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Determinants of IBD-related disability: a cross-sectional survey from the GETAID

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Summary

Background: The burden of inflammatory bowel disease (IBD) is rising worldwide. The goal of IBD treatment is to achieve clinical and endoscopic remission but also prevent disability.

Aims: To identify the predictive factors of disability in a large population of patients with IBD.

Patients and methods: We conducted a cross-sectional survey in 42 tertiary centres in France and Belgium. A self-administered questionnaire was designed to explore patients and their IBD characteristics. IBD-disk is a validated tool to measure disability in patients with IBD. The IBD-disk score was then calculated for each patient. Based on a previous study, an overall IBD-disk score ≥40 was associated with moderate-to-severe disability.

Results: Among the 2011 patients, 1700 were analysed, including 746 (44%) in self-reported clinical remission and 752 (44.2%) declaring clinical activity. The patient global assessment of global remission was missing in 200 (11.8%) of 1700 patients. Moderate-to-severe disability was significantly increased in patients with BMI >25 kg/m^2 (OR = 1.66; 95% CI [1.29-2.14]), in those having perception of need for a psychotherapist (OR = 2.24; 95% CI [1.79-3.05]) and social worker (OR = 1.54; 95% CI [1.08-2.21]). Conversely, male gender (OR = 0.83; 95% CI [0.69-0.99]), ulcerative colitis (OR = 0.69; 95% CI [0.53-0.92]), self-reported clinical remission (OR = 0.59; 95% CI [0.46-0.77]) and employed or student occupational status (OR = 0.69; 95% CI [0.52-0.92]) were inversely correlated with disability. Overall, 257 (34.5%) patients who declared being in clinical remission had disability.

All the members of the GETAID-patient experience study group are listed in the Appendix 1.

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Conclusion: Determinants of IBD-related disability include IBD-related factors but also psychological and social factors. This highlights the importance of a multidisciplinary team in the management of patients with IBD.

1 | INTRODUCTION

Management of patients with inflammatory bowel disease (IBD) has been largely focused on clinical and endoscopic targets, while the impact of IBD on disability has been quite underestimated.[1] Although working disability had been reported, the paradigm of IBD-related disability has only been recently described.[2] Indeed, IBD negatively affects the daily life of patients in multidimensional ways, including physical, psychological, familial and social aspects.[3]

Disability is an umbrella term, covering impairments, activity limitations and participation restrictions, summing up the functional dimensions of this handicap.[4] The IBD-disability index is a validated questionnaire assessing IBD-related disability based on 0-5 Likert scales exploring nine dimensions of disability.[5] The IBD-disk questionnaire was developed by the IBD Connect group based on a Delphi consensus process to assess IBD-related disability in simpler and self-administered ways[6] and has been recently validated to assess IBD-related disability and daily-life burden.[7,8] In a large cohort study of 2011 patients with IBD, we demonstrated with a visual analogic scale of IBD daily-life burden that an overall IBD-disk score equal to or greater than 40 was associated with moderate-to-severe disability.[8]

The aim of the present study was to identify the determinants of moderate-to-severe IBD-related disability in a large population of patients with IBD.

2 | PATIENTS AND METHODS

2.1 | Study population

We conducted a cross-sectional survey in 42 tertiary centres in France and Belgium affiliated to the Groupe d'Etude Therapeutique des Affections Inflammatoires du tube Digestif (GETAID). Investigators were asked to include all consecutive adult outpatients with IBD between 26 November and 30 November 2018. The study was conducted in accordance with the ethical principles and French regulatory agency requirements through reference methodology MR-004 (registration number 2210131).

2.2 | Survey instrument

A four-page self-administered questionnaire was first designed by the Educational GETAID Committee and then submitted to 20 consecutive outpatients to assess completion rate and reliability of the questionnaire. The final questionnaire, which is provided in Figure S1, was designed to explore the following:

- Patients and IBD characteristics, including demographics, type of IBD, duration of IBD, age at diagnosis of IBD, history of surgical treatment of IBD, current medical treatment of IBD, occupational status, frequency of appointments with physicians and general practitioners, distance between home and the clinic and IBD-related sick leave rate.
- Disease activity was defined according to patient global assessment as the absence or presence of clinical remission.
- IBD-related disability: an IBD-disk questionnaire including 0-10 visual analogue scales (VAS; 0 = no burden; 10 = maximal burden) assessing each component of disability during the last week: joint pain, abdominal pain, body image, education and work, emotions, energy, interpersonal interactions, regulating defecation, sexual functions and sleep. The overall IBD-disk score was calculated as the sum of its 10 components, ranging from 0 to 100.
- Concerns about IBD-related treatment, current use and perceived need for other healthcare professionals were measured using multiple choice questions.
- Knowledge about IBD and IBD-related treatment and overall patient satisfaction with the patient-physician relationship and with current treatment were all measured using a 10-point VAS (0 = awful and 10 = perfect).

The questionnaire was filled-in by the patients and retrieved after full completion. The assistance of a trained nurse or gastroenterologist was possible if required.

2.3 | Study objectives

Based on a previous study, overall IBD-disk score equal to or greater than 40 was associated with moderate-to-severe disability.[9] The aim of the present study was to compare patients with and without moderate-to-severe disability according to their IBD-disk score, and to identify factors associated with moderate-to-severe disability.

2.4 | Statistical analysis

The data are expressed as numbers (%) for qualitative data and as the mean ± standard deviation (SD) or median [interquartile range] for quantitative data. Missing values were generated using multiple imputations. Based on sociodemographic data and the available subscores in the IBD-disk, 50 different complete datasets were

generated and combined into a pooled dataset. Based on a previous study, overall IBD-disk score equal to or greater than 40 was associated with moderate-to-severe disability.[9] To identify predictors of moderate-to-severe disability, univariate analysis using logistic regression was performed. Subsequent multivariate analysis using binary logistic regression models was performed and adjusted for using the above-mentioned variables. Variables with $P < 0.10$ in the univariate analysis were considered to be potential adjustment variables for the multivariate analysis. All the analyses were two-tailed, and P values less than 0.05 were considered significant. All statistics were calculated using R software.[10]

3 | RESULTS

3.1 | Study population

Among the 2011 participants, 10 items of the IBD-disk were completed in 1484 (73.8%) patients, six to nine in 216 (10.8%), one to five in 57 (2.8%) and none in 254 (12.6%). Patients who completed at least 5 of the 10 items were included in the study (n = 1700), including 67.6% with Crohn's disease (CD) and 32.3% with ulcerative colitis (UC). Table 1 summarises the main characteristics of the study population. The median duration of IBD was 10.5 [interquartile range 5.4-18.4] years. Current treatment included 5-aminosalicylates in 10.6% of the cases, immunomodulator alone in 10.5%, anti-TNF agents in 54.7%, vedolizumab in 13.8% and ustekinumab in 6.5%. No treatment was currently prescribed in 8.9% of the cases.

3.2 | IBD-disk overall score and subscores

The mean overall IBD-disk score was 39.3 ± 23.0. The mean IBD-disk subscore ranged from 2.5 (interpersonal interactions) to 5.7 (energy) (Figure 1). According to the original instructions, any subscore >5 represents a significant disability for each IBD-disk component. The proportions of patients with significant disability are presented in Table 2.

Among the 1700 patients included, 793 (46.6%) had moderate-to-severe disability (overall IBD-disk score ≥40). According to patient global assessment, 44% of patients were declared to be in clinical remission (n = 746) and 34.5% of them (n = 257) had moderate-to-severe disability. IBD-disk subscore >5 was significantly associated with clinical disease activity according to the patient global assessment in all 10 items of the score (Table 2).

3.3 | Predictors of IBD-related moderate-to-severe disability in the study population

In univariate analysis, moderate-to-severe disability was significantly increased in patients with age >40, increased in patients with BMI >25 kg/m^2, history of intestinal resection, IBD-related sick leave and in those having perception of need for dietician, psychotherapist, sexologist, IBD nurse, sports coach or social worker. On the other hand, moderate-to-severe disability was significantly decreased in men, employed or student occupational status, patients with UC, patients with clinical remission assessed by patient global assessment and patients who were generally satisfied with their treatment and their patient-physician relationship (Table 3).

In the multivariate analysis, moderate-to-severe disability was significantly increased in patients with BMI >25 kg/m^2 (OR = 1.66, 95% CI [1.29-2.14], $P < 0.001$), and in those having perception of need for a psychotherapist (OR = 2.24, 95% CI [1.79-3.05], $P < 0.001$) and social worker (OR 1.54, 95% CI [1.08-2.21], $P = 0.02$), whereas it was decreased in men (OR = 0.83, 95% CI [0.69-0.99], $P = 0.04$), patients with UC (OR = 0.69, 95% CI [0.53-0.92], $P = 0.01$), patients with clinical remission assessed by patient global assessment (OR = 0.59, 95% CI [0.46-0.77], $P < 0.001$)

TABLE 1 Demographic, disease and medication characteristics of the study population

Characteristic	Overall population (n = 1700)
Age at diagnosis, years (mean ± SD, range)	40.9 ± 14.5 [17-82]
Male gender, n (%)	799 (47.0)
BMI, kg/m^2 (mean ± SD)	24.3 ± 5.1
Duration of IBD, years (mean ± SD)	13.1 ± 10.3
Age at diagnosis, n (%)	
A1: ≤16 years	354 (20.8)
A2: 17-40 years	1083 (63.7)
A3: > 40 years	263 (15.5)
Type of inflammatory bowel disease (%)	
Crohn's disease	67.6
Ulcerative colitis	32.3
History of intestinal resection, n (%)	760 (44.7)
Occupational status (%)	
Employed	62.8
Unemployed	8.5
Homemaker	9.0
Student	8.0
Retired	11.6
Distance between home and clinic (km) (mean ± SD)	40.0 ± 51.4
Current treatment (%)	
None	8.9
5-ASA	10.6
Immunomodulator alone	10.5
Anti-TNF	54.7
Vedolizumab	13.8
Ustekinumab	6.5

Abbreviations: 5-ASA, 5-aminosalicylic acid; BMI, body mass index; IBD: inflammatory bowel disease.

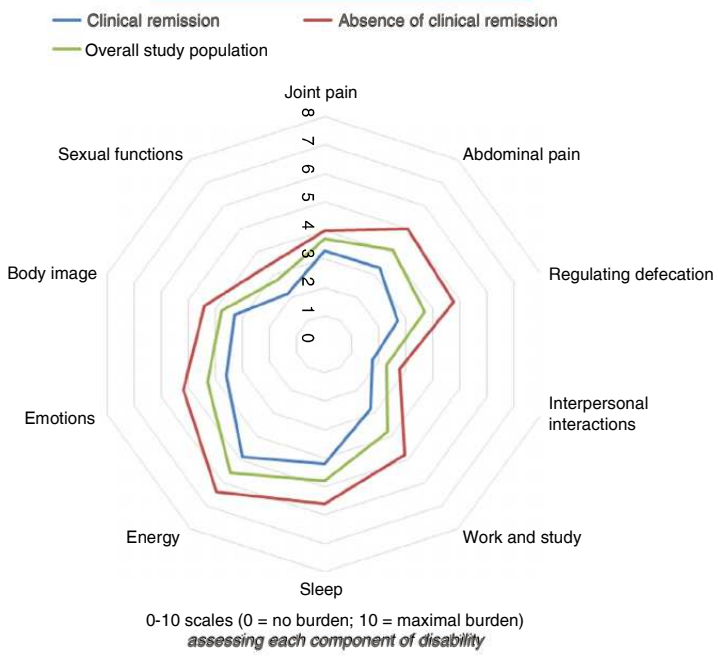

FIGURE 1 IBD-disk subscores according to the presence of clinical remission

TABLE 2 Proportion of patients with IBD-disk subscore > 5 according to the patient global assessment of clinical remission

Proportions of patients with IBD-disk subscore > 5	Overall study population (n = 1700)	Presence of clinical remission (n = 746)[a]	Absence of clinical remission (n = 752)[a]	*P*
Joint pain	538 (31.6)	202 (27.1)	266 (35.4)	0.001
Abdominal pain	606 (35.6)	181 (24.3)	360 (47.9)	<0.001
Regulating defecation	557 (32.7)	155 (20.1)	334 (44.4)	<0.001
Interpersonal interactions	317 (18.6)	115 (15.4)	172 (22.9)	0.001
Education and work	588 (34.5)	181 (24.3)	337 (44.9)	<0.001
Sleep	801 (47.0)	288 (38.6)	421 (55.9)	<0.001
Energy	924 (54.2)	333 (44.6)	488 (64.9)	<0.001
Emotions	677 (39.7)	224 (30.0)	377 (50.1)	<0.001
Body image	588 (34.3)	213 (28.6)	299 (39.8)	<0.001
Sexual functions	440 (25.8)	146 (19.6)	232 (30.9)	<0.001

Note: Values within parenthesis are expressed in percentage.

Abbreviation: IBD, inflammatory bowel disease.

[a]The patient global assessment of global remission was missing in 200 of 1700 patients.

and employed or student occupational status (OR = 0.69, 95% CI [0.52-0.92], *P* = 0.01) (Table 3).

3.4 | Predictors of IBD-related moderate-to-severe disability in patients with clinical remission assessed by patient global assessment

Among the 746 patients (43.8%) who declared to be in clinical remission, 257 (34.5%) had moderate-to-severe disability. In the univariate analysis, moderate-to-severe disability was significantly increased in patients with BMI >25, in women, in patients with IBD-related sick leave and in those who perceived the need for a dietician, psychotherapist, sexologist, IBD nurse, sports coach or social worker. On the other hand, moderate-to-severe disability was significantly decreased in employed or student occupational status, patients with clinical remission assessed by patient global assessment and those who were generally satisfied with their treatment and their patient-physician relationship (Table 4).

TABLE 3 Predictors of moderate-to-severe disability according to the overall IBD-disk score equal to or greater than 40 in our study population of 1700 patients

	OR [95% CI] on univariable analysis	P	OR [95% CI] on multivariable analysis	P
Age > 40	1.22 [1.01-1.47]	0.03	1.10 [0.85-1.42]	0.45
Male gender	0.84 [0.73-0.97]	0.02	0.82 [0.69-0.98]	0.03
BMI > 25	1.43 [1.17-1.74]	<0.001	1.65 [1.28-2.13]	<0.001
Employed or student	0.55 [0.45-0.68]	<0.001	0.69 [0.52-0.91]	0.01
Distance between home and Clinic > 50 km	1.11 [0.89-1.38]	0.33	—	—
Ulcerative colitis	0.80 [0.65-0.99]	0.04	0.69 [0.52-0.91]	0.01
Duration of IBD > 10 years	1.09 [0.905-1.325]	0.349	—	—
History of intestinal resection	1.29 [1.06-1.56]	0.009	1.12 [0.86-1.45]	0.39
Age at diagnosis according to Montreal classification				
A1	1.00	—	—	—
A2	1.05 [0.82-1.33]	0.68	—	—
A3	0.79 [0.58-1.11]	0.17	—	—
Clinical remission assessed by patient global assessment	0.34 [0.27-0.42]	<0.001	0.59 [0.46-0.76]	<0.001
IBD-related sick leave	1.69 [1.36-2.11]	<0.001	1.27 [0.95-1.68]	0.09
Current treatment				
None	0.89 [0.60-1.29]	0.54	—	—
Aminosalicylates alone	0.81 [0.59-1.10]	0.18	—	—
Immunomodulator alone	0.84 [0.57-1.22]	0.37	—	—
Biological agent	0.95 [0.77-1.17]	0.65	—	—
Combination therapy	0.91 [0.79-1.17]	0.49	—	—
Route of administration of treatment				
Oral	0.82 [0.63-1.06]	0.14	—	—
Subcutaneous	1.29 [0.97-1.71]	0.08	—	—
Intravenous	0.87 [0.72-1.06]	0.18	—	—
Treatment satisfaction	0.81 [0.78-0.84]	<0.001	0.75 [0.71-0.81]	<0.001
Treatment information	0.88 [0.84-0.92]	<0.001	0.94 [0.88-1.01]	0.12
Physician-patient communication	0.91 [0.87-0.95]	<0.001	1.01 [0.95-1.07]	0.78
Perceived need for healthcare professionals				
Dietician	1.84 [1.50-2.25]	<0.001	1.28 [0.98-1.67]	0.007
Psychotherapist	2.98 [2.43-3.67]	<0.001	2.33 [1.79-3.05]	<0.001
Sexologist	2.43 [1.76-3.41]	<0.001	1.28 [0.83-1.99]	0.26
Sports coach	1.41 [1.11-1.75]	0.002	1.09 [0.81-1.47]	0.57
IBD nurse	1.95 [1.54-2.48]	<0.001	1.33 [0.98-1.81]	0.07
Social worker	2.68 [2.04-3.55]	<0.001	1.54 [1.08-2.21]	0.02

Note: Odds ratio (OR) with 95% confidence interval (CI) was estimated using binary logistic regression.

Abbreviations: BMI, body mass index; CI, confidence interval; IBD, inflammatory bowel disease; OR, odds ratio.

In the multivariate analysis, moderate-to-severe disability was significantly increased in patients with BMI > 25 (OR = 1.77, 95% CI [1.25-2.51], $P < 0.001$), patients with IBD-related sick leave (OR = 1.49, 95% CI [1.01-2.22], $P = 0.04$) and those who perceived the need for a psychotherapist (OR = 2.76, 95% CI [1.915-3.979], $P < 0.001$) and social worker (OR 1.71, 95% CI [1.07-2.74], $P = 0.03$), whereas it was decreased in patients with clinical remission assessed by patient global assessment (OR = 0.47, 95% CI [0.37-0.60], $P < 0.001$), employed or student occupational status (OR = 0.66, 95% CI [0.45-0.97], $P = 0.03$) and those who were generally satisfied with their treatment (OR = 0.77, 95% CI [0.68-0.85], $P < 0.001$) (Table 4).

TABLE 4 Predictors of moderate-to-severe disability according to the overall IBD-disk score equal to or greater than 40 in patients with clinical remission assessed by patient global assessment (n = 746 patients)

	OR [95% CI] on univariable analysis	*P*	OR [95% CI] on multivariable analysis	*P*
Age > 40	1.29 [0.96-1.75]	0.09	–	–
Male gender	0.77 [0.61-0.97]	0.02	0.82 [0.63-1.06]	0.13
BMI > 25	1.42 [1.04-1.93]	0.02	1.77 [1.25-2.51]	<0.001
Employed or student	0.64 [0.46-0.90]	0.01	0.66 [0.45-0.97]	0.03
Distance between home and Clinic > 50 km	0.97 [0.68-1.37]	0.85	–	–
Ulcerative colitis	0.82 [0.59-1.15]	0.26	–	–
Duration of IBD > 10 years	1.26 [0.94-1.71]	0.13	–	–
Age at diagnosis according to Montreal classification				
A1	1.00	–	–	–
A2	0.99 [0.68-1.46]	0.97	–	–
A3	0.78 [0.58-1.11]	0.17	–	–
Clinical remission assessed by patient global assessment	0.34 [0.27-0.42]	<0.001	0.47 [0.37-0.60]	<0.001
IBD-related sick leave	1.69 [1.37-2.11]	<0.001	1.49 [1.01-2.22]	0.04
Current treatment				
None	0.89 [0.61-1.30]	0.55	–	–
Aminosalicylates alone	0.81 [0.60-1.10]	0.18	–	–
Immunomodulator alone	0.84 [0.57-1.23]	0.37	–	–
Biological agent	0.95 [0.77-1.18]	0.66	–	–
Combination therapy	0.91 [0.79-1.18]	0.49	–	–
Route of administration of treatment				
Oral	0.82 [0.64-1.06]	0.14	–	–
Subcutaneous	1.29 [0.97-1.72]	0.08	–	–
Intravenous	0.87 [0.72-1.06]	0.18	–	–
Treatment satisfaction	0.81 [0.78-0.84]	<0.001	0.76 [0.68-0.85]	<0.001
Treatment information	0.88 [0.84-0.92]	<0.001	0.98 [0.89-1.08]	0.64
Physician-patient communication	0.91 [0.87-0.95]	<0.001	1.02 [0.93-1.11]	0.69
Perceived need for healthcare professionals				
Dietician	1.84 [1.51-2.25]	<0.001	0.97 [0.67-1.40]	0.86
Psychotherapist	2.98 [2.43-3.67]	< 0.001	2.75 [1.91-3.98]	<0.001
Sexologist	2.43 [1.76-3.41]	<0.001	1.32 [0.74-2.34]	0.34
Sports coach	1.41 [1.11-1.75]	0.002	1.05 [0.69-1.56]	0.82
IBD nurse	1.95 [1.54-2.48]	<0.001	0.96 [0.61-1.45]	0.87
Social worker	2.69 [2.04-3.55]	<0.001	1.71 [1.06-2.74]	0.02

Note: Odds ratio (OR) with 95% confidence interval (CI) was estimated using binary logistic regression.
Abbreviations: BMI, body mass index; CI, confidence interval; IBD, inflammatory bowel disease; OR, odds ratio.

4 | DISCUSSION

Disability is the human multidimensional experience of impaired body functions and structures, activity limitations and participation restrictions in the interaction with environmental factors. Obviously, clinical disease activity is a major component of IBD-related disability as demonstrated in previous studies.[11,12] In this large multicentre study, we showed that moderate-to-severe disability was influenced by sex, BMI, disease activity and occupational status but not by the history of intestinal resection and IBD duration. Moreover, the perceived need for psychological and social support were predictive factors of moderate-to-severe IBD-related disability in the multivariate analysis.

Furthermore, we showed that patients may still disclose high disability, even when they considered themselves in clinical remission. Indeed, patients with clinical remission as assessed by patient global assessment disclosed moderate-to-severe disability in 34.5% of the cases. In those cases, as well as in the overall study population, IBD-related disability was significantly increased in retired

or unemployed patients and in those who perceived the need for psychological or social support. These results highlight the great negative psychological and social impact of the disease. In fact, the emotional dimensions of chronic conditions are well established, where compared 4%-8% in the general population, the prevalence of depression in patients with chronic illness may exceed 30%.[13] In patients with rheumatoid arthritis, stress management interventions can produce important clinical benefits.[14] Furthermore, writing about emotionally traumatic experiences in patients with mild to moderately severe asthma or rheumatoid arthritis had a beneficial effect at 4 months with clinically relevant changes in health status.[15] Therefore, we suggest that an IBD multidisciplinary team may be implemented with other healthcare professionals, such as the psychotherapist and social worker.

Obesity is increasingly common among patients with IBD. Cross-sectional studies in patients with IBD show that approximately 15% to 40% of adults with IBD are obese, and an additional 20%-40% are overweight.[16,17] Obesity may also contribute to the development of IBD through creating a perpetual state of chronic low-grade inflammation. In our study, 36% of patients had BMI > 25, which was significantly associated with moderate-to-severe IBD-related disability in the multivariate analysis. Longitudinal studies show variable effects of obesity on IBD disease course and the development of complications.[16-20] A recent retrospective study suggested that obesity negatively influences the clinical course of IBD and may increase the burden of disease and treatment.[21] In a large cohort study including 7296 patients with IBD, compared to non-obese patients with IBD, obese patients were more likely to have persistent symptoms and higher anxiety, depression, fatigue, pain and inferior social function scores.[22] Furthermore, intra-abdominal surgeries in patients with obesity are technically challenging and are usually associated with higher rates of post-operative complications.[23] We suggest that the impact of obesity on patients with IBD should be more widely considered in our clinical practice.

Our study had four major limitations: First, we had more than 20% of missing data. However, the present study is a large multicentre study including 2011 patients where 73% of them completed all 10 items of the IBD-disk questionnaire. On the other hand, missing data were handled using multiple imputations with 50 permutations. Second, our study enrolled solely from tertiary referral academic medical centres. Therefore, the study sample may not be representative of the overall IBD population. Indeed, two-thirds of the patients had CD, most patients were treated with biologics and approximately half of the patients had a history of intestinal resection, all of which are hallmarks of patients treated in tertiary care centres. However, patients with more severe IBD are probably the best target for more ambitious management, taking into account both new treatment and monitoring strategies and disability. It is also important to mention that the IBD-disk we used in this study shows some deviations from the original IBD-disk, which is a VAS-scale ranging from 0 (absolutely disagree) to 5 (neither agree nor disagree) to 10 (absolutely agree). Le Berre et al chose to adapt the scale from 0 (absolutely no complaint) to 10 (maximal complaint). We also use this modified version of the IBD-disk since it has been validated in a large cohort with an 80% completion rate.[7] Disease activity was defined according to patient global assessment to guaranty anonymity and not using validated and dedicated clinical scores. However, Le Berre et al recently showed a good correlation with partial Mayo score for patients with UC and Harvey-Bradshaw index for patients with CD.[7] Last, our questionnaire was designed without a validated methodology but includes all relevant topics in the field of IBD-related disability.

In conclusion, the social and psychological impact of IBD may contribute to disability even in patients who declare to be in clinical remission. Clinicians should particularly assess anxiety and depression among their patients with active disease but also among those who are in remission. Management of IBD must involve a multidisciplinary team, including healthcare workers, psychotherapists, social workers and dieticians. Further studies are needed to assess the determinants of IBD-related disability adequately by taking into account factors associated or not with IBD, such as irritable bowel syndrome, psychological distress and socio-economic parameters.

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DATA AVAILABILITY STATEMENT

The data underlying this article will be shared on reasonable request to the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information will be found online in the Supporting Information section.

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APPENDIX 1

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