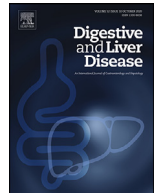




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## Alimentary Tract

Patients' real-world experience with inflammatory bowel disease: A cross-sectional survey in tertiary care centres from the GETAID group<sup>☆</sup>

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## ARTICLE INFO

## Article history:

Received 17 July 2020

Accepted 12 October 2020

Available online xxx

## Keywords:

Crohn's disease

Inflammatory bowel disease

Patients experience

Ulcerative colitis

## ABSTRACT

**Background:** Patients' experience with healthcare professionals could influence their clinical outcomes.

**Aims:** To assess inflammatory bowel disease (IBD) patients' experience with their disease, their treatment and their relationship with their physician.

**Methods:** A one-week cross-sectional study was conducted in 42 IBD centres. 2011 consecutive outpatients with IBD completed an anonymous self-report questionnaire assessing their experience with and knowledge of IBD.

<sup>☆</sup> All of the members of the GETAID patient experience study group are listed in the appendix.

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<sup>1</sup> Members of the GETAID-patient experience study group are listed in the Appendix (following the References).

**Results:** A quantitative assessment of the doctor-patient relationship revealed that patients' knowledge of IBD and IBD treatment ranged from 7.4 to 8.3 out of 10. In addition to IBD physicians, other sources of information about IBD and current treatment mainly included the internet (80% and 63%, respectively) and general practitioners (61% and 54%). Knowledge about education programmes (28%) was poor, resulting in a lack of willingness to further use these resources (25%). Concerns about IBD treatment were raised in 76% of patients, mostly related to the fear of adverse events (47%) and a lack of efficacy (33%). The need of alternative healthcare professionals was reported by 89% of the sample.

**Conclusion:** In a large cohort of patients, we highlighted gaps in the management of patients with IBD regarding the need for higher-quality information and the implementation of alternative healthcare professionals.

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## 1. Introduction

The advent of biological agents has dramatically changed the management of patients with inflammatory bowel disease (IBD) [1,2]. Beyond the standardization of more ambitious clinical outcomes, the consideration of the impact of IBD on patients' quality of life is now a standard of care [3]. Patients' experiences with IBD are multidimensional, including disability and doctor-patient relationships, and these experiences could influence clinical outcomes and treatment adherence [4]. Such perspectives have often been driven by physicians through Delphi and consensus processes based on their own experience. However, few studies have recently assessed patients' experiences with IBD.

The management of patients with IBD requires patient-professional interactions between patients and multidisciplinary care teams, which include physicians and nurses and other healthcare providers such as psychologists, social workers or physiotherapists [5,6]. There is little information regarding IBD patients' experience with healthcare providers and their perceived needs in IBD.

We recently identified 3124 hospital visits of IBD patients in 42 IBD centres during a one-week cross-sectional survey [7]. Therefore, we conducted a large real-world cross-sectional survey of adult patients with IBD in 42 centres of the Groupe d'Etude Thérapeutique des Affections Inflammatoires du tube Digestif (GETAID) group to describe patients' experience with IBD in order to identify gaps and opportunities for improvement.

## 2. Patients and methods

### 2.1. Study population

A one-week cross-sectional survey was conducted in 42 tertiary centres affiliated with the GETAID group in France and Belgium. The survey was conducted from November 26th to November 30th, 2018. Investigators were asked to include consecutive ambulatory adult (>18 years) outpatients with a proven diagnosis of IBD. The paper questionnaire was distributed to patients by their GI specialist or IBD nurse, retrieved before the visit and entered into an anonymous electronic database.

The study was conducted in accordance with the ethical principles expressed in the Declaration of Helsinki and the requirements of applicable French regulations. The patients' experience study was conducted through the French reference methodology MR-004, supervised by and registered in the GETAID (registration number 2210131). All authors had access to the study data and reviewed and approved the final manuscript.

### 2.2. Survey instrument

A 4-page self-report questionnaire was first designed by the Educational GETAID Committee and then submitted to twenty con-

secutive outpatients to assess completion rate and reliability of the questionnaire. The final questionnaire, which is provided in the supplementary materials (Fig. S1), was designed to explore the following:

- Patients and IBD characteristics: demographics, type and duration of IBD, age at diagnosis, history of surgical treatment, current medical IBD treatment, occupational status, distance between home and the IBD clinic.
- IBD activity: Overall health and IBD daily-life burden, measured using a 10-point Visual Analogue Scale (VAS), history of sick leave and patient's global assessment of clinical remission.
- Patients' overall satisfaction with the patient-physician relationship, measured using a 10-point VAS, as well as the frequency of appointments with physicians and general practitioners.
- Knowledge about IBD and IBD-related treatment, measured using a 10-point VAS as well as questions about the source of information and knowledge about biosimilars and educational programmes.
- Use of complementary and alternative medicine, measured using a 10-point VAS.
- Adherence to IBD-related treatment, measured using a 10-point VAS.
- Concerns about IBD-related treatment, measured using a multiple choice question.
- Current use of and perceived need for healthcare providers, measured using multiple choice questions.

### 2.3. Statistical analysis

The data are expressed as numbers (%) for qualitative data and as the means  $\pm$  standard deviation (SD) or medians [interquartile range] for quantitative data. Qualitative variables were compared using Chi<sup>2</sup> test or the Fisher exact test and quantitative variables using Mann-Whitney test. All of the analyses were two-tailed, and p values less than 0.05 were considered significant. All statistics were calculated using the SPSS Statistics<sup>®</sup> software (SPSS Inc., v23, Chicago, IL, USA).

## 3. Results

### 3.1. Study population

We included 2011 outpatients with IBD, including 67.8% with Crohn's disease (CD) and 32.2% with ulcerative colitis (UC.). The main characteristics of the study population are shown in Table 1. The median duration of IBD was 10.5 [4.5–18.5] years. At the time of the survey, most of the patients (73.9%) were treated with a biological agent, 8.5% were treated with an immunosuppressant alone, 11.6% were treated with 5-aminosalicylic acid, and 6.3% had no treatment. A total of 70.6% of patients were employed or students, 8.5% were unemployed, 8.5% were homemakers, and 12.3% were retired. The mean distance between home and the IBD clinic

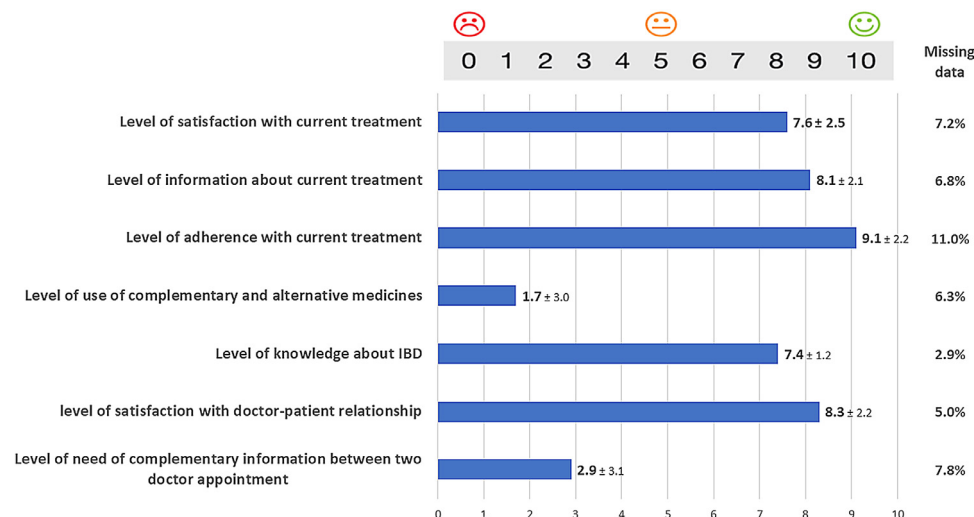
**Table 1**

Demographic and disease and medication characteristics of 2011 patients with inflammatory bowel disease.

Characteristic	Overall population (n = 2011)	Missing data (%)
<b>Age at diagnosis, years</b>	40.0 [29.0–52.0]	1.8%
<b>Male gender, no (%)</b>	53.1%	2.4%
<b>BMI, kg/m<sup>2</sup></b>	24.4 ± 6.5	2.9%
<b>Duration of IBD, years</b>	10.5 [4.5–18.5]	10.2%
<b>Age at diagnosis, no (%)</b>		10.2%
A1: ≤16 years	14.2%	
A2: 17 – 40 years	67.6%	
A3: > 40 years	18.2%	
<b>Type of inflammatory bowel disease, (%)</b>		5.1%
Crohn's disease	67.8%	
Ulcerative colitis	32.2%	
<b>History of intestinal resection, no (%)</b>	45.6%	2.4%
<b>Occupational status, %</b>		3.8%
Employed	62.2%	
Unemployed	8.6%	
Homemaker	8.5%	
Student	8.4%	
Retired	12.3%	
<b>Distance from home, km</b>	46.8 ± 99.6	12.0%
<b>Current treatment</b>		4.9%
None	6.3%	
5-ASA	11.6%	
Immunosuppressant alone	8.5%	
Anti-TNF	56.0% (including 14.9% with combination therapy)	
Vedolizumab	11.1% (including 1.0% with combination therapy)	
Ustekinumab	6.8% (including 0.9% with combination therapy)	
<b>Clinical remission</b>	49.1%	14.3%

5-ASA: 5-aminosalicylic acid; TNF: tumor-necrosis factor; BMI: body mass index; GI: gastrointestinal; IBD: inflammatory bowel disease.

Variables are presented as n (%), mean ± standard deviation or median (interquartile range).

**Fig. 1.** Visual analogic scales to evaluate patients' experiences in IBD.

was 46.8 ± 99.6 km. Clinical remission was reported in 49.1% of patients.

### 3.2. Patients experience with IBD

Patients' perceived knowledge of IBD had a mean score of 7.4 ± 1.2 (Fig. 1). Patients' perceived knowledge of IBD was higher in patients with long duration of IBD (> 10 years), history of intestinal resection, early diagnosis of IBD according to Montreal classification and patients in clinical remission. In addition to treating physicians, the main complementary sources of information on IBD were the internet (79.8%), general practitioners (61.4%), newspapers and magazines (29.0%), patients associations (20.6%), pharmacists (10.9%) and educational programmes (8.0%). A total of 97.4% of patients reported having free dialogue about their IBD with

family members, 80.5% reported having free dialogue with their friends, 48.9% reported having free dialogue with their coworkers, and 39.3% reported having free dialogue with other IBD patients. Regarding dedicated education programmes on IBD, 28.2% had knowledge of educational programmes patients, 10.4% had already participated, and 25.1% were willing to participate. Regarding sick leave, 71.2% of patients reported taking sick leave at least once since their IBD diagnosis, and the mean frequency of sick leaves per year was 0.8 ± 1.8.

### 3.3. Patients experience with current treatment

The levels of satisfaction with and information about current treatment were very good, with mean scores of 7.6 ± 2.5 and 8.1 ± 2.1, respectively (Fig. 1). The level of information was higher in

**Table 2**

Visual analogic scales to evaluate patients' experiences in IBD according to patients' characteristics.

	Level of knowledge about IBD		Level of satisfaction with current treatment		Level of information about current treatment		Level of adherence to current treatment		Level of satisfaction with doctor-patient relationship		Level of need of complementary information between two doctor appointment	
	VAS	p	VAS	p	VAS	p	VAS	p	VAS	p	VAS	p
<b>Gender</b>		0.61		0.20		0.19		0.45		0.39		<b>0.01</b>
Male	7.4 ± 1.8		7.7 ± 2.5		8.1 ± 2.1		9.0 ± 2.3		8.3 ± 2.2		<b>2.7 ± 3.2</b>	
Female	7.5 ± 1.9		7.5 ± 2.4		9.0 ± 2.1		9.1 ± 2.1		8.4 ± 2.2		<b>3.1 ± 3.1</b>	
<b>Age</b>		0.53		0.47		0.11		<b>0.003</b>		<b>0.001</b>		0.30
< 40 years	7.4 ± 1.8		7.6 ± 2.4		8.0 ± 2.1		<b>8.9 ± 2.3</b>		<b>8.1 ± 2.2</b>		2.9 ± 3.0	
40-60 years	7.4 ± 1.9		7.5 ± 2.5		8.0 ± 2.1		<b>9.1 ± 2.2</b>		<b>8.4 ± 2.2</b>		3.0 ± 3.2	
> 60 years	7.6 ± 2.0		7.7 ± 2.6		8.3 ± 2.1		<b>9.5 ± 1.8</b>		<b>8.7 ± 2.0</b>		2.7 ± 3.3	
<b>Type of IBD</b>		0.12		0.56		0.70		<b>0.02</b>		<b>0.01</b>		<b>0.01</b>
Crohn's disease	7.5 ± 1.8		7.6 ± 2.4		8.1 ± 2.1		<b>9.0 ± 2.3</b>		<b>8.2 ± 2.2</b>		<b>2.8 ± 3.0</b>	
Ulcerative colitis	7.4 ± 1.8		7.6 ± 2.5		8.0 ± 2.1		<b>9.2 ± 1.9</b>		<b>8.5 ± 2.1</b>		<b>3.2 ± 3.2</b>	
<b>Past intestinal resection</b>		<b>0.01</b>		0.69		0.86		0.91		0.19		0.78
Yes	<b>7.6 ± 1.8</b>		7.6 ± 2.5		8.1 ± 2.1		9.1 ± 2.3		8.4 ± 2.1		2.9 ± 3.1	
No	<b>7.3 ± 1.8</b>		7.6 ± 2.4		8.0 ± 2.1		9.1 ± 2.1		8.3 ± 2.2		2.9 ± 3.1	
<b>Duration of IBD</b>		<b>&lt;0.001</b>		<b>0.04</b>		0.89		<b>&lt;0.001</b>		0.45		<b>0.05</b>
> 10 years	<b>7.3 ± 1.7</b>		<b>7.7 ± 2.3</b>		8.1 ± 2.1		<b>8.9 ± 2.1</b>		8.2 ± 2.2		<b>2.8 ± 3.0</b>	
≤ 10 years	<b>7.2 ± 1.8</b>		<b>7.5 ± 2.5</b>		8.1 ± 2.0		<b>9.2 ± 2.3</b>		8.5 ± 2.2		<b>3.0 ± 3.1</b>	
<b>Age at diagnosis</b>		<b>&lt;0.001</b>		0.98		0.46		0.52		<b>0.05</b>		0.42
A1: <16 years	<b>7.9 ± 1.6</b>		7.6 ± 2.5		8.0 ± 1.9		9.2 ± 1.9		<b>8.3 ± 2.1</b>		2.7 ± 3.0	
A2: 16-40 years	<b>7.6 ± 1.8</b>		7.6 ± 2.4		8.0 ± 2.1		9.1 ± 2.2		<b>8.2 ± 2.2</b>		2.9 ± 3.0	
A3: > 40 years	<b>7.2 ± 1.9</b>		7.6 ± 2.6		8.2 ± 2.1		9.2 ± 2.2		<b>8.6 ± 2.1</b>		3.0 ± 3.3	
<b>Active worker or student</b>		0.97		<b>0.02</b>		0.22		<b>0.02</b>		0.14		0.54
Yes	7.4 ± 1.8		<b>7.7 ± 2.4</b>		8.1 ± 2.0		<b>9.0 ± 2.3</b>		8.3 ± 2.2		2.9 ± 3.1	
No	7.4 ± 2.0		<b>7.4 ± 2.7</b>		8.0 ± 2.3		<b>9.3 ± 2.0</b>		8.4 ± 2.2		3.0 ± 3.3	
<b>BMI &gt; 24 kg/m<sup>2</sup></b>		0.18		<b>0.03</b>		0.92		0.91		0.80		0.91
Yes	7.4 ± 1.9		<b>7.7 ± 2.3</b>		8.1 ± 2.1		9.1 ± 2.2		8.3 ± 2.2		2.9 ± 3.1	
No	7.5 ± 1.8		<b>7.5 ± 2.6</b>		8.1 ± 2.0		9.1 ± 2.2		8.3 ± 2.2		3.0 ± 3.3	
<b>Distance home - clinic</b>		0.40		0.30		0.43		0.14		<b>0.007</b>		<b>0.002</b>
> 25 km	7.5 ± 1.8		7.6 ± 2.5		8.1 ± 2.0		9.2 ± 2.0		<b>8.4 ± 2.0</b>		<b>2.6 ± 3.0</b>	
≤ 25 km	7.4 ± 1.8		7.7 ± 2.4		8.1 ± 2.1		9.0 ± 2.2		<b>8.2 ± 2.3</b>		<b>3.1 ± 3.1</b>	
<b>Current treatment</b>		0.21		<b>0.002</b>		0.48		<b>&lt;0.001</b>		0.08		<b>0.02</b>
None or 5-ASA	7.3 ± 2.1		<b>7.2 ± 3.1</b>		8.1 ± 2.5		<b>8.2 ± 3.3</b>		8.5 ± 2.5		<b>3.3 ± 3.3</b>	
Immunosuppressant	7.4 ± 1.9		<b>7.5 ± 2.5</b>		8.2 ± 2.1		<b>9.3 ± 1.9</b>		8.5 ± 2.1		<b>3.0 ± 3.4</b>	
Biologics	7.5 ± 1.8		<b>7.7 ± 2.3</b>		8.0 ± 2.0		<b>9.2 ± 1.9</b>		8.2 ± 2.2		<b>2.8 ± 3.0</b>	
<b>Current clinical remission</b>		<b>&lt;0.001</b>		<b>&lt;0.001</b>		<b>&lt;0.001</b>		0.78		<b>&lt;0.001</b>		<b>&lt;0.001</b>
Yes	<b>7.7 ± 1.7</b>		<b>8.5 ± 1.8</b>		<b>8.4 ± 1.9</b>		9.1 ± 2.2		<b>8.5 ± 2.0</b>		<b>2.4 ± 2.9</b>	
No	<b>7.3 ± 1.9</b>		<b>6.5 ± 2.7</b>		<b>7.7 ± 2.2</b>		9.1 ± 2.1		<b>8.1 ± 2.3</b>		<b>3.4 ± 3.1</b>	

5-ASA: 5-aminosalicylates; BMI: body mass index; IBD: inflammatory bowel disease; VAS: visual analogic score.

Variables are presented as n (%), mean ± standard deviation

patients in clinical remission whereas the level of satisfaction with current treatment was higher in patients with long IBD duration (>10 years), those with BMI > 24 kg/m<sup>2</sup>, active workers or student, patients in clinical remission and patients treated with biologics and/or immunosuppressants (Table 2). On the other hand, 93.9% of patients felt the need for additional information about their current treatment. In addition to their treating physician, sources of information about their current treatment included the internet (62.9%), general practitioners (54.3%), newspapers and magazines (18.2%), other patients (14.4%), pharmacists (11.5%) and educational programmes (6.7%). The self-reported level of adherence to current treatment was high, with a mean score of 9.1 ± 2.2. The self-reported level of adherence to current treatment was higher in patients with ulcerative colitis, those with recent diagnosis (≤ 10 years), active workers or students and patients treated with biologics and/or immunosuppressants. Concerns about the current treatment were raised by 75.6% of patients and were related to the risk of adverse events (47.4%), a lack of efficacy (32.9%), the hospital's administration of biological agents (21.5%), difficulties in the daily use of medicines (5.9%) and difficulties with self-administered subcutaneous injection (4.9%; this was reported by 9 out of 346 patients treated with subcutaneous injection of methotrexate, adalimumab, golimumab and/or methotrexate at the time of the survey) (Fig. 2).

Overall, 28.2% of patients reported that they used complementary and alternative medicines. The level of use of complementary and alternative medicines was 1.7 ± 3.0 (Fig. 1). The frequent use (VAS > 5) of complementary and alternative medicines was reported by 19.4% of patients.

Patients were asked whether they had heard of generic drugs and biosimilars, whether they had already taken some and if they were willing to take some if their GI specialist would give them a prescription. Whereas 86.7% and 77.6% of patients had already heard of or taken generics, respectively, only 20.4% and 11.0% had heard of or taken biosimilars. In patients treated with infliximab, 26.1% were aware of biosimilars, and 16.1% had received some. Regarding whether patients were willing to take a generic drug or a biosimilar, 53.5% and 21.5% responded positively, respectively, whereas 46.5% and 78.5% responded negatively or did not know the answer.

#### 3.4. Patients' experience with the patient-doctor relationship

The mean number of physician appointments per year was 3.2 ± 2.8 for GI specialists and 2.6 ± 3.9 for general practitioners. Regarding patients' evaluation of the doctor-patient relationship with their IBD-treating physician, the mean VAS score was 8.3 ± 2.2. The evaluation of the doctor-patient relationship was higher in

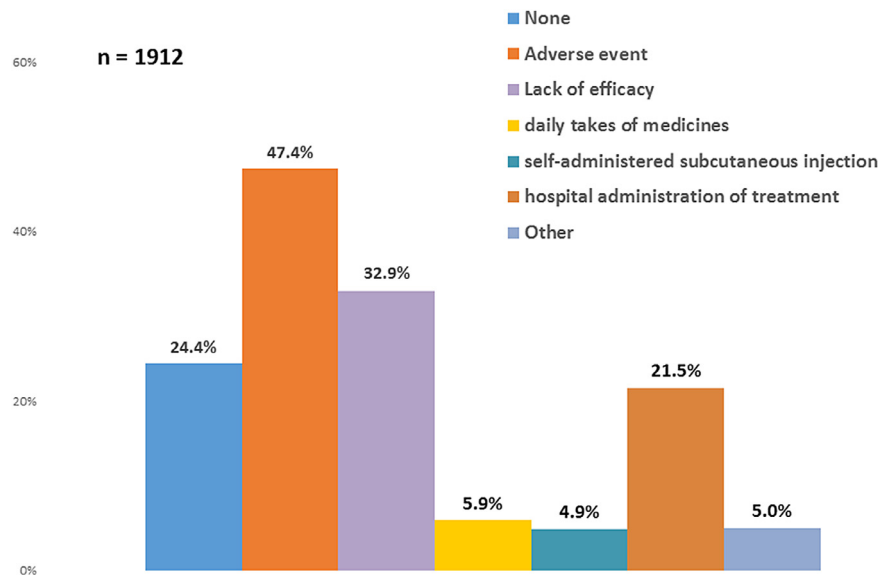


Fig. 2. Concerns about current treatment, measured using a multiple choice question.

patients > 40 years, patients with ulcerative colitis, patients with diagnosis of IBD after 40 years (Montreal A3), patients in clinical remission and patients living far from the Clinic (> 25 km) (Table 2). The mean VAS score regarding the need for additional information between appointments with their GI specialist was  $2.9 \pm 3.1$ . In these cases, 62.6%, 31.6%, and 1.5% of patients contacted their GI specialist by phone, email and mail, respectively. The need for additional informal between appointments with their GI specialist was increased with female gender, patients with ulcerative colitis, those with active disease, those not treated with biologics, those with recent diagnosis ( $\leq 10$  years) and those living close to the Clinic ( $\leq 25$  km).

Beyond GI specialists, 62.0% of patients reported having previously consulted other healthcare professionals, including dietitians (47.3%), psychotherapists (24.8%), IBD nurses (16.6%), social workers (9.3%), sports coaches (4.9%), and sexologists (1.9%). A total of 89.2% of patients reported a perceived need for management with other healthcare professionals, including dietitians (24.9%), sport coaches (22.0%), psychotherapists (14.6%), sexologists (9.4%), social workers (8.4%) and IBD nurses (6.4%).

#### 4. Discussion

This observational survey was primarily designed to assess the real-world experience of patients with IBD in the biologics era. During a single week, 2011 consecutive outpatients from 42 GETAID centres responded to this survey to assess the multidimensionality of patients' experiences with IBD. Despite inclusion of a very high rate of patients on biologics, we observed a high level of satisfaction, adherence to treatment and knowledge about IBD and IBD-related treatment. However, we highlighted a lack of knowledge and a lack of willingness to use generic drugs, biosimilars and educational programmes as well as perceived needs for combining IBD professionals with other healthcare professionals. Last, we highlighted the pivotal role of general practitioners in the management of IBD patients, which has not been sufficiently considered to date.

For a better understanding of our results, we aimed to introduce the French health care system, which is one of universal national health insurance. The financial and operational management of health insurance relies on compulsory income-proportional contributions, access to care according with needs (partial coverage

for most of health care costs and full coverage in case of costly or long-term ailments) and determination of the prices of goods and services refunded. There are public hospitals as well as private hospitals that could be linked to the public system for nonprofit organization.

The overall acceptance of medication is often considered as a risk-benefit ratio [8]. In that setting, distinctions should be made between patients' perceived risk of treatment and evidence-based medicine. In addition, even if the benefits are superior to the risks, high concerns could remain and may affect long-term acceptance and adherence. In a recent study assessing beliefs about medicines in patients with longstanding infliximab therapy (median duration of 4.1 [2.3–6.0] years), concerns about medications were reported in approximately half of the patients [9]. In the present study, concerns about current treatment were raised in 75% of patients. The vast majority of concerns were related to the risk of adverse events and the risk of a lack of efficacy; there were fewer concerns about the mode of administration of treatments. Improving the quality of information and the implementation of shared decision-making processes is therefore mandatory in patients with IBD even in patients with longstanding disease and continuous treatment [10,11].

Overweight is a common issue in adult patients with IBD like [12]. The increase of visceral adiposity may contribute to enhance the systemic inflammatory burden and impair the clinical course of IBD. In the present study, patients with BMI  $\geq 24$  kg/m<sup>2</sup> had paradoxically higher level of satisfaction with current treatment. We could hypothesize that patients with deeper remission and higher satisfaction with treatment may be more prone to express overweight predisposition.

Biosimilars were first introduced in the early 2010s based on the demonstration of pharmacokinetics and clinical biosimilarity with an originator [13,14]. They are now widely used in many inflammatory immune-mediated diseases, and they have a positive economic impact due to being more accessible for patients [15,16]. In two successive online surveys by the European Federation of Crohn's and Ulcerative Colitis Association in 2014–15 and 2018, 36% and 44% of the patients had previously heard of biosimilars, respectively [17,18]. Among them, only 32% and 35% were fully confident about the use of biosimilars even if they were prescribed by their treating physician. In our study, only 20.4% of patients had heard of biosimilars and only 21.5% were willing to take some. These results indicated a lack of knowledge and awareness about



biosimilars. Efforts should be made to better inform patients about this topic through education programmes and to include these programmes in treatment-related decision-making processes.

Although direct access to information about IBD without guidance could generate anxiety, increasing knowledge about IBD and related treatments is a cornerstone in the management of patients with IBD [10,19]. Beyond GI specialists, patient education could be delivered through various supports such as the internet, newspapers and magazines, educational programmes, other patients associations and general practitioners. As previously described, most of our patients obtained information from the internet [19–21]. Surprisingly, despite our tertiary care centre recruitment, very few patients obtained additional information about IBD and related treatments from other patients and education programmes. Efforts to promote education programmes and daily interaction with other patients should be made to improve patients' access to education programmes.

Interestingly, more than half of the reported declared receiving additional information about IBD and their current treatment from their general practitioners. General practitioners are expected to play a pivotal role in the management of patients with chronic diseases based on a particular relationship developed over time, and thus, they can be an alternative source of information and management. To date, the role of general practitioners in the management of patients with IBD has been poorly studied and is often not considered in guidelines such as ECCO consensus statements [5,6]. Additional efforts should be made to reinforce the link between general practitioners and GI specialists and to set up education programmes on IBD for general practitioners.

Complementary and alternative medicine (CAM) encompasses a wide range of diverse medical and health care systems, practices and products that are not presently considered part of conventional medicine [22]. Although there is limited evidence on the efficacy of CAM in IBD, it is common to use CAM in patients with IBD [23,24]. The association Francois Aupetit, the French representative of the European Federation of the Crohn's and Ulcerative Colitis Association, recently administered an online survey on the use of CAM. Among the 767 participants, 65.6% reported a current use of CAM while an additional 12% reported a previous use of CAM [25]. In our study, only 28.2% of patients reported ever using CAM while 19.4% reported frequent use. In multivariate analysis (data not shown), the use of CAM was higher in women due to concerns about adverse events, concerns about a lack of efficacy of traditional treatment, the perceived need for a sexologist and a regulating defecation subscore > 5. Our results may underline the heterogeneity between patients recruited in tertiary care centres or in patients associations.

The main purpose of the current study was to obtain a global perspective on the management of patients with IBD from the patient's point of view. Although the questionnaire provided a global overview of patients' management, knowledge and perceived needs, it may be biased by the absence of predefined outcomes and the multiplicity of the area of investigation. However, it provides useful information for improving daily practice with our patients and for developing a working hypothesis for further studies. One other limitation of this survey was the potential for recruitment bias. Indeed, two-thirds of the patients had Crohn's disease, 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. Last, our questionnaire was developed with IBD-treating physicians and not by patients themselves, which may have led to the underestimation of some patient-reported outcomes.

In conclusion, this survey examined the provision of adequate and multidisciplinary care to patients with IBD and identified some gaps, especially with respect to patients' information on IBD and IBD-related treatment. Concerns about adverse events and a lack of efficacy should be more widely discussed in daily practice through shared decision-making processes. The role of the general practitioner is pivotal for patients and should be more adequately considered and reinforced in IBD units and in national and international organizations.

## Conflict of Interest

Maria Nachury has received consulting and travel accommodation fees from Abbvie, Adacyte, Amgen, Biogen, Boehringer-Ingelheim, Ferring, Janssen, Mayoli Spindler, MSD, Takeda.

Yoram Bouhnik has received lecture and consulting fees from Abbvie, Biogaran, Boehringer-Ingelheim, CTMA, Ferring, Gilead, Hospira, ICON, Inception IBD, Janssen, Lilly, Mayoli Spindler, Merck, MSD, Norgine, Pfizer, Robarts Clinical Trials, Roche, Sanofi, Shire, Takeda, UCB and Vifor Pharma. This author has also stock ownership of Inception IBD, San Diego, CA, USA.

Melanie Serrero has received lecture or consulting fees from Abbvie, Ferring, Amgen, Celltrion, Janssen, Ferring, Takeda and Tillots.

Jerome Filippi has received lecture and consulting fees from Abbvie, Astellas pharma, Covidien, Ferring, Jansen, MSD, Pfizer, Takeda.

Xavier Roblin reported a relationship with MSD, Abbvie, Amgen, Sandoz, Pfizer, Takeda and Janssen.

Guillaume Bouguen received lecture fees from Abbvie, Ferring, MSD, Takeda and Pfizer and consultant fees from Takeda, Janssen.

Denis Franchimont is research director of FNRS; he has received educational grants from Abbvie, Takeda, MSD, and has received honoraria fees for lectures or consultancy from Ferring, Falk, Chiesi, Abbvie, MSD, Centocor, Pfizer, Amgen, Janssen, Mundipharma, Takeda and Hospira.

Guillaume Savoye has received lecture fees from Vifor Pharma, Takeda, Pfizer, HAC Pharma, Abbvie, MSD, and Ferring France. This author has also received travel accommodations from Ferring, Abbvie, and MSD France as well as a research grant from Ferring.

Anthony Buisson has received research funding from Pfizer, lecture fees from Abbvie, Ferring, Hospira, MSD, Janssen, Sanofi-Aventis, Takeda and Vifor Pharma and consulting fees from Abbvie, Biogen, Janssen, Pfizer and Takeda.

Edouard Louis has received fees for: Research Grant: Takeda, Pfizer; Educational Grant: Abbvie, Takeda, Janssen; Speaker Fees: Abbvie, Ferring, MSD, Falk, Takeda, Hospira, Janssen, Pfizer, Celgene; Advisory Board: Abbvie, Ferring, MSD, Takeda, Celgene, Hospira, Janssen; Consultant: Abbvie

Stephane Nancey has received consulting fees from Merck, Abbvie, Takeda, Ferring, Norgine, Vifor Pharma, Novartis, Janssen Cilag, Hospira, Takeda and HAC Pharma

Vered Abitbol has received lecture fees from Amgen, Biogen, Mylan, Sandoz, Pfizer, Takeda, Janssen, Tillots, Gilead, Ferring

Jean-Marie Reimund has received consulting fees from Hospira and Pfizer. This author has also received lectures fees from Abbvie, Ferring, Janssen Cilag, Pfizer and Takeda. This author has also received travel accommodations from Ferring, Abbvie, MSD, Janssen Cilag, Pfizer, Hospira and Takeda

Olivier DeWitt has received lecture and/or consultant fees from Abbvie, Ferring, Fresenius-Kabi, Janssen, Mylan, MSD, Pfizer, Takeda.

Lucine Vuitton has received lecture fees from Abbvie, MSD, Takeda, Ferring, Janssen and Pfizer, and research grants from MSD, Takeda and Pfizer.

Nicolas Mathieu has received lecture fees from Abbvie, Amgen, Biogen, Janssen, MSD, Takeda, Pfizer, Ferring France and Vifor Pharma. This author has also received travel accommodations from Abbvie, Takeda and Pfizer as well as consulting fees from Amgen, Janssen, MSD, Sandoz, and Takeda.

Laurent Peyrin-Biroulet has received consulting fees from Merck, Abbvie, Janssen, Genentech, Ferring, Norgine, Tillots, Vifor, Shire, Therakos, Pharmacosmos, Pilège, BMS, UCB-Pharma, Hospira, Celltrion, Takeda, Biogaran, Boehringer-Ingelheim, Lilly, Pfizer, and HAC-Pharma. This author has also received lecture fees from Merck, Abbvie, Takeda, Janssen Cilag, Ferring, Norgine, Tillots, Vifor, Therakos, HAC-Pharma, and Mitsubishi.

Cyrielle Gilletta received lecture fees from Abbvie, Takeda, Pfizer and Janssen and consulting fees from Abbvie, Janssen and Celltrion.

Matthieu Allez has received honoraria from Novo Nordisk, MSD, Abbvie, Ferring, Genentech, Janssen, Pfizer, GSK, Hospira, UCB, Novartis, Takeda, Mayolo-Spindler.

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Ludovic Caillio received board and lecture fees from Abbvie, Janssen, Pfizer, Takeda, Amgen

David Laharie has received counseling, boards, transports and/or fees from Abbvie, Biogaran, Biogen, Ferring, HAC-pharma, Janssen, MSD, Novartis, Pfizer, Prometheus, Roche, Takeda, Theradiag, Tillots.

Aurelien Amiot has received consulting fees from Abbvie, Hospira, Takeda, Gilead and Biocodex as well as lecture fees and travel accommodations from Abbvie, Janssen, Biocodex, Hospira, Ferring, Takeda and MSD. This author has also received advisory board fees from Gilead, Takeda and Abbvie.

No conflicts of interest are claimed by the remaining authors.

## Data availability statements

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

## Study funding

This study was supported by Abbvie with an institutional grant

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.dld.2020.10.020](https://doi.org/10.1016/j.dld.2020.10.020).

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