Epidemiological characteristics of a population visiting a patient-centered informative website about irritable bowel syndrome

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Abstract

Background and aims: **Irritable bowel syndrome (IBS) is a chronic disorder characterized by abdominal pain and an altered bowel habit. The aim of this study was to evaluate the characteristics of a population visiting a patient-centered informative website about IBS.**

Methods: **Five digital surveys were used to assess the Rome IV criteria, red flag symptoms, healthcare use, psychological comorbidities, quality of life, symptom severity, diet, physical activity. Patients were divided into a Rome positive and negative population with the Rome positive population being further subtyped based on dominant stool pattern.**

Results: **Red flag symptoms (42%) and comorbid psychological disorders (65% anxiety and 39% depression) were common. Despite consulting health care professionals and therapy, most patients (96%) still experienced moderate to severe symptoms with an average impact on quality of life. 73% performed regular physical exercise and 25% of the Rome positive population followed the FODMAP diet. Almost all participants consulted a health care professional at one point in time and used some form of therapy. 54% of the patients believed there is generally sufficient information available and 57% thinks that their physician takes IBS seriously. However, only 41% thinks that their physician has sufficient knowledge about IBS.**

Conclusions: **This study underlines the importance of a thorough characterization of IBS patients. Furthermore, patients expressed an urgent need for high quality information and education for both health care professionals and patients.** (Acta gastroenterol. belg., **2023,** 86, **17-25**).

Keywords: Irritable bowel syndrome, IBS, epidemiology, motility, neurogastroenterology.

Introduction

Irritable bowel syndrome (IBS) is a chronic disorder characterized by abdominal pain and an altered bowel habit (1). It is one of the most prevalent gastrointestinal disorders affecting around 11% of the population, mostly women and young people (2). Based on dominant stool pattern patients can be divided into four subtypes: diarrhea (IBS-D), constipation (IBS-C), mixed (IBS-M), and unspecified (IBS-U).

The exact etiology is largely unknown, but patients often report an infectious, traumatic, or stressful event preceding the onset of symptoms (3). The underlying pathophysiology is multifactorial, and involves increased permeability, dysmotility, dysbiosis, food hypersensitivity, visceral hypersensitivity, inflammation, genetics, and psychological stress (4,5). There has been a lot of attention for the role of the brain-gut-axis and the interplay between IBS and psychological disorders. A recent meta-analysis noted that psychological comorbidities are prevalent in IBS patients with 44% suffering from anxiety and 36% from depression (6). There is a complex interplay with stress exacerbating symptoms and excessive symptoms causing further stress. Recent large-scale genome-wide analysis has shown shared genetic pathways between IBS and mood disorders such as anxiety and depression (7).

Over 60% of patients report a clear link between symptoms and food intake. This makes dietary changes an appealing therapeutic option, however, little is known on the percentage of the population using various dietary options (8). A group of foods frequently discussed in relation to IBS are the fermentable oligo-, di-, monosaccharides and polyols (FODMAPs). FODMAPs are poorly absorbed in the small intestine causing an osmotic effect with subsequent increased water content in the lumen. When these FODMAPs arrive in the colon they are fermented by the microbiota causing gas production (8). Apart from these osmotic and fermentation effects, FODMAPs can also cause immune activation and changes in gut microbiota (9,10).

IBS has a major impact on quality of life of patients and is associated with high healthcare costs because of difficulties in diagnosis and treatment leading to frequent consultations with health care providers (11,12). A positive diagnosis of IBS is made with help of the Rome IV criteria and some limited blood and stool sample testing to exclude other gastrointestinal diseases which can present similarly such as inflammatory bowel disease, celiac disease, and colon cancer. Additional testing can be necessary in the presence of red flag symptoms like blood in the stools, anemia, weight loss, fever, older age at the start of symptoms, or a family history of colon cancer (1). Subsequent treatment is focused on the predominant symptom (abdominal pain, constipation, or diarrhea) and can consist of dietary-, pharmacological-, and/or psychotherapy. Patients are also encouraged to

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make lifestyle changes with sufficient sleep, relaxation, and physical exercise (13,14).

Education and a strong physician-patient relationship positively impact symptoms and improve quality of life through illness coherence and acceptance (15). However, research has shown that 77% of IBS patients feel insufficiently informed and have misconceptions on the cause and appropriate treatment for IBS (16,17). There is a demand for information coming from patients with an increasing role for internet-based resources (18,19).

The aim of this study was to evaluate the characteristics of a Dutch speaking population visiting a Belgian patient-centered informative website about IBS. We wanted to gain better insight in the presence of symptoms, red flags, use of the health care system, psychological comorbidities, symptom severity, quality of life, and lifestyle habits of our local IBS population.

Methodology

Study population

Participants were recruited through a patient-centered informative website (www.ibsbelgium.org) developed in 2019 by KVM and HDS. Most visitors of the website found it through a Google search. The website was promoted via several social media channels and flyers distributed amongst patients and general practitioners. Apart from promotion on the website and social media no further measures were taken to increase the number of respondents. On the website visitors had the possibility to participate in several surveys aimed at evaluating different aspects of IBS. Five surveys will be discussed in this manuscript, each of these contained elements of multiple questionnaires. Participants were free to decide how many of these surveys they wanted to complete. The 'Symptom assessment' was a short survey on the homepage of the website, it was also the only survey of which patients received a result. The other surveys were solely for the purpose of research with no benefit to the participants and could be found in the 'research section' of the website. Data was collected via QUALTRICS, licensed via the University of Antwerp, except for the 'Symptom assessment' which was a build in feature of the website. Furthermore, apart from the 'Symptom assessment', all surveys were directed at patients who received a diagnosis of IBS while the former was directed towards all visitors of the website who suspected they might have IBS. Before participation, visitors were required to give informed consent as approved by the Ethics Committee of the University of Antwerp/ Antwerp University hospital (19/41/449). All data was collected anonymously and cannot be traced back to the individual participant. It is not possible to know if visitors completed more than one survey. Therefore, it was also not possible to correlate the results if patients completed multiple surveys. Patients were excluded if they reported comorbid inflammatory bowel disease, celiac disease, or another gastrointestinal disorder which could influence the reported symptoms.

The Rome IV criteria for IBS were evaluated in each survey, patients were subsequently divided into a Rome positive and Rome negative population for further analysis. In the Rome positive population patients were further subtyped based on the dominant stool pattern into IBS-diarrhea, IBS-constipation, IBS-mixed, and IBS-unspecified.

Questionnaires

The questioned red flag symptoms were bloody stools, fever, weight loss (>3kg in the last 3 months), family history of colon cancer, and start of symptoms after 50 years of age. To evaluate symptom severity the IBS symptom severity index (IBS-SSS) was used (20). The IBS-SSS contains five questions, each scored between 0 and 100, assessing abdominal pain, bloating, stool pattern, and influence on daily life. A total score between 75 and 174 indicated mild IBS, between 175 and 299 moderate IBS, and more than 300 severe IBS. The Visceral sensitivity index (VSI) assesses gastrointestinal (GI) specific anxiety, fear, and hypervigilance (21). It contains 15 questions each scored between 0 and 5, with a higher score indicating more GI-specific anxiety. To assess comorbid anxiety and depression the Hospital anxiety and depression score (HADS) was used (22). It consists of two subscales with seven questions each. A score of more than eight suggests comorbid anxiety or depression (23). To assess IBS-related quality of life two similar questionnaires were used. The IBS Quality of life (IBS-QOL) contains 34 questions, and the IBS-36 contains 36 questions (24,25). They evaluate the influence of IBS on different aspects of daily life. Both questionnaires were normalized to a score between 0 and 100 with a higher score indicating a worse quality of life. Physical activity levels were assessed with the Baecke physical activity questionnaire looking at daily physical activity, sports, and leisure (26). The Food frequency questionnaire (FFQ) was used to evaluate food intake in the last three months (27). It also contained some general questions assessing special diets (vegetarian, veganism, FODMAP) and exclusion of certain food groups (dairy, meat, poultry, eggs, fish).

Statistical analysis

Categorical characteristics were expressed as n (%) and analyzed with Fisher's exact test (Rome positive versus Rome negative) or Chi square (IBS-D versus IBS-C versus IBS-M versus IBS-U). Continuous variables following a Gaussian distribution were expressed as mean (standard deviation) and analyzed using unpaired t-tests (Rome positive versus Rome negative) or one-way ANOVA (IBS-D versus IBS-C versus IBS-M versus IBS-U). Non- parametric continuous variables were expressed as median (range) and analyzed with Mann-

Whitney U (Rome positive versus Rome negative) or Kruskal-Wallis (IBS-D versus IBS-C versus IBS-M versus IBS-U). A significance level of 0.05 was used throughout the analysis.

Results

Symptom assessment

A total of 2000 participants completed the 'Symptom assessment' evaluating the prevalence of Rome IV criteria for IBS and red flag symptoms (table 1, figure 1). Of these, 69.2% fulfilled the Rome IV criteria. When patients did not fulfil the Rome IV criteria (more than one reason possible) this was mostly (49.2%) due to a symptom duration shorter than six months. Other reasons were insufficient relation with defecation or stool form (45.8%), and insufficient days with abdominal pain (30.7%).

When looking at the dominant stool pattern in the Rome IV positive population we found that the predominant subtype was IBS-M (44.4%) followed by IBS-D (35.9%), IBS-C (17.6%), and IBS-U (2.0%).

Approximately 40% of participants had at least one red flag symptom (figure 1). This was not significantly different between Rome positive and negative patients. When patients had at least one red flag symptom they received the advice to consult a health care professional. The most prevalent red flag symptom in all patients was a family history of colon cancer (14.2%). This was followed by weight loss in the Rome negative population (13.5%) and bloody stools in the Rome positive population (12.5%). The prevalence of red flag symptoms was not significantly different between patient subtypes except for bloody stools (p=0.004), which was less prevalent in IBS-D compared to other subtypes.

General assessment

A total of 74 patients completed the 'General assessment' (table 2, figure 2) of which 68.9% fulfilled the Rome IV criteria. There were no significant differences between patients when looking at BMI, alcohol use, or smoking. Circa one in five patients reported a post-infectious onset of their symptoms, this was more prevalent in the Rome negative group (26.1% Rome negative versus 17.7% Rome positive). Almost all patients (95.9%), had consulted a general practitioner (GP) for their complaints at one point in time, this was however more prevalent in the Rome positive population (87.0% Rome negative versus 100% Rome positive). When we look at the last three months, approximately

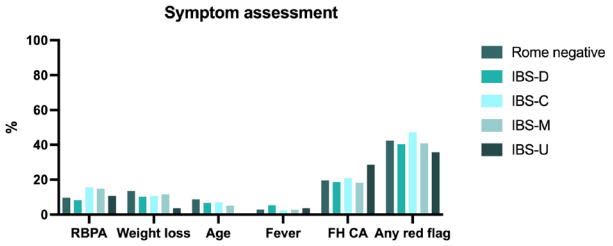

Figure 1. — Prevalence of red flag symptoms.
-C = constipation; -D = diarrhea; FH CA = family history of colon cancer; IBS = irritable bowel syndrome; -M = mixed; RBPA = red blood loss per anum; -U = unspecified.

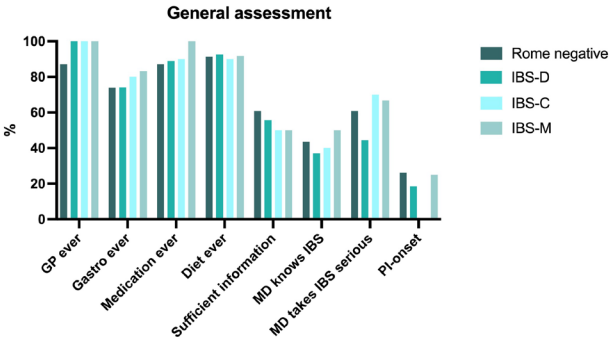

Figure 2. — Use of the health care system and post-infectious onset.
Because of limited sample size IBS-U is not shown. -C = constipation; -D = diarrhea; Gastro = gastroenterologist; GP = general practitioner; IBS = irritable bowel syndrome; MD = medical doctor; -M = mixed; PI = post-infectious.

Table 1. — **Symptom assessment**

	All	Rome negative	Rome positive						
			Total	p-value†	IBS-D	IBS-C	IBS-M	IBS-U	p-value‡
N (%)	2000	616 (30.8)	1384 (69.2)		497 (35.9)	244 (17.6)	615 (44.4)	28 (2.0)	
RBPA (%)	232 (11.6)	59 (9.6)	173 (12.5)	0.07	41 (8.2)	38 (15.6)	91 (14.8)	3 (10.7)	**0.004**
Weight loss (%)	232 (11.6)	83 (13.5)	149 (10.8)	0.08	51 (10.3)	26 (10.7)	71 (11.5)	1 (3.6)	0.57
Age >50years (%)	135 (6.8)	54 (8.8)	81 (5.9)	**0.02**	33 (6.6)	17 (7.0)	31 (5.0)	0 (0)	0.31
Fever (%)	69 (3.5)	18 (2.9)	51 (3.7)	0.43	27 (5.4)	6 (2.5)	17 (2.8)	1 (3.6)	0.08
FH CA (%)	284 (14.2)	120 (19.5)	164 (11.9)	0.85	93 (18.7)	51 (20.9)	112 (18.2)	8 (28.6)	0.47
Any red flag symptom (%)	838 (41.9)	261 (42.4)	577 (41.7)	0.81	201 (40.4)	115 (47.1)	251 (40.8)	10 (35.7)	0.27

-C = constipation; -D = diarrhea; FH CA = family history of colon cancer; IBS = irritable bowel syndrome; -M = mixed; RBPA = red blood loss per anum; -U = unspecified. Significant differences are in bold? †Comparison Rome positive and Rome negative population with Fisher's exact. ‡Comparison IBS subtypes with Chi square.

Table 2. — **General assessment**

	All	Rome negative	Rome positive						
			Total	p-value†	IBS-D	IBS-C	IBS-M	IBS-U	p-value‡
N (%)	74	23 (31.1)	51 (68.9)		27 (36.5)	10 (19.6)	12 (16.2)	2 (2.7)	
Age (mean, SD)	41 (14)	44 (15)	41 (13)	0.39	41 (12)	46 (16)	38 (14)	21 (4)	0.11
N females (%)	66 (89.2)	18 (78.3)	48 (94.1)	0.10	26 (96.3)	8 (80.0)	12 (100)	2 (100)	0.19
BMI (mean, SD)	24.0 (5.0)	24.1 (5.1)	23.9 (5.0)	0.90	23.8 (5.2)	22.2 (3.2)	26.0 (5.7)	20.6 (3.4)	0.24
Units of alcohol per week (median, range)	1 (0-25)	1 (0-25)	1 (0-21)	0.73	1 (0-21)	2 (0-15)	1 (0-6)	0 (0-0)	0.24
Smoking (%)	6 (8.1)	2 (8.7)	4 (7.8)	1.00	3 (11.1)	0 (0.0)	1 (8.3)	0 (0.0)	0.70
GP ever (%)	71 (95.9)	20 (87.0)	51 (100)	**0.03**	27 (100)	10 (100)	12 (100)	2 (100)	1.00
GP last 3 months (%)	32 (43.2)	11 (47.8)	21 (41.2)	0.62	12 (44.4)	4 (40.0)	5 (41.7)	0 (0.0)	0.68
Gastro ever (%)	56 (75.7)	17 (73.9)	39 (76.5)	1.00	20 (74.1)	8 (80.0)	10 (83.3)	1 (50.0)	0.74
Gastro last 3 months (%)	13 (17.6)	6 (26.1)	7 (13.7)	0.21	4 (14.8)	2 (20.0)	1 (8.3)	0 (0.0)	0.81
Medication ever (%)	67 (90.5)	20 (87.0)	47 (92.2)	0.67	24 (88.9)	9 (90.0)	12 (100)	2 (100)	0.65
Medication last 3 months (%)	49 (66.2)	16 (69.6)	33 (64.7)	0.79	16 (59.3)	7 (70.0)	9 (75.0)	1 (50.0)	0.86
Diet ever (%)	67 (90.5)	21 (91.3)	46 (90.2)	1.00	25 (92.6)	9 (90.0)	11 (91.7)	1 (50.0)	0.28
Diet last 3 months (%)	55 (74.3)	18 (78.3)	37 (72.5)	0.78	18 (66.7)	9 (90.0)	9 (75.0)	1 (50.0)	0.47
Sufficient information (%)	40 (54.1)	14 (60.9)	26 (51.0)	0.46	15 (55.6)	5 (50.0)	6 (50.0)	0 (0.0)	0.51
MD knows IBS (%)	30 (40.5)	10 (43.5)	20 (39.2)	0.80	10 (37.0)	4 (40.0)	6 (50.0)	0 (0.0)	0.59
MD takes IBS seriously (%)	42 (56.8)	14 (60.9)	28 (54.9)	0.80	12 (44.4)	7 (70.0)	8 (66.7)	1 (50.0)	0.42
Post-infectious onset (%)	15 (20.3)	6 (26.1)	9 (17.7)	0.53	5 (18.5)	0 (0.0)	3 (25.0)	1 (50.0)	0.26

BMI = body mass index; -C = constipation; -D = diarrhea; Gastro = gastroenterologist; GP = general practitioner; IBS = irritable bowel syndrome; MD = medical doctor; -M = mixed; SD = standard; deviation; -U = unspecified. Significant differences are in bold. †Comparison Rome positive and Rome negative population with Fisher's exact for categorical characteristics; Mann-Whitney U for non-parametric continuous variables; Unpaired t-tests for parametric continuous variables. ‡Comparison IBS subtypes with Chi square for categorical characteristics; Kruskal-Wallis for non-parametric continuous variables; One-way ANOVA for parametric continuous variables.

half of the patients consulted their GP. Seventy-six percent of patients had consulted a gastroenterologist at one point in time and 18% had seen a gastroenterologist in the last three months (figure 2).

Most patients (90.5%) had tried any form of medication and/or diet to relieve their symptoms, although we did not ask for the details of the treatment strategy or diet. When comparing the Rome positive and negative population we could see a trend for higher use of the health care system in the last three months with the Rome negative population.

Only 61% of the Rome negative population believed there was sufficient information available about IBS, in the Rome positive group this was even lower with 51%. Only 41% of patients thought their physician had sufficient knowledge about IBS and a slightly higher percentage, 57%, felt that their physician took IBS seriously.

Symptom severity and psychological symptoms

Seventy-one patients completed the survey evaluating symptom severity and psychological comorbidities (table 3, figure 3) and 74.6% were Rome positive. Most patients had moderate to severe symptoms with a mean IBS-SSS score of 272 in the Rome negative population and 282

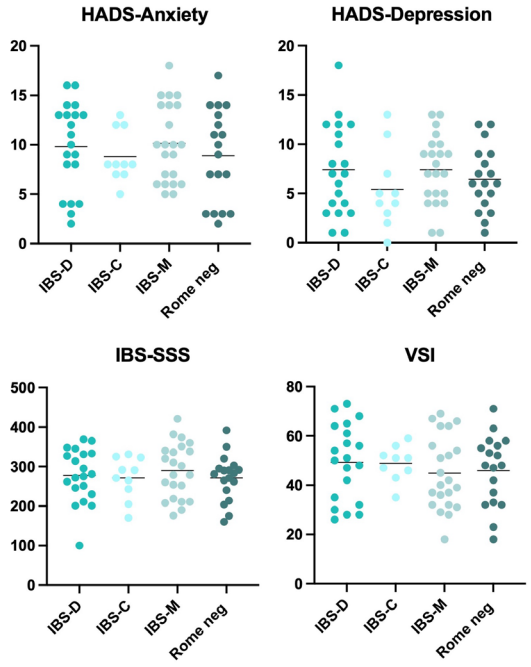

Figure 3. — Symptom severity and psychological symptoms. Because of limited sample size IBS-U is not shown. A = anxiety; -C = constipation; -D = diarrhea; D = depression; HADS = hospital anxiety and depression score; IBS = irritable bowel syndrome; IBS-SSS = symptom severity score; -M = mixed; VSI = visceral sensitivity index.

Table 3. — **Symptom severity and psychological symptoms**

	All	Rome negative	Rome positive						
			Total	p-value†	IBS-D	IBS-C	IBS-M	IBS-U	p-value‡
N (%)	71	18 (25.4)	53 (74.6)		20 (28.2)	10 (14.1)	22 (31.0)	1 (1.4)	
N females (%)	59 (83.1)	15 (83.3)	44 (83.0)	1.00	16 (80)	10 (100)	18 (36.4)	0 (0)	0.07
Age (mean, SD)	45 (17)	49 (15)	44 (17)	0.27	46 (17)	47 (15)	41 (18)	52 (0)	0.69
IBS-SSS (mean, SD)	279 (63)	272 (58)	282 (65)	0.55	278 (68)	272 (53)	290 (69)	300 (0)	0.87
HADS-Anxiety (mean, SD)	9.4 (4.2)	8.9 (4.7)	9.6 (4.0)	0.53	9.8 (4.4)	8.8 (2.6)	10.1 (3.9)	2.0 (0)	0.22
Positive anxiety score§ (%)	46 (64.8)	10 (55.6)	36 (67.9)	0.40	15 (75)	7 (70)	14 (63.6)	0 (0)	0.43
HADS-Depression (mean, SD)	6.9 (3.8)	6.4 (3.3)	7.0 (4.0)	0.60	7.4 (4.6)	5.4 (4.0)	7.4 (3.5)	6.0 (0)	0.56
Positive depression score§ (%)	28 (39.4)	6 (33.3)	22 (41.5)	0.59	9 (45)	2 (20)	11 (50)	0 (0)	0.34
VSI (mean, SD)	46.9 (13.9)	45.9 (14.2)	47.2 (13.8)	0.73	49.3 (15.4)	48.9 (7.2)	45.0 (14.8)	41.0 (0)	0.72

A = anxiety; -C = constipation; -D = diarrhea; D = depression; HADS = hospital anxiety and depression score; IBS = irritable bowel syndrome; IBS-SSS = symptom severity score; -M = mixed; SD = standard deviation; -U = unspecified. Significant differences are in bold. †Comparison Rome positive and Rome negative population with Fisher's exact for categorical characteristics; Unpaired t-tests for parametric continuous variables. ‡Comparison IBS subtypes with Chi square for categorical characteristics; One-way ANOVA for parametric continuous variables. §A positive score is defined as >8.

Table 4. — **Diet and exercise**

	All	Rome negative	Rome positive						
			Total	p-value†	IBS-D	IBS-C	IBS-M	IBS-U	p-value‡
N (%)	51	6 (11.5)	45 (88.2)		15 (28.8)	10 (19.2)	19 (37.3)	1 (1.9)	
N females (%)	47 (92.2)	6 (100)	41 (89.1)	1.00	12 (80.0)	9 (90.0)	19 (100)	1 (100)	0.55
Age (mean, SD)	41 (14)	45 (12)	41 (15)	0.58	45 (16)	44 (12)	37 (14)	28 (0)	0.28
BMI (mean, SD)	22.7 (4.4)	24.2 (6.3)	22.6 (4.2)	0.40	22.5 (4.0)	23.0 (4.1)	22.6 (4.5)	19.6 (0)	0.89
BMI: underweight (%)	6 (11.8)	0 (0.0)	6 (13.0)	1.00	1 (6.7)	1 (10.0)	4 (21.1)	0 (0.0)	0.65
BMI: normal (%)	37 (72.5)	5 (83.3)	32 (69.6)	0.66	12 (80.0)	6 (60.0)	13 (68.4)	1 (100)	0.61
BMI: overweight (%)	4 (7.8)	0 (0.0)	4 (8.7)	1.00	0 (0.0)	3 (30.0)	1 (5.3)	0 (0.0)	0.06
BMI: obese (%)	5 (9.8)	1 (16.7)	4 (8.7)	0.47	2 (13.3)	0 (0.0)	2 (10.5)	0 (0.0)	0.68
Most time: work (%)	35 (68.6)	5 (83.3)	30 (65.2)	0.65	9 (60.0)	6 (60.0)	14 (73.7)	1 (100)	0.79
Most time: house (%)	11 (21.6)	1 (16.7)	10 (21.7)	1.00	4 (26.7)	4 (40.0)	2 (10.5)	0 (0.0)	0.25
Most time: study (%)	5 (9.8)	0 (0.0)	5 (10.9)	1.00	2 (13.3)	0 (0.0)	3 (15.8)	0 (0.0)	0.62
Sport (%)	37 (72.5)	4 (66.7)	33 (73.3)	0.61	12 (80.0)	7 (70.0)	13 (68.4)	1 (100)	0.71
Sport: <1h (%)	1 (2.7)	0 (0.0)	1 (3.0)	1.00	0 (0.0)	1 (14.3)	0 (0.0)	0 (0.0)	0.28
Sport: 1-2h (%)	15 (40.5)	0 (0.0)	15 (45.5)	0.13	6 (50.0)	3 (42.9)	6 (46.2)	0 (0.0)	0.81
Sport: 2-3h (%)	8 (21.6)	2 (50.0)	6 (18.2))	0.20	4 (33.3)	1 (14.3)	1 (7.7)	1 (100)	0.09
Sport: 3-4h (%)	5 (13.5)	0 (0.0)	5 (15.2)	1.00	1 (8.3)	1 (14.3)	3 (23.1)	0 (0.0)	0.74
Sport: >4h (%)	8 (21.6)	2 (50.0)	6 (18.2)	0.20	4 (33.3)	1 (14.3)	1 (7.7)	0 (0.0)	0.38
Vegetarian (%)	9 (19.6)[a]	1 (20.0)[b]	8 (19.5)[c]	1.00	2 (13.3)	5 (55.6)[d]	1 (6.3)[e]	0 (0.0)	**0.02**
Vegan (%)	4 (8.7)[a]	0 (0.0)[b]	4 (9.8)[c]	1.00	1 (6.7)	2 (22.2)[d]	1 (6.3)[e]	0 (0.0)	0.56
FODMAP (%)	10 (21.7)[a]	0 (0.0)[b]	10 (24.4)[c]	0.57	4 (26.7)	1 (11.1)[d]	4 (25.0)[e]	1 (100)	0.26
Other diet (%)	10 (21.7)[a]	1 (20.0)[b]	9 (22.0)[c]	1.00	3 (20.0)	3 (33.3)[d]	3 (18.8)[e]	0 (0.0)	0.78
Lactose free (%)	13 (28.3)[a]	2 (40.0)[b]	11 (26.8)[c]	0.61	5 (33.3)	3 (33.3)[d]	3 (18.8)[e]	0 (0.0)	0.70

-C = constipation; -D = diarrhea; IBS = irritable bowel syndrome; -M = mixed; SD = standard deviation. [a]46 participants; [b]5 participants; [c]41 participants; [d]9 participants; [e]16 participants. Significant differences are in bold. †Comparison Rome positive and Rome negative population with Fisher's exact for categorical characteristics; Mann-Whitney U for non-parametric continuous variables; Unpaired t-tests for parametric continuous variables. ‡Comparison IBS subtypes with Chi square for categorical characteristics; Kruskal-Wallis for non-parametric continuous variables; One-way ANOVA for parametric continuous variables.

in the Rome positive population. In the Rome positive population, a higher percentage of patients had severe symptoms (43.4%) compared to the Rome negative population (22.2%).

The Rome positive population also had a higher percentage of patients fulfilling the criteria for comorbid anxiety (67.9% Rome positive versus 55.6% Rome negative) or depression (41.5% Rome positive versus 33.3% Rome negative). Both groups had a VSI score around 45 (45.9 Rome negative versus 47.2 Rome positive). There were no significant differences between the patient subtypes for any of the discussed scores.

Diet and exercise

There were 51 participants who completed the survey about diet and exercise (table 4, figure 4). Only six participants (11.8%) were Rome negative, the remaining 45 participants (88.2%) were Rome positive. 72.5% of patients had a normal BMI with an average BMI of 24.2 in the Rome negative group and 22.6 in the Rome positive group. The majority of participants (68.6%) spent most of their day working, while a slightly higher percentage of the Rome positive population (21.7% Rome positive versus 16.7% Rome negative) spent most of their time on household tasks. 73% of participants practiced at least one sport. No Rome negative participants followed the FODMAP diet compared to 24.4% in the Rome positive population. However, the Rome negative population had a higher percentage of participants following a lactose-free diet (40.0% Rome negative versus 26.8% Rome positive).

Quality of life

Thirty-four patients completed the survey looking into their quality of life (table 5, figure 5) of which 73.5% were Rome positive, no participants belonged to the IBS-U subtype. The Rome positive and negative group had similar scores with an average of 63.2 and 55.4 on the IBS-QOL, and 54.9 and 64.0 on the IBS-36. However, when we compared the different IBS subtypes with each other we did see a difference with an average score for the IBS-QOL of 58.5 in IBS-D, 55.8 in IBS-C, and 70.6 in IBS-M (p=0.04). In the IBS-36 these were 51.0, 46.5, and 63.0 respectively (p=0.01).

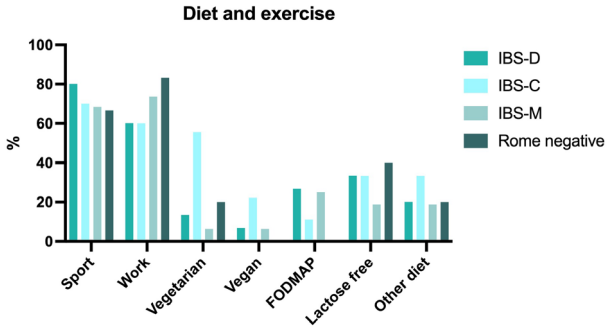

Figure 4. — Diet and exercise
Because of limited sample size IBS-U is not shown. -C = constipation; -D = diarrhea; FODMAP = fermentable oligo-, di-, monosaccharides and polyols; IBS = irritable bowel syndrome; -M = mixed.

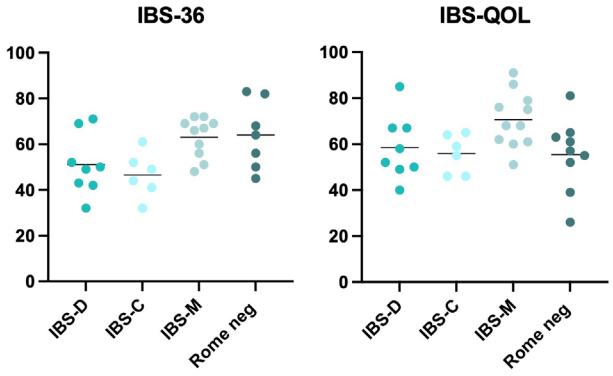

Figure 5. — Quality of life
-C = constipation; -D = diarrhea; IBS = irritable bowel syndrome; IBS-QOL = quality of life score; -M = mixed.

Discussion and conclusion

Irritable bowel syndrome is one of the most prevalent gastrointestinal disorders, but trustworthy information can be difficult to find for patients. After establishing a patient-centered informative website about IBS, we decided to further characterize patients visiting the website. We can assume that people who complete our 'symptom assessment' are suffering from gastrointestinal complaints which they believe could be due to IBS. In the end, 70% of these people fulfilled the Rome IV criteria. However, when participants did not fulfil the criteria, this was in almost half of the cases due to an insufficient duration of symptoms (less than six months). We can suspect that part of these participants will continue to experience symptoms and will fulfil the Rome IV criteria when re-evaluating later. Another reason for not fulfilling the Rome IV criteria was insufficient abdominal pain or insufficient changes in the stool pattern. However, this could point towards a milder phenotype or a well-treated patient.

Table 5. — **Quality of life**

	All	Rome negative	Rome positive					
			Total	p-value†	IBS-D	IBS-C	IBS-M	p-value‡
N (%)	34	9 (26.5)	25 (73.5)		8 (32.0)	6 (24.0)	11 (44.0)	
N females (%)	30 (88.2)	8 (88.9)	22 (88.0)	1.00	7 (87.5)	5 (83.3)	10 (90.9)	0.90
Age (mean, SD)	43 (14)	50 (16)	41 (13)	0.12	35 (7)	50 (17)	41 (13)	0.09
IBS-QOL (mean, SD)	61.1 (14.2)	55.4 (15.8)	63.2 (13.4)	0.16	58.5 (14.1)	55.8 (8.4)	70.6 (12.0)	**0.04**
IBS-36 (mean, SD)	56.9 (13.3)	64.0 (14.8)	54.9 (12.5)	0.11	51.0 (13.3)	46.5 (9.9)	63.0 (8.7)	**0.01**

-C = constipation; -D = diarrhea; IBS = irritable bowel syndrome; IBS-QOL = quality of life score; -M = mixed; SD = standard deviation. Significant differences are in bold. †Comparison Rome positive and Rome negative population with Fisher's exact for categorical characteristics; Unpaired t-tests for parametric continuous variables. ‡Comparison IBS subtypes with Chi square for categorical characteristics; One-way ANOVA for parametric continuous variables.

IBS subtypes were further determined with the help of the Bristol stool chart. Most of the patients assessed their IBS as being from the mixed phenotype. This is in contrast with other studies reporting an IBS-D predominant population (28). Assessing dominant stool pattern is, however, very subjective and it is unclear if these patients would be classified the same if seen by a health care professional. Furthermore, it has been described that patients often change subtype over time making a single assessment of stool consistency less accurate (29).

There was a high prevalence of red flag symptoms (42%) in patients completing the 'symptom assessment', mainly familial history of colon cancer, weight loss, and rectal bleeding. However, since we have no information on pre-existing conditions or if prior testing has already been performed, we do not know if this statement is applicable to all IBS patients.

For example, it is possible that IBS patients experiencing red flag symptoms are more inclined to search the internet for information. It does, however, emphasizes the importance of a thorough anamnesis when seeing patients to make an accurate diagnosis and not miss other diseases like colon cancer, inflammatory bowel disease, or celiac disease which might develop over time.

Of the patients completing the 'general assessment', one in five remembered a post-infectious onset of their symptoms which is slightly higher compared to previous studies reporting a prevalence of 6-17% (30,31). However, this higher prevalence is mainly evident in the Rome negative group with a prevalence of 26% compared to 18% in the Rome positive population. When we take a closer look at these Rome negative PI-IBS patients half of them have a symptom duration shorter than six months. Therefore, it is possible these patients experience lingering effects from the infection rather than a PI-IBS.

When evaluating the use of our health care system we can see that most patients had consulted a health care professional and tried some form of therapy to relieve their symptoms at one point. The Rome negative population had a higher use of the health care system in the last three months which can be because they are in the process of actively searching for a diagnosis and treatment.

Sadly, less than half of participants believed their treating physician had sufficient knowledge about IBS. However, over half of participants did have the feeling that their physician took IBS seriously. According to participants there is also a major lack in accessible and scientifically correct information for patients which is in accordance with other studies looking into this topic (18,19). This emphasizes the urgent need for information and education not only for patients but also for health care professionals.

A large percentage reported severe symptoms, and the presence of comorbid anxiety disorders was also higher than reported in other studies, 65% versus 44% previously (6). The presence of depression in our population was 40% which is similar to the previously reported 36% (6). Additionally, most patients reported an important impact of their symptoms on QOL with IBS-D and IBS-M reporting a larger impact on QOL compared to IBS-C. This is in accordance with a previous study comparing QOL between the different subtypes (32). They found that patients with IBS-D or IBS-M experienced more difficulties with daily activities and avoided food more frequently with defecation frequency being an important determinant (32).

The reported disease severity and impact on QOL could in part be due to an inclusion bias. Patients with severe symptoms might be more inclined to search for information on the internet to better cope with their disease. By searching for information online there is a higher chance of finding our call for participation in digital questionnaires. Furthermore, it is possible that patients participating in scientific research are more actively thinking about their disease throughout the day which can lead to a hypervigilance about symptoms.

Most participants had a BMI within the normal range and exercise regularly both of which have a beneficial effect on symptoms. Most participants spend much of their time at work with around one fifth of the Rome positive population spending most of their time on their household. When looking at dietary therapy no Rome negative patients followed the FODMAP diet, there was however, a larger percentage of Rome negative patients following a lactose-free diet. This could be because a lactose-free diet is oftentimes a first-line therapy while the FODMAP diet is a more elaborate and difficult to follow diet which is mostly suggested after failing other therapy options. Furthermore, patients can easily initiate a lactose-free diet without any professional guidance making it an easily accessible treatment option early in the disease course.

A limitation of our study is the limited number of participants in some surveys. This might be partly explained by differences in location on the website and the time surveys were online. The 'Symptom assessment' was clearly visible on the homepage of the website and while the other surveys were also promoted on the homepage, respondents had to visit the 'research section' to participate. Furthermore, the 'Symptom assessment' had been available since the start of the website whereas the other surveys were published at a later time.

Furthermore, since inclusion is digital, we are dealing with a poorly defined patient population, and we cannot know for certain if symptoms are related to IBS or another gastrointestinal disease. The Rome IV criteria are relatively strict, and we can assume that part of the Rome negative population are clinically diagnosed and treated as IBS patients. For this reason, we decided to also report data about the Rome negative population separately and compare them to the Rome positive population. Few differences were observed between the Rome negative

and positive population. It is likely that, at least part of, the Rome negative population presents a fifth subgroup of IBS patients rather than a distinctly separate population. We repeated statistical analyses with the Rome negative population as a fifth subtype, however, since this did not significantly alter our results and conclusions, we did not report these results.

Lastly, since data was collected anonymously, we were not able to link the answers of the surveys to each other limiting our ability to connect different aspects of IBS. While it is a limitation in the current study it demonstrates areas of interest and reveals several potential research topics for future IBS research, we will briefly discuss some of them. First, it would be interesting to be able to correlate the different aspects we studied with each other. On the one hand, we could achieve this by conducting a large study evaluating all these aspects at once. On the other hand, it would be interesting to highlight certain aspects and study these correlations in more detail, for example the relation between dietary measures and QOL. Second, it would be interesting to further study the effect of information and patient – health care professional relationship. For example, do patients reporting insufficient information have different characteristics. Or perhaps even a trial that studies education as an intervention. Third, we demonstrated a high prevalence of red flag symptoms. However, we do not have any other information about these patients like prior testing or follow-up. A more in dept analysis of these patients would be valuable; do they consult a health care professional, which tests are performed, is there another diagnosis in the end.

In conclusion, our study further validates the importance of a thorough characterization of IBS patients we encounter in our clinical practices. Red flag symptoms are prevalent as well as comorbid psychological disorders. Despite consulting health care professionals and trying different therapies a lot of patients still experience moderate to severe symptoms with an important impact on quality of life. One of the main take-home messages of this study is the urgent need of information of high scientific quality and the need for education of both health care professionals and patients.

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