

Original Article

Self-reported Symptom Burden in Individuals with Inflammatory Bowel Disease

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Abstract

Background and Aims: Individuals with inflammatory bowel disease experience debilitating symptoms on a daily basis, but little is known about symptom burden in IBD. The objectives were to (i) identify the most prevalent symptoms and the average number of symptoms experienced; (ii) assess symptom frequency, severity and distress; and (iii) determine the most burdensome symptoms experienced by individuals with inflammatory bowel disease.

Methods: A cross-sectional descriptive design was used to collect data in a single regional treatment centre in Ireland. A consecutive and unique sample of 247 individuals diagnosed with Crohn's disease and ulcerative colitis completed a modified disease-specific version of the Memorial Symptom Assessment Scale.

Results: Participants reported experiencing a median of 10 symptoms during the last week, but as many as 16 symptoms were experienced by those with active disease. Of the symptoms experienced, lack of energy was identified as the most burdensome symptom. Bowel symptoms of urgency and diarrhoea and irritable bowel syndrome-type symptoms such as feeling bloated and flatulence were also problematic. Worry was ranked the most burdensome psychological symptom experienced. Symptom burden scores varied according to disease type and disease status, with significant differences found between those with active and inactive disease.

Conclusions: Individuals with inflammatory bowel disease experience a considerable number of symptoms and are burdened by both physical and psychological symptoms, particularly during active disease. Healthcare professionals' focus of assessment needs to be broadened to encompass multiple symptoms. Greater attention needs to be given to fatigue and psychological symptoms.

Key Words: Inflammatory bowel disease; symptoms; symptom burden

1. Introduction

Inflammatory bowel disease (IBD) represents a group of chronic, complex inflammatory disorders of the digestive tract. Crohn's disease and ulcerative colitis are the two main commonly recognized forms of IBD and are characterized by periods of relapse and remission. Over the last decade the incidence and prevalence of IBD has significantly increased and it has been recently recognized as a global long-term condition.^{1,2} Approximately 5 million people are diagnosed with IBD worldwide, with a prevalence of between 2.5

and 3 million in Europe. Cardinal symptoms of IBD include diarrhoea, abdominal pain, weight loss and rectal bleeding. In addition, it is now known that individuals with IBD experience irritable bowel syndrome-type symptoms, such as flatulence and bloating, particularly during periods of remission.^{3,4} These symptoms can be particularly problematic for patients on a daily basis and raise the question of whether patients experience symptom burden. To date, there has been little research investigating symptom burden among patients with IBD. Many researchers have measured disease activity

in terms of relapse and remission. Various endoscopic, clinical and histological indices exist, with the Harvey–Bradshaw Index (HBI)⁵ and the Simple Clinical Colitis Activity Index (SCCAI)⁶ among the most commonly used clinical indices in Crohn's disease and ulcerative colitis respectively. However, these clinical indices are limited in terms of assessing symptoms from the patient's perspective and provide little information with regard to symptom burden.⁷

The aim of this paper is to present results of research on the self-reported symptom burden of individuals with IBD. The objectives were to (i) identify the most prevalent symptoms and the average number of symptoms experienced; (ii) assess the symptom frequency, severity and distress; and (iii) determine the most burdensome symptoms experienced by individuals with Crohn's disease and ulcerative colitis, including those with active and inactive disease.

2. Methods

2.1. Sample and procedure

A descriptive, cross-sectional design was used as part of a larger mixed methods study. The study setting was an outpatient IBD clinic in one large acute urban university teaching hospital in the Republic of Ireland. Data were collected from a consecutive and unique sample of patients ($n = 247$) drawn from the caseload of one consultant physician. Inclusion criteria included individuals with a documented diagnosis of either Crohn's disease or ulcerative colitis in their medical records. In addition, participants were required to be aged 16 years or over, able to understand and speak English and to have no history of cognitive impairment.

Nursing staff screened the medical records to establish potentially eligible participants. Information about the study, including an information leaflet, was provided to potential participants. Following agreement to participate, informed written consent was obtained. Patients completed the questionnaire during their clinical visit. The researcher was available during this time to address any questions raised. Prior to the main study, a pilot study was conducted to test the feasibility of the study and ethical principles were upheld throughout. Ethics approval was sought and granted from the local ethics committee.

2.1. Measures

Symptom burden was assessed using a 45-item modified disease-specific version of the Memorial Symptom Assessment Scale (MSAS) for IBD. The original 32-item MSAS was developed by Portenoy et al.⁸ in cancer populations and has since been used as a reliable and valid measure of symptom burden in other chronic illnesses.^{9,10} Following a review of the literature, a total of 13 IBD-specific symptoms were added to the original MSAS, yielding a total of 35 physical symptoms and 10 psychological symptoms. Participants reported the presence or absence of symptoms during the previous week. For each symptom experienced, participants rated the frequency, severity and distress experienced using Likert scales. Four-point Likert scales were used for measuring self-reported symptom frequency (1 = rarely to 4 = almost constant) and symptom severity (1 = slight to 4 = very severe). Symptom distress was measured using a 5-point Likert scale (0.8 = not at all to 4 = very severe). Symptom burden scores were determined from the mean scores of the frequency, severity and distress of each symptom. As in the original MSAS, a measure of frequency was not appropriate for some symptoms (e.g. constipation, weight loss, hair loss).⁸ Therefore, the symptom burden of a total of 9 symptoms in the modified MSAS for IBD was calculated as the mean of the severity and distress scores. Higher scores indicated

greater frequency, severity and distress. The internal consistency of the modified MSAS for IBD was established using Cronbach's α . The reliability estimates for the 3 subscales, namely total physical symptom burden, total psychological symptom burden and total symptom burden subscales, were 0.89, 0.85 and 0.92 respectively. Content validity of the modified MSAS for IBD was also established through an extensive review of the literature and validation by a panel of experts, including patients with IBD, who indicated that all symptoms experienced were covered adequately.

Disease status was measured using appropriate clinical disease activity indices. The HBI⁵, a 5-item disease activity index, was used to measure the disease status of participants with Crohn's disease, with scores less than 5 indicating remission. The SCCAI⁶, a 6-item disease activity index, was used to assess the disease status of participants with ulcerative colitis, with scores less than 3 indicating remission. These disease activity indices were completed by the consulting gastroenterology physician on the day of data collection to determine each participant's current disease status.

2.2. Data analysis

Data were analysed using Predictive Analytics SoftWare (PASW Statistics 18 for Windows) and were presented as frequencies and percentages, medians, means and standard deviations. Mann–Whitney U -tests and χ^2 tests were used to compare data by disease type and disease status. A p -value of <0.05 was considered significant.

3. Results

3.1. Sample characteristics

A participation rate of 98% was achieved, with a sample of 255 individuals partaking in the study. According to Portenoy et al.,⁸ who developed the original MSAS, a recommended maximum of 13% missing data are allowed on the items in the scale to exclude the participant from the data analysis. Due to missing data, analysis was conducted on a sample of 247 participants. For the 247 participants included in the data analysis, the median age was 36 years ($n = 239$, interquartile range [IQR] 29–47 years), ranging from 16 to 84 years. There was an equal distribution of males (48.6%, $n = 120$) and females (51.4%, $n = 127$). The vast majority of participants (94.4%, $n = 216$) were educated to secondary school (45.9%, $n = 105$) or third levels (48.5%, $n = 111$). Almost two-thirds of participants had a diagnosis of Crohn's disease (65.6%, $n = 162$) and over one-third had a diagnosis of ulcerative colitis (34.4%, $n = 85$). The length of time since diagnosis varied from 1 to 50 years, with a median of 10 years (IQR 5–17 years). Overall, participants self-reported their current disease status to be well controlled (median score of 8 on an ordinal scale of 0–10). Furthermore, a median of 3 bowel motions (IQR 2–5 bowel motions) over the previous 24 hours and 2 flare-ups over the last 2 years were reported. Based on the clinical disease activity indices, 71% of participants were in remission ($n = 166$) compared with 29% with relapsing disease ($n = 68$). Table 1 presents the clinical and demographic characteristics of the participants in further detail.

3.2. Symptom prevalence

Of the 45 symptoms assessed, a median number of 10 were reported by participants during the previous week (IQR 5–16; range 0–39). Of these symptoms, a median of 6 were physical (IQR 1–11; range 0–27) and a median of 2 were psychological (IQR 0–4; range 0–9). No significant difference in the median number of symptoms was found for participants with Crohn's disease (11, IQR 5–16.25) or

ulcerative colitis (10, IQR 5–16) ($p = 0.548$). However, when data were categorized according to clinical disease activity status, the median number of symptoms was significantly greater for those with

Table 1. Demographic and clinical characteristics of the sample ($n = 247$).

Variable	n (%) ^a
Age (y) ($n = 239$)	
Median (IQR)	36 (29–47)
Range	16–84
Gender	
Male	120 (48.6)
Female	127 (51.4)
Living with a supportive adult ($n = 245$)	192 (78.4)
Medical cover	201 (81.4)
Educational status ($n = 229$)	
Primary school	13 (5.7)
Secondary school	105 (45.9)
Third level	111 (48.5)
Disease type	
Crohn's disease	162 (65.6)
Ulcerative colitis	85 (34.4)
Years since diagnosis	
Median (IQR)	10 (5–17)
Range	1–50
Number of bowel motions in the last 24 h ($n = 215$)	
Median (IQR)	3 (2–5)
Range	0–15
Number of flares in the last 2 y ($n = 214$)	
Median (IQR)	2 (0–4)
Range	0–40
Absenteeism from work/education due to illness/flare-up ($n = 240$)	139 (57.9)
Withdrawal from work/education due to illness/flare-up ($n = 240$)	58 (24.2)
Currently has a stoma formed ($n = 233$)	24 (10.3)
Bowel surgery in the last 12 months ($n = 245$)	24 (9.8)
Smoking status ($n = 229$)	
Non-smoker	95 (41.5)
Past smoker	90 (39.8)
Current smoker	44 (19.2)
Number of cigarettes smoke per day ($n = 35$)	
Median (IQR)	10 (6–16)
Range	2–20
Other chronic illness diagnosed ($n = 240$)	63 (26.3)
Medications status ($n = 230$)	
Aminosalicylates	121 (52.6)
Immunomodulators	63 (27.4)
Biologic therapies	52 (22.6)
Steroids	35 (15.2)
Antibiotics	5 (2.2)
No. courses of steroids in the last 2 y ($n = 213$)	
Median (IQR)	1 (1–2)
Range	0–20
Self-reported disease control ($n = 239$)	
Median (IQR)	8 (5–9)
Range	0–10
Harvey–Bradshaw Index ($n = 156$) ^b	
Median (IQR)	2 (0–4)
Range	0–16
Simple Clinical Colitis Activity Index ($n = 78$) ^c	
Median (IQR)	2 (0–4)
Range	0–13

^aUnless otherwise stated; ^bfor participants with Crohn's disease; ^cfor participants with ulcerative colitis

active disease (16 symptoms, IQR 11–19) than for those with inactive disease (9 symptoms, IQR 4–13.25) ($p < 0.001$). Furthermore, participants with active disease reported almost twice as many physical symptoms and four times as many psychological symptoms than participants with inactive disease ($p < 0.001$) (Table 2).

The most prevalent physical symptoms were lack of energy, bowel urgency, diarrhoea and feeling bloated, each of which were reported by 50% or more of the participants (Table 3). Almost 30% or more of the participants reported individual psychological symptoms, the most prevalent being worrying, followed by difficulty sleeping, feeling irritable, difficulty concentrating, feeling sad and feeling embarrassed. The prevalence of symptoms is presented in Table 3.

When data were split according to disease type (i.e. Crohn's disease and ulcerative colitis), lack of energy and bowel urgency remained the most prevalent symptoms for participants. All symptoms were more prevalent in participants with active disease compared with those with inactive disease. For participants with active disease, more than half ($n = 68$) reported experiencing 12 symptoms over the previous week. For participants with active disease, bowel urgency (83.8%, $n = 57$) was found to be the most commonly experienced symptom. Participants with active disease predominantly reported experiencing physical symptoms among the most prevalent symptoms, but psychological symptoms were also commonly experienced (Table 3). Use of the χ^2 test indicated a statistically significant difference in symptom prevalence for a total of 20 symptoms when participants with active and inactive disease were compared.

3.3. Symptom frequency

The frequency variable was transformed into binary variables (dichotomous) to determine symptoms with high and low frequency. Symptoms rated 'frequently' to 'almost constantly' represented highly frequent symptoms. As can be seen in Table 4, the percentage of participants reporting highly frequent symptoms ranged from 21.4 to 64.7. Eight individual physical symptoms were each reported as highly frequent for 50% or more of participants; these were problem with urination, diarrhoea, joint pain, lack of appetite, flatulence, problem with sexual interest and activity, lack of energy and bowel urgency. Individual psychological symptoms were less prevalent than individual physical symptoms. Eight of the 10 assessed individual psychological symptoms were each reported as highly frequent by over one-third of participants, ranging from 34.4 to 56%. In descending order from higher to lower frequency, these symptoms were: difficulty sleeping, feeling embarrassed, feeling nervous, feeling irritable, feeling sad, worrying, feeling fearful and feeling angry.

3.4. Symptom severity

Among the subset of participants reporting the presence of a symptom, moderate to very severe severity was reported by more than three-quarters of participants for 23 symptoms, including 19 physical symptoms and 4 psychological symptoms. The top 5 physical symptoms rated highly severe were bowel urgency, problem with

Table 2. Median and interquartile range of the total number of physical and psychological symptoms reported by each participant according to disease activity.

Group	Physical symptoms	Psychological symptoms
Active disease ($n = 56$ –60)	11 (9–14)	4 (1.25–6)
Inactive disease ($n = 142$ –148)	6 (3–10)	1 (0–3)

Table 3. Symptom prevalence by disease status.

Symptom	Active disease (<i>n</i> = 68) (%)	Inactive disease (<i>n</i> = 166) (%)	χ^2	<i>p</i> -value
Physical symptoms				
Bowel urgency	83.8	50.0	21.58	<0.001
Lack of energy	80.6	63.8	5.95	0.019
Diarrhoea	74.6	40.4	21.07	<0.001
Flatulence	63.6	42.0	7.97	0.005
Pain	62.7	36.8	11.85	<0.001
Feeling bloated	61.8	44.2	5.24	0.022
Abdominal pain	55.9	35.5	7.41	0.006
Abdominal cramps	54.4	26.5	15.39	<0.001
Stool mucus	50.0	17.0	24.79	<0.001
Rectal bleeding	41.2	17.5	13.45	<0.001
Nausea	38.2	16.9	11.23	<0.001
Dry mouth	37.3	19.9	6.86	0.009
Blood in stool	36.8	10.8	19.91	<0.001
Lack of appetite	36.8	20.5	5.95	0.015
Bowel incontinence	31.3	8.5	17.15	<0.001
Numbness and tingling in hands and feet	27.9	15.1	4.43	0.035
Shortness of breath	26.5	14.5	3.95	0.047
Dizziness	25.4	13.3	4.12	0.042
Weight loss	23.5	11.5	4.54	0.033
Vomiting	11.8	2.4	6.79	0.009
Psychological symptoms				
Worrying	62.7	37.9	10.77	<0.001
Difficulty sleeping	50.0	32.7	5.40	0.020
Feeling embarrassed	49.3	21.0	16.96	<0.001
Feeling irritable	48.5	27.3	8.84	0.003
Difficulty concentrating	41.8	26.5	4.46	0.035
Feeling angry	39.7	21.1	7.66	0.006
Feeling fearful	30.8	15.8	5.66	0.017

urination, lack of appetite, problem with sexual activity and flatulence. A total of 4 psychological symptoms were rated at least moderately severe by over 75% of the sample: difficulty sleeping, feeling angry, worrying and feeling irritable (Table 4).

3.5. Symptom distress

The percentage of participants rating individual symptoms as highly distressing ('quite a bit' or 'very much') ranged from 3.6 to 55.3. The top 5 symptoms rated highly distressing were bowel incontinence, diarrhoea, blood in stool, problem with urination and bowel urgency. The most highly distressing psychological symptoms included feeling embarrassed, feeling angry and feeling fearful, which were reported in over one-third of the sample who experienced the symptom (Table 4).

3.6. Symptom burden

Of the 45 symptoms that participants reported experiencing during the previous week, the most burdensome were lack of energy, bowel urgency, diarrhoea, flatulence, feeling bloated, worrying, pain and abdominal pain (Table 4). Symptom burden scores ranged from 0.12 to 1.59 on a scale of 0–4. Of these, the two most burdensome symptoms reported by participants with Crohn's disease and ulcerative colitis respectively, based on the mean (standard deviation) scores, were lack of energy (1.64 [1.31] vs 1.51 [1.27]) and bowel urgency (1.45 [1.37] vs 1.44 [1.40]). Diarrhoea was rated the third most burdensome symptom for participants with Crohn's disease (1.36 [1.40]) compared with feeling bloated for participants with ulcerative colitis (0.98 [1.1]). Mann–Whitney *U*-tests revealed no significant difference ($p < 0.05$) in symptom burden scores between disease type, with the exception of 5 symptoms. Participants with Crohn's

disease reported significantly greater symptom burden for diarrhoea, feeling sad and difficulty concentrating ($p = 0.001$ to $p = 0.035$). In contrast, participants with ulcerative colitis reported significantly greater symptom burden for cough and problem with urination ($p = 0.001$ to $p = 0.006$).

The 3 most burdensome symptoms reported by participants with active disease were bowel urgency (2.12 [1.28]), lack of energy (1.94 [1.22]) and diarrhoea (1.90 [1.38]). Symptoms rated most burdensome by participants with inactive disease included lack of energy (1.44 [1.31]), bowel urgency (1.19 [1.33]) and flatulence (0.95 [1.21]). Mann–Whitney *U*-tests revealed statistically significant differences ($p < 0.05$) in symptom burden scores between disease activity groups for 28 of the 45 symptoms assessed.

4. Discussion

In this cross-sectional survey, participants reported experiencing up to 10 symptoms during the previous week, which ranged from 9 symptoms per week for those with inactive disease to 16 symptoms per week for those with active disease. Previous research has not reported the prevalence of symptoms in individual patients with IBD, thus limiting comparisons. However, the high number of symptoms reported during active disease is greater than the number reported in other chronic illnesses, such as cancer, HIV, renal disease and cystic fibrosis, and in palliative cohorts.^{10,12,13,14,15,16,17,18}

2 The disease status of participants, in terms of active and inactive disease, was assessed in this research. Although most patients in this sample were in remission, the top 3 physical symptoms were reported by more than 50% of the sample and 20 physical and psychological symptoms were prevalent in 25% of the sample.

Table 4. Symptom prevalence, highly frequent, highly severe and highly distressing symptoms and symptom burden ($n = 241$ – 247 , ranked by prevalence).

Symptom	Symptom prevalence (%)	Of those reporting each individual symptom, n (%)			Mean symptom burden score (SD)
		Reporting high frequency	Reporting high severity	Reporting high distress	
Lack of energy	68.7	84 (51.2)	125 (79.1)	63 (40.1)	1.59 (1.30)
Bowel urgency	59.1	73 (50.3)	122 (87.8)	58 (41.7)	1.45 (1.38)
Diarrhoea	50.8	75 (61.0)	97 (82.2)	54 (47.8)	1.22 (1.36)
Feeling bloated	49.6	52 (43.3)	90 (81.1)	28 (25.5)	1.06 (1.20)
Flatulence	47.9	62 (54.4)	95 (86.4)	31 (28.2)	1.10 (1.28)
Worrying	45.2	39 (36.1)	84 (79.2)	34 (32.4)	1.02 (1.26)
Pain	44.0	39 (37.9)	84 (83.2)	41 (41.0)	0.99 (1.25)
Abdominal pain	42.1	36 (35.0)	81 (77.1)	39 (40.2)	0.95 (1.23)
Difficulty sleeping	37.8	51 (56.0)	78 (92.9)	35 (40.2)	0.91 (1.30)
Joint pain	36.8	52 (57.1)	71 (80.7)	29 (34.1)	0.86 (1.24)
Abdominal cramps	35.2	36 (41.4)	68 (84.0)	33 (40.7)	0.82 (1.22)
Feeling irritable	34.6	32 (38.6)	64 (78.0)	25 (32.1)	0.75 (1.14)
Difficulty concentrating	30.6	23 (31.1)	47 (67.1)	14 (20.9)	0.60 (0.98)
Feeling sad	29.7	26 (36.6)	49 (68.1)	23 (31.9)	0.65 (1.08)
Feeling embarrassed	29.3	31 (44.3)	61 (87.1)	30 (42.9)	0.71 (1.18)
Sweats	27.2	28 (42.4)	49 (77.8)	14 (22.6)	0.58 (1.04)
Feeling angry	26.3	22 (34.4)	49 (80.3)	26 (42.6)	0.60 (1.12)
Stool mucus	26.3	26 (41.3)	36 (63.2)	17 (29.8)	0.52 (0.99)
Feeling drowsy	26.1	27 (42.2)	43 (71.7)	20 (32.8)	0.55 (1.02)
Lack of appetite	25.5	35 (55.6)	53 (86.9)	22 (36.7)	0.59 (1.07)
Dry mouth	24.8	25 (41.7)	40 (70.2)	2 (3.6)	0.47 (0.89)
Feeling nervous	24.6	23 (39.7)	36 (65.5)	17 (30.4)	0.52 (1.00)
Rectal bleeding	24.3	17 (28.3)	34 (64.2)	17 (32.7)	0.47 (0.93)
Nausea	22.7	24 (42.9)	34 (68.0)	13 (26.5)	0.45 (0.92)
Feeling fearful	20.2	17 (35.4)	33 (70.2)	20 (42.6)	0.46 (1.01)
Weight gain	20.2	*	24 (48.0)	11 (25.0)	0.34 (0.77)
Cough	20.1	19 (40.4)	23 (52.3)	5 (11.6)	0.35 (0.80)
Numbness and tingling in hands and feet	19.4	15 (31.9)	25 (56.8)	9 (22.0)	0.36 (0.82)
Shortness of breath	19.1	18 (38.3)	32 (72.7)	6 (14.6)	0.37 (0.83)
Blood in stool	18.6	16 (34.8)	29 (72.5)	19 (47.5)	0.40 (0.93)
Itching	17.1	13 (31.7)	26 (68.4)	7 (18.4)	0.34 (0.82)
Dizziness	16.7	12 (29.3)	33 (80.5)	11 (28.2)	0.37 (0.86)
Weight loss	15.9	*	19 (50.0)	11 (31.4)	0.28 (0.75)
Problem with sexual interest and activity	15.6	20 (54.1)	33 (86.8)	21 (55.3)	0.42 (1.04)
Bowel incontinence	15.4	12 (34.3)	26 (81.3)	18 (56.3)	0.33 (0.87)
Change in skin	15.1	*	24 (66.7)	12 (35.3)	0.31 (0.82)
Constipation	13.5	*	25 (75.8)	8 (25.0)	0.29 (0.80)
Don't look like myself	13.0	*	23 (74.2)	12 (38.7)	0.28 (0.79)
Mouth sores	10.6	*	14 (53.8)	1 (4.0)	0.17 (0.52)
Change in the way food tastes	10.6	*	16 (64.0)	4 (17.4)	0.18 (0.58)
Hair loss	10.2	*	12 (50.0)	9 (37.5)	0.19 (0.65)
Difficulty swallowing	7.3	4 (25.0)	12 (85.7)	4 (28.6)	0.13 (0.54)
Problem with urination	7.3	11 (64.7)	14 (87.5)	7 (43.8)	0.16 (0.64)
Vomiting	5.7	3 (21.4)	11 (84.6)	4 (30.8)	0.12 (0.50)
Swelling of arms and legs	5.7	*	11 (78.6)	4 (28.6)	0.12 (0.54)

*Frequency not measured.

Furthermore, when data were categorized according to disease status, findings clearly pointed to individuals continuing to experience symptoms during inactive disease. More than 50% of the sample with inactive disease reported bowel urgency and lack of energy during the previous week. The presence of symptoms during inactive disease supports the findings of an American qualitative study in a sample of patients with Crohn's disease, which showed that few patients equated remission with a complete return to normal in terms of being symptom-free.²¹

3 For all participants, regardless of disease status and disease type, the most burdensome symptoms were lack of energy, bowel urgency and diarrhoea. Symptom burden scores varied during active and inactive disease. These findings demonstrate that symptoms identified as most problematic are not just the cardinal symptoms of IBD. This is an important consideration for the clinical assessment of patients with IBD because cardinal symptoms are the focus of the clinical disease activity indices used in practice. Furthermore, physicians often underestimate the impact of IBD on patient's lives¹⁹ or overestimate

the impact of certain symptoms, such as bowel symptoms, compared with the patients' own experiences of these symptoms.²⁴

4 IBS-like symptoms, such as flatulence and feeling bloated, were reported among the most burdensome symptoms, particularly during inactive disease. These findings highlight that IBS-like symptoms are a clinically important group of symptoms that should not be overlooked. In support of this, a systematic review and meta-analysis by Halpin and Ford²² notes the need for management strategies targeted at IBS-like symptoms in individuals with IBD.

5 This study highlights the need to broaden the clinical and research assessment of physical symptoms beyond those characteristic of IBD. For example, lack of energy was found to be the most burdensome symptom for participants during inactive disease and the second most burdensome symptom during active disease. Fatigue, as a highly prevalent symptom in populations with IBD, has been identified in previous studies.^{19,20,25,26,27,28} These high levels of fatigue are comparable with those of oncology patients²⁹ and patients with other chronic illnesses, such as chronic obstructive pulmonary disease,^{30,31} heart failure,^{9,30,31} cystic fibrosis¹⁰ and chronic renal disease.^{14,32} Moreover, a recent study by Jelsness-Jørgensen et al.³³ found that chronic fatigue, defined as substantial fatigue with duration more than 6 months, was significantly more common in patients with ulcerative colitis and Crohn's disease than in healthy controls. In this study, 40% of participants reported lack of energy to be highly distressing and almost 80% reported fatigue as highly severe. The finding that lack of energy was the most burdensome symptom during inactive disease concurs with a recent qualitative study by Czuber-Dochan et al.,³⁴ who found that fatigue was the most troublesome symptom even during disease remission. Despite this, however, the lack of research attention to fatigue or lack of energy as a primary symptom for patients with IBD is evident. A systematic review by van Langenberg and Gibson²⁵ found that in the previous decade only 10 studies had in some way assessed fatigue; of these only 1 study investigated fatigue as its primary focus and this was on a sample of children. The reviewers described fatigue as a disabling symptom of IBD that remains poorly understood and in need of urgent research investigation. Furthermore, clinical guidelines for the management of IBD published by Mowat et al. in 2011³⁵ cautioned against ignoring fatigue as a problematic symptom because it can have significant adverse implications for a person's quality of life. Interestingly, a specific focus on fatigue in IBD is now beginning to emerge in the empirical literature, with the recent development and validation of an IBD fatigue patient self-assessment scale³⁶ and the commencement of a Cochrane review on interventions for fatigue in IBD,³⁷ which will identify evidence on more effective interventions for managing this problematic symptom. The finding of this study that lack of energy is one of the most burdensome symptoms in IBD reinforces the need to prioritize fatigue as a specific focus of future symptom research.

6 The findings of this study offer new knowledge on symptom burden in IBD – not just physical symptoms but also psychological symptoms. Six of the 10 psychological symptoms assessed were ranked among the 15 most burdensome symptoms. Among the 7 most burdensome symptoms, worry was identified during active and inactive disease. Evidence of the psychological implications of living with IBD can be gleaned from a small but growing number of qualitative studies highlighting experiences of worrying, fear and embarrassment, mainly associated with the unpredictable nature of bowel symptoms.^{21,23,38,39,40} There is a need to rethink the concept of symptom burden by including psychological symptoms as well as physical symptoms in both clinical and research assessments of patients' symptom experiences in IBD.⁴¹

7 According to Petrie and Weinman⁴² patients build a cognitive representation of his or her illness, including beliefs around the cause, symptoms, consequences, cure and duration of the illness, which subsequently guides their behaviours in terms of disease management. Illness perceptions change rapidly over the illness trajectory and have been associated with important outcomes such as emotional distress and disability. Patients' illness beliefs or perceptions may influence their symptom experiences, with negative beliefs associated with worsening symptoms and burden even in the absence of active disease. Van der Have et al.⁴³ found that self-reported disability, using the IBD-Disability Index, was significantly associated with illness identity, indicating that patients who attributed a wide range of symptoms to their illness experienced greater disability. This suggests that there is a link between symptoms and disability, with patients' illness perceptions an important mediating factor.

8 The sampling type and the sample characteristics limit the generalizability of the study findings. Although participants' disease status varied in the study, the majority of the sample had inactive disease at the time of data collection. Therefore, patients with active disease may have been under-represented in the study. However, it could be argued that patients with active disease are over-represented in the study because they are likely to attend outpatient clinics more frequently than those with inactive disease. In this study, 68 patients had return appointments within the 3-month data collection period. This study examined the symptom burden experiences of individuals with IBD in an outpatient setting in a single centre. Because this study was performed at a single centre and was not population-based, it had an unavoidable bias. A larger sample across diverse healthcare settings in multiple centres is recommended to overcome this limitations. Data were collected using modified disease-specific version of the MSAS, and the results from modified instruments often need to be interpreted with caution. However, following careful review of the conceptual and empirical literature around symptom burden in IBD and other chronic illnesses, the MSAS was identified as the most appropriate scale.⁷ Consequently, the modified MSAS for IBD was developed based on a thorough and comprehensive review of symptom research in IBD and significant efforts were made to ensure robustness. In addition, it is important to note that clinical disease activity indices, such as the HBI and the SCCAI, may also identify subjective symptoms as a measure of disease activity, e.g. general wellbeing, abdominal pain and the number of liquid stools per day.⁵ However, these indices provide numerical measures of severity based on clinical criteria gleaned during a single clinic consultation.^{5,6} Objective parameters of activity, such as endoscopy or imaging, were not included in this study. Therefore, clinic-based disease activity indices were used for differentiating participants with active and inactive disease. Furthermore, the HBI and the SCCAI are completed by clinicians and were not designed to glean data on the patient's self-reported symptoms in terms of associated burden.

9 Despite these limitations, this study provides important insights into the symptom prevalence, frequency, severity, distress and overall symptom burden experienced by individuals with IBD. It contributes to clinical and empirical knowledge about the multitude of concurrent burdensome symptoms experienced by individuals with IBD in different disease states and it supports findings from previous studies^{44,45} in terms of the impact of the disease on the lives of patients and their families. Routine comprehensive symptom assessment inclusive of both physical and psychological symptoms should be undertaken in clinical practice to identify these often undisclosed symptoms, and this should subsequently facilitate discussions about symptom perceptions and earlier symptom management.

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Conflict of Interest

The authors have no conflicts of interest to disclose.

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Author Contributions

All authors have made substantial contributions to this paper in terms of the conception and design of the study. DF was involved in data collection, data analysis, interpretation of data and drafting of this paper. ES and GMcC critically reviewed the paper for important intellectual content. All authors have approved the final version of the paper submitted.

Conference Presentations

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Farrell D, Savage E, McCarthy G. A mixed methods study of the symptom burden experiences in individuals with inflammatory bowel disease. 2013 Advances in Inflammatory Bowel Disease Crohn's and Colitis Foundation's Clinical and Research Conference, Hollywood, Miami, Florida, December 2013.

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