preparations were commonly used, as were steroids (65%) and the immunomodulator azathioprine (38%). Relatively few patients in Portugal (6.9% overall) received the newer biological therapies (Table 2). When asked if the medications that were taken caused the patients to experience any side effects, over a third of respondents answered 'yes'.

### Surgery

Over 40% of CD patients had required surgery due to their IBD compared to only 7% of UC patients (Fig. 3a). Of the

CD patients who had surgery due to IBD, 19% were ostomized (temporarily or permanently) in comparison with 42% of patients with UC (Fig. 3b).

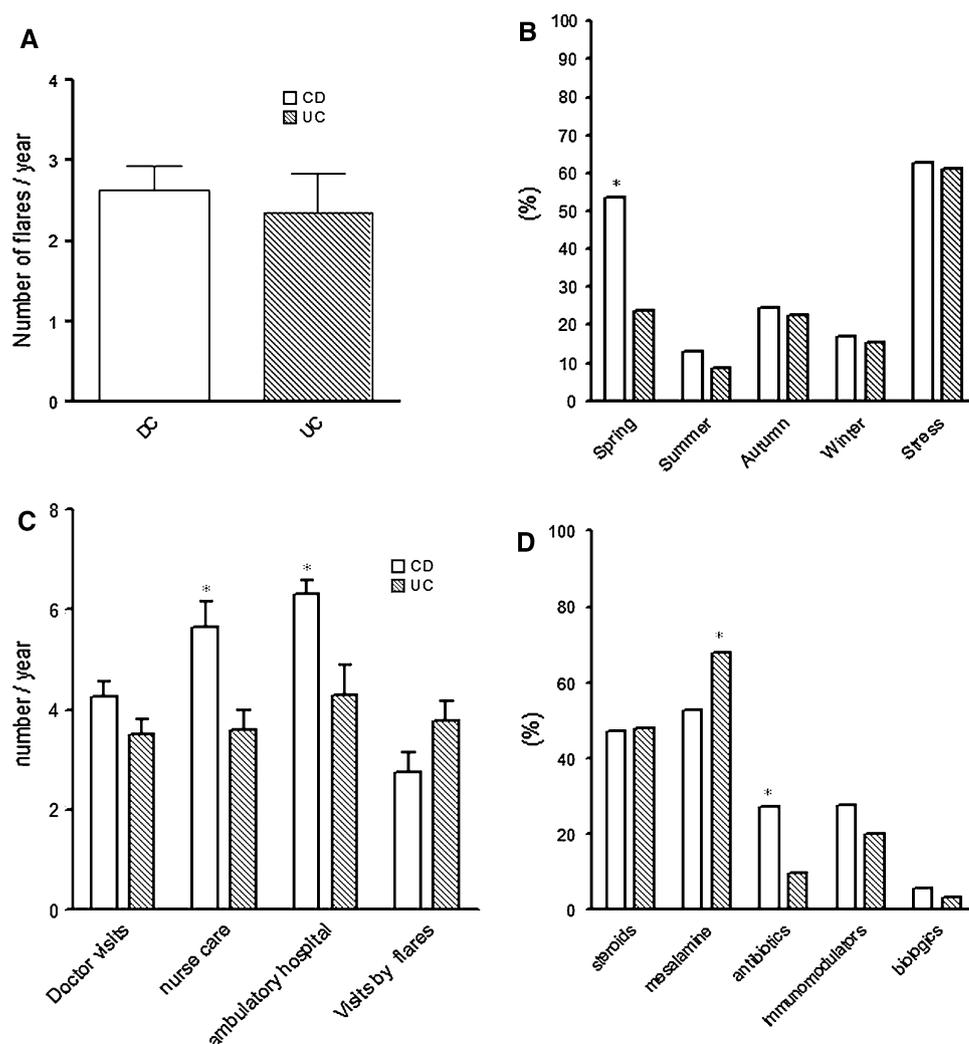
### Quality of Life

Five quality of life domains were evaluated in the survey. Over 80% of all patients reported having no problems with their mobility, nearly 60% with daily activities, and 89% with personal hygiene. It is very interesting to note that results in the first two domains were linked to gender—24.2% of females reported some problems with their mobility (14.3% for males,  $P < 0.001$ ) and 37% of females felt some daily activity limitations (30% males,  $P = 0.001$ ). Problems with personal hygiene were more frequent in those with a basic level of education (18.3 vs. 9.0%,  $P = 0.02$ ). Over half of all patients (59%) had experienced pain at some time or severe pain compared with 37% of patients who had not experienced any pain. Similar findings were reported in the anxiety/depression domain, with both domains (pain and anxiety) related to gender ( $P < 0.001$ ). The effect on overall quality of life was similar for both CD patients and UC patients and was not related to gender. On the VAS scale, where 0 represented the worst quality of life and 100 excellent health status, the average score for all patients in the survey was 71 (Table 3).

### Effect on Work

Problems associated with the symptoms of IBD were found to interfere with working capacity, with some patients reporting the need to take time off work or school. IBD patients in the survey reported that 2 h 48 min (7.5% of a typical EU working week) of work

**Fig. 2** **a** Number of flares per year (mean  $\pm$  SEM) in CD patients and in ulcerative colitis patients. **b** Relative frequency reported by CD and UC patients in relation to time of year and stress. **c** Number of medical consultations (mean  $\pm$  SEM), nursing care, ambulatory hospital care, and visits to hospital by flares reported by year. **d** Treatment reported to be taken during flares. \* $P < 0.005$



had been lost in the past seven days due to the symptoms of IBD. When analyzed by disease type, UC patients lost more working time than CD patients, 3.8 h (10.1%) per week versus 2.3 h (6.1%) per week, respectively (Fig. 4a). The productivity of IBD patients while at work was also affected. Work productivity was measured on a scale of 1–10; a score of 1 represented no effect of the symptoms of IBD on the ability to work and a score of 10 meant that a patient's ability to work was completely restricted by their disease symptoms. In the survey, CD patients scored an average of 2.7 and UC patients an average of 2.4 on the productivity scale. The problems associated with IBD occasionally led to a respondent losing a job, missing a school year, or not being offered employment (Fig. 4b). School-aged children with CD were more likely to miss a whole school year than children with UC (16.4 and 9.4%, respectively), whereas the percentage of adults who lost a job because of their disease was similar in both CD and UC patients (10.0 and 8.8%, respectively).

#### Caregivers

As described above, patients with IBD in the survey experienced many problems related to their disease; however, the lives of people who care for patients with IBD were also found to be affected, especially in the areas of quality of life and employment. A total of 324 caregivers of IBD patients returned completed questionnaires, of which 202 were carers of CD patients (margin of error 6.8%, 95% CI) and 122 (margin of error 8.8%, 95% CI) were carers of UC patients. The majority of caregivers were older than 40 years and a total of 58% in both categories were female (Table 4). Ninety-three percent of carers were patients' relatives (61% were spouses, 19% were the mother, and 6% a child carer). The impact of live caregivers in both CD and UC patients was most affected by the presence of tension due to caring for the patient with IBD, followed by conflict with the patient themselves (Fig. 5a, b).

Furthermore, manipulation by the patient and unreasonable requests from the patient also had an effect on the

**Table 2** Therapies in the last year

Therapies	CD <i>n</i> (%)	UC <i>n</i> (%)	Total <i>n</i> (%)
<b>5-Aminosalicylic acid</b>			
Eudragit L	111 (44.2)	128 (74.9)	239 (56.6)
Eudragit S	24 (9.6)	29 (17.0)	53 (12.6)
Eudragit L/S	21 (8.4)	27 (15.8)	48 (11.4)
Slow release	108 (43.0)	44 (25.7)	152 (36.0)
Sulfasalazine	18 (7.2)	22 (12.9)	40 (9.5)
<b>Steroids</b>			
Prednisolone	94 (37.5)	69 (40.4)	163 (38.6)
Methylprednisolone	11 (4.4)	2 (1.2)	13 (3.1)
Budesonide	63 (25.1)	33 (19.3)	96 (22.7)
<b>Immunomodulators</b>			
Azathioprine	113 (45.0)	48 (28.1)	161 (38.2)
Methotrexate	7 (2.8)	2 (1.2)	9 (2.1)
Antibiotics	101 (40.2)	36 (21.1)	137 (32.5)
Biologics	23 (9.2)	6 (3.5)	29 (6.9)
<b>Side effects</b>			
Yes	91 (36.3)	64 (37.4)	155 (36.7)
No	146 (58.2)	103 (60.2)	249 (59.0)
No response	14 (5.6)	4 (2.3)	18 (4.3)

CD Crohn’s disease, UC ulcerative colitis

**Table 3** Impact of inflammatory bowel disease on quality of life

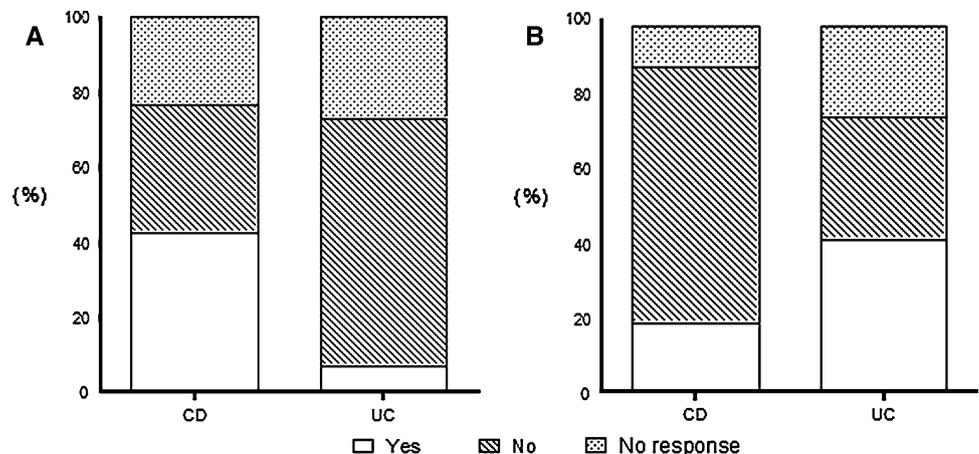
Evaluation criteria	CD <i>n</i> (%)	UC <i>n</i> (%)	Total <i>n</i> (%)
<b>Mobility</b>			
Without problems	204 (81.3)	132 (77.2)	336 (79.6)
Some problems	36 (14.3)	33 (19.3)	69 (16.4)
Most time spent in bed	2 (0.8)	1 (0.6)	3 (0.7)
<b>Daily activity</b>			
Without problems	158 (62.9)	107 (62.6)	265 (62.8)
Some problems	79 (31.5)	57 (33.3)	136 (32.2)
Unable to do	3 (1.2)	3 (1.8)	6 (1.4)
<b>Personal hygiene</b>			
Without problems	226 (90.0)	150 (87.7)	376 (89.1)
Some problems	12 (4.8)	13 (7.6)	25 (5.9)
<b>Pain</b>			
Without	92 (36.7)	66 (38.6)	158 (37.4)
Sometimes	145 (57.8)	88 (51.5)	233 (55.2)
Severe	7 (2.8)	9 (5.3)	16 (3.8)
<b>Anxious/depressed</b>			
Without	87 (34.7)	51 (29.8)	138 (32.7)
Moderate symptoms	139 (55.4)	93 (54.4)	232 (55.0)
Severe symptoms	16 (6.4)	19 (11.1)	35 (8.3)
Overall feeling	70.5 ± 20	71.3 ± 18.6	70.8 ± 19.5

CD Crohn’s disease, UC ulcerative colitis

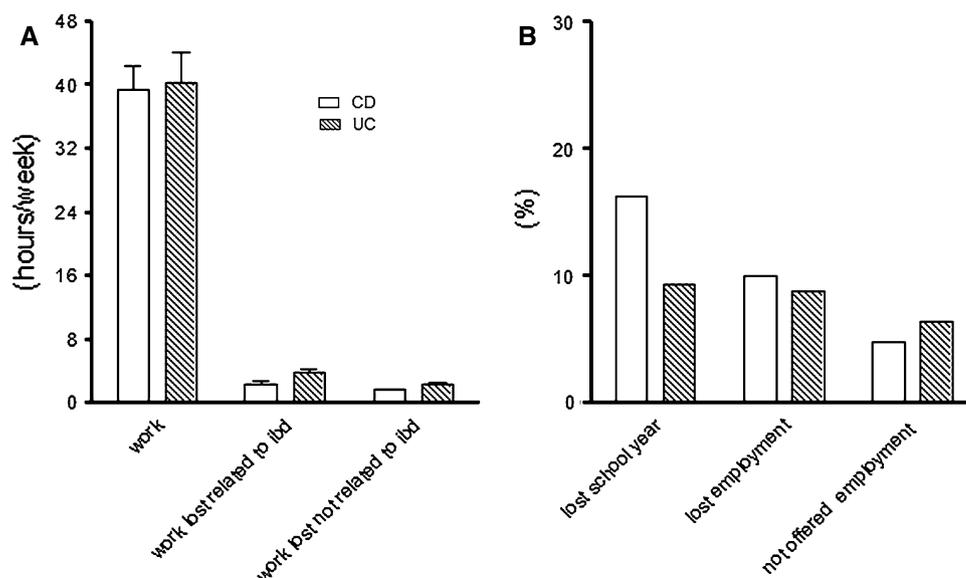
caregivers’ life. Having time to themselves, privacy, and time for hobbies had the least effect on the caregivers. The impact on the ability to work of the caregivers of IBD patients was not affected in the majority of carers (87% of CD carers and 89% of UC carers). However, caring for a patient with IBD does have an impact on some aspects of work function, with 10.5% of CD patient carers and 5.7% of UC patient carers either retiring early, changing to part-time work or a less demanding job, or being dismissed from a job (Fig. 6a). The ability to work was related to

gender (affecting 11.8% of females and 7.5% of males,  $P < 0.017$ ), level of education (affecting 25.5% caregivers with basic education and 4.6% of those with at least one university degree,  $P < 0.0001$ ), and age (affecting 15% of those older than 40 years and 4.5% of those younger than 40 years,  $P < 0.001$ ). The major worry of caregivers linked to IBD was the risk of the patient developing cancer, but other key worries included a lack of information and knowledge about the disease, and family and social problems such as work and school (Fig. 6b).

**Fig. 3** a Percentage of patients submitted to surgery. b Relative frequency of patients submitted to surgery and being ostomized



**Fig. 4 a** Number of hours worked (mean  $\pm$  SEM) and amount of work lost by week related to IBD and no IBD related events. **b** Impact of CD and UC on work



**Table 4** Baseline population characteristics of caregivers

Population characteristics	CD (n = 202) n (%)	UC (n = 122) n (%)	Total (n = 324) n (%)
<b>Gender</b>			
Male	85 (42)	45 (37)	130 (40)
Female	111 (55)	76 (62)	187 (58)
No response	6 (3)	1 (1)	7 (2)
<b>Age of caregivers</b>			
<20 years	3 (1.5)	1 (0.8)	4 (1.2)
20–25 years	7 (3.5)	5 (4.1)	12 (3.7)
26–30 years	14 (6.9)	5 (4.1)	19 (5.9)
31–35 years	30 (14.9)	17 (13.9)	47 (14.5)
36–40 years	29 (14.4)	17 (13.9)	46 (14.2)
≥40 years	74 (56.9)	74 (60.7)	189 (58.3)
No response	4 (2.0)	3 (2.5)	7 (2.2)
<b>Education level</b>			
Basic	53 (26.2)	34 (27.9)	87 (26.9)
High-school diploma	88 (43.6)	50 (41.0)	138 (42.6)
Bachelor degree	4 (2.0)	2 (1.6)	6 (1.9)
First degree	49 (24.3)	29 (23.8)	78 (24.1)
Post-graduate	6 (3.0)	7 (5.5)	13 (4.0)
No response	2 (1.0)	0	2 (0.6)

CD Crohn's disease, UC ulcerative colitis

#### Actions to Improve IBD Care

Another objective of the questionnaire was to discover which actions could be taken to improve the lives of both the IBD patients and their caregivers. Both IBD patients and caregivers thought that information on new drugs and

having regular contact with a doctor would have the biggest impact on improving care. Patients and caregivers also agreed that the actions that would have the smallest impact on improving care would be talking about IBD, having internet contact with other IBD patients, and participating in patient groups. However, caregivers with a basic level of education considered these latter actions more relevant than those with a university degree (very important to 44.3% caregivers with basic education vs. 15.2% caregivers with a university degree,  $P < 0.001$ ). Generally, patients and caregivers thought that all of the initiatives mentioned would have a positive impact on care (Fig. 7a, b).

#### Discussion

The prevalence of IBD in Portugal is estimated to be 118 per 100,000 inhabitants, thereby leading to an estimated 12,500 Portuguese patients with IBD. This figure is based on mesalamine consumption during the year 2005 and a daily drug intake-defined dose of 2 g/day. The same study estimated a prevalence of CD of 60 per 100,000 inhabitants, giving an estimated 6,400 Portuguese patients with CD [7]. It is possible to use mesalamine consumption as a measure of CD prevalence in Portugal as most patients with CD are prescribed this drug. The results reported in this study are most probably representative of a population of IBD patients in Portugal because 251 valid questionnaires from CD patients (margin of error 6.1%; 95% CI) and 171 questionnaires from UC patients (margin of error 7.4%; 95% CI) were analysed and it was not a single hospital cohort. Only consecutive non-selected out-patients were included. At least 45% of the patients studied had

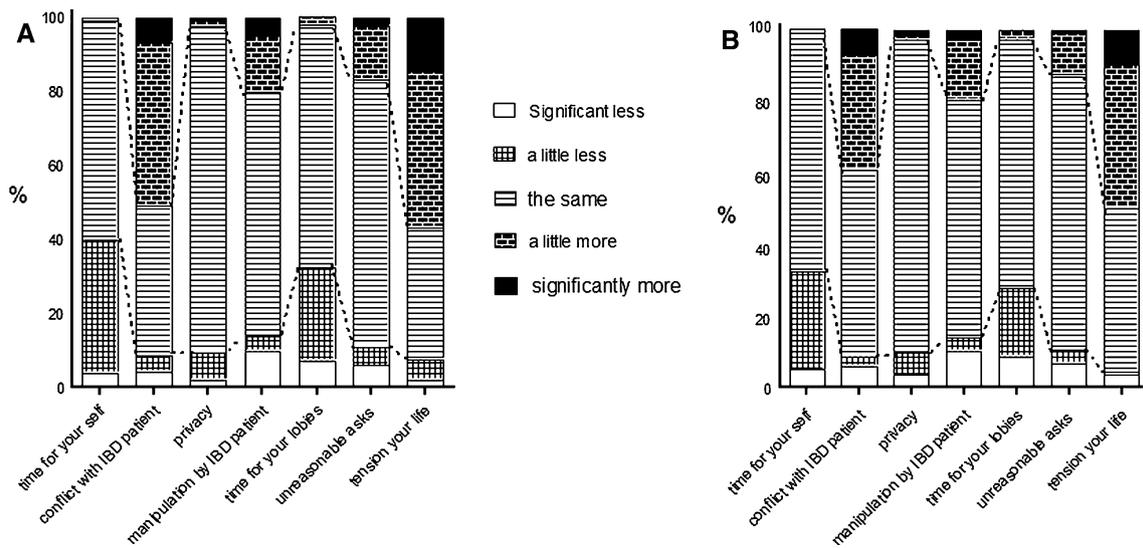


Fig. 5 Impact on life events in caregivers of patients with CD (a) and UC (b)

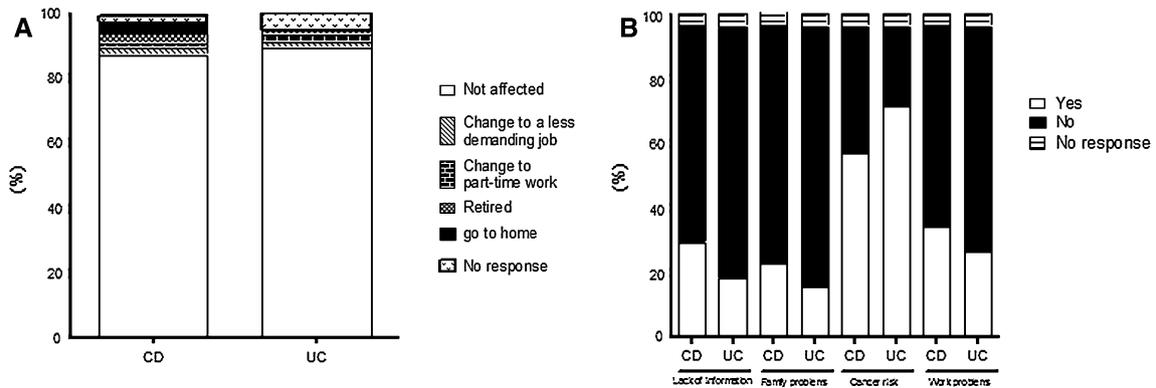


Fig. 6 a Impact on work capability in patients caregivers. b Major fears of the family linked to IBD

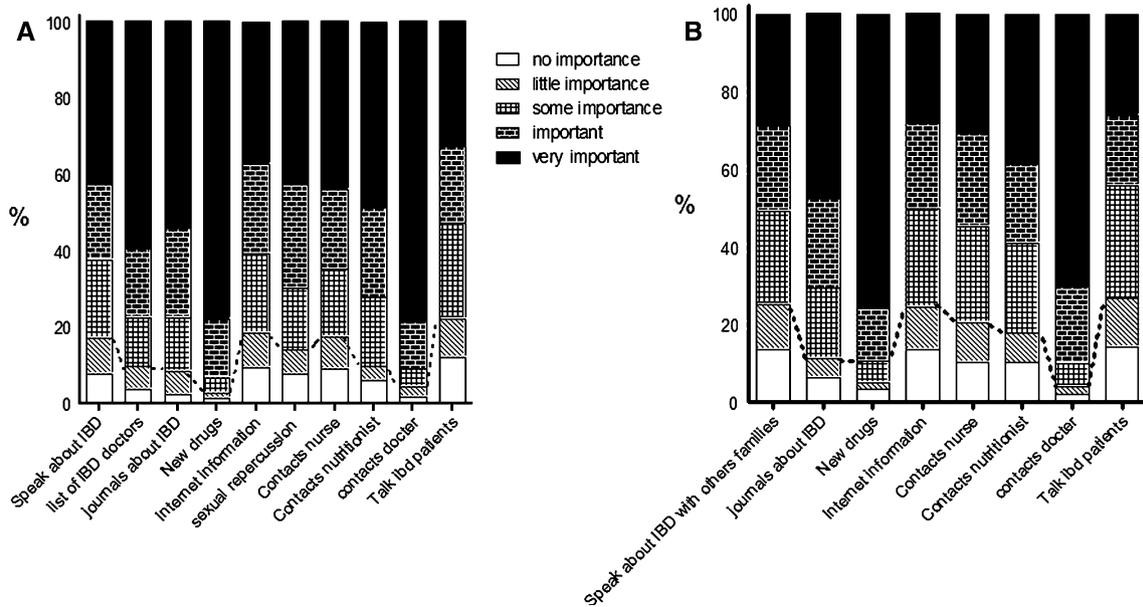


Fig. 7 Actions to improve care for IBD patients (a) and IBD patients' caregivers (b)

been diagnosed with IBD more than ten years previously, suggesting that the responses were provided by a study population with a good understanding of their condition. The patients' distribution according to type of disease (UC vs. CD) is similar to the findings of other studies of IBD. For example, Ghosh et al. and Levenstein et al. reported on the demographics of IBD in multiple countries [8, 9], and determined the split of CD and UC patients to be 57 and 43%, respectively. This is very similar to the numbers found in our series (59% for CD, 41% for UC). The percentage of females reported in these three studies ranges from 56 to 58%, and they report similar results for age range and number of years since diagnosis.

In our survey the most commonly reported symptoms of IBD were diarrhea and rectal bleeding, with rectal bleeding being more frequent in UC patients, and approximately 15% of CD patients required surgery for an acute abdominal event. An average of 2.5 disease flares per year was reported and most of them were related to episodes of stress and had a seasonal component; the greatest numbers of disease flares occurred in the spring. Crohn's disease has been shown to be sensitive to the effects of stress in about 50% of patients [10] and responsible for 40% variance in the frequency of abdominal pain.

A step-up strategy is probably the major approach used in Portugal as all IBD patients had taken mesalamine in the last year and 64% of the population had used steroids. It is interesting to note however, that 38% of patients in the survey had taken immunomodulators and 7% had taken biologics. About a third of the participants in the study reported that these medications caused side effects. In a study by Ghosh et al. [8], the treatment of patients has some similarities, although use of steroids and immunomodulators was more common in Portugal than in Western Europe as a whole, and surgery was found to be performed less often in Portugal. The assessment of quality of life in the survey based on a VAS was 71, with most experiencing no problems with mobility, daily activity, or personal hygiene. However, 63% of patients reported symptoms of depression and anxiety at some time. It is not known how these figures compare to those observed in the general population in Portugal, but other studies have reported rates of depression three times that seen in the general population [11]. Casellas et al. also used a VAS to assess the quality of life of CD patients in Spain [12] with comparable results ranging from median scores of 60.0 to 70.0 depending on age, disease location, and disease behaviour. Of the five quality of life domains evaluated, three of them (mobility, daily activity, and anxiety/depression) were related to gender, and problems with personal hygiene were more frequent in those with lowest level of education. This has been previously reported by Irvine [13], who reported that HRQoL is linked to non-disease elements such as

gender, age, cultural factors, and coping skills, as well as disease elements.

It is often difficult to compare the quality of life results found in different studies as a variety of methods for measuring quality of life have been used. Five different factors have been reported to be associated with HRQoL: disease activity [14–16], psychological status [17, 18], coping patterns [19], and social support [20]. Furthermore, the method of administration of the questionnaire, either by interview or self-reported, appears to affect results, with better HRQoL scores seen from self-reporting questionnaires [14]. The productivity and the number of hours worked by patients in the survey was not substantially affected by symptoms, even though some school-aged children missed an entire school year (16.4% of CD and 9.4% of UC patients) and a minority of adults reported losing a job (10.0% CD and 8.8% of UC patients). It is not clear if this figure is similar in a matched demographic group in the general population. This suggests that the symptoms associated with IBD do have some impact on the ability to work normally and on the education of some patients. Ananthakrishnan et al. [21] found a permanent work disability in 5.3% of CD patients and that this was related to the number of surgeries or medical hospitalizations the patient had experienced. Disease location (small bowel vs. colon), disease type (inflammatory, stricturing, or fistulizing), or specific treatment strategies were not found to be associated with increased work disability.

This study also found that the life of caregivers of IBD patients is substantially affected by anxieties, tension, and conflict between the caregiver and the patient, and approximately 20% of caregivers suffer from manipulation by the patient. The major worry of caregivers linked to IBD was the risk of the patient developing cancer as well as fear of family and social problems such as those related to work and school activities. In fact, the ability to work of some caregivers was found to be affected, with 10.5% of CD patient carers and 5.7% of UC patient carers either retiring early, changing to part-time work or to a less demanding job, or being dismissed from a job. Actions that respondents thought would have the greatest impact on improving care of both IBD patients and caregivers were thought to be the availability of more information on new drugs and having more contact time with a doctor. It is very interesting to note that initiatives by various IBD support or representative groups were felt to have limited value.

It should be noted that the methods used in this survey created an inherent selection bias similar to that in the study by Ghosh et al. [8] in that members of patient self-help organizations are very familiar with the issues associated with IBD and wish to generate more awareness of QoL issues and 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. It cannot be determined from this survey whether non-responders were similar in demographic and disease characteristics to those who responded.

Overall, results from this study have shown that the symptoms and complications of IBD have a considerable impact on the lives of patients and their caregivers. There are several actions that could be taken which both patients and their caregivers thought would make an improvement in QoL.

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