Expectations of IBS patients concerning disease and healthcare providers: Results of a prospective survey among members of a French patients' association

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HAL Id: hal-02533639

https://normandie-univ.hal.science/hal-02533639

Submitted on 15 Dec 2022

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EXPECTATIONS OF IBS PATIENTS CONCERNING DISEASE AND HEALTHCARE PROVIDERS: RESULTS OF A PROSPECTIVE SURVEY AMONG MEMBERS OF A FRENCH PATIENTS' ASSOCIATION

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Short title : Expectations of IBS patients concerning disease, healthcare and a patients' organization

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ABSTRACT
Background and aims

IBS patients have an impaired quality of life (QoL) and feel dissatisfaction with medical care. We aim to describe the expectations of members of the French Association of IBS patients (APSSII) concerning health care providers (HCPs) and a patients' organization.

Patients and Methods

From January to June 2013, APSSII members were asked to answer questionnaires on their expectations and experiences concerning IBS and HCP.

Results

222/330 (67%) responded (women: 68.5%, 46.5±17.7 years, disease duration: 8.8±0.7 years, IBS-D 33.6%, IBS-C 26.7%, IBS-M 38.2%. IBS-SSS > 300 in 53 % and HAD score>19 in 45%). QoL impairment was correlated with disease severity and HAD score (r=-0.707 and r=-0.484, p<0.001 respectively), but not with IBS subtype. Expectations for IBS were "improved health", "better information on causes and treatments" (94%) and "better disease recognition" (86%). A significant gap was observed between expectations and experiences with HCPs. Better information, less isolation, recognition of the disease and a decrease in medical expenses were the main expectations for joining a patients' organization.

Conclusions

French IBS patients have a severe disease with a significant psychological impact and impaired QoL in half of the patients, certain unsatisfied expectations concerning HCP and high expectations in joining a patients' organization.

Abbreviations:

IBS: Irritable Bowel Syndrome QoL Quality of Life

APSSII : Association des patients souffrant du Syndrome de l'Intestin Irritable

HCP: Health Care Provider

IBS-C: Irritable Bowel Syndrome with constipation

IBS -D: Irritable Bowel Syndrome with diarrhea

IBS-M: Mixed Irritable bowel Syndrome

IBS-SSS score: IBS Severity Scoring System

FDDQL score: Functional Digestive Disorders Quality of Life score

INTRODUCTION

IBS is a chronic functional disease in which abdominal pain is associated with an abnormal transit pattern [1]. Although this is not a life-threatening disease, IBS considerably affects quality of life (QoL) [1] and work productivity [2], and imposes a profound burden on patients, their relatives, physicians and the health care system [1]. Due to the chronicity of symptoms, a poorly-understood underlying pathogenesis of the disease and many unmet treatment needs, clinical management of patients remains difficult and unsatisfactory in routine practice. Many patients feel dissatisfied by medical care [3]; this often leads to a difficult relationship with health care providers (HCPs).

In January 2011, an organization of adult patients suffering from IBS ("**A**ssociation des **P**atients **S**ouffrant du **S**yndrome de l'**I**ntestin **I**rritable": APSSII, www.apssii.org) was created in France, where the prevalence of IBS is between 5 and 10 % of the general population [4]. The objectives of this organization were to improve patients and their families' knowledge of IBS, to help them to feel less isolated, to facilitate clinical trials in IBS and also to help IBS patients in their dealings with health authorities. Information on this new organization can be obtained in newspapers, flyers and a specific website.

This prospective cross-sectional qualitative survey conducted on the members of a French association of IBS patients aimed to analyze their expectations concerning IBS, joining the organization, and HCPs, in comparison with their past experiences.

PATIENTS AND METHODS

From January to June 2013, all members of APSSII were asked to answer a questionnaire, sent either by mail or by internet. Questionnaires sent online or via mail were identical. The national postal service (with a prepaid return envelope) was used until the agreement of the French Data Protection Authority (Commission Nationale de l'Informatique et des Libertés) was obtained for the online study. Subsequently, only the online questionnaire was proposed to new members. Privacy of subject information was ensured by password-protected access to the data collection forms, recording no information that could reveal the identity of individual subjects in the online response database, and storing the online database on a secured Internet server. No compensation was given for participation in the study.

The study questionnaire was divided into three parts. The aim of the first one was to collect demographic data, to describe the disease (diagnosis lag time, duration of symptoms, completion of Rome Criteria III [5], subtype, IBS-Severity Scoring System (IBS-SSS) for severity [6], to assess the psychological status with the HAD score [7] and the impact of IBS on quality of life (QoL) using the Functional Digestive Disorders Quality of Life score (FDDQL) [8]. In this first part, the type of HCP previously treatingthe IBS, and past and current treatments were also documented. The second part of the questionnaire included questions on expectations and experiences in relation to the disease and the health care system. This part of the questionnaire was written according to previously unmet needs, highlighted in particular by Halpert et al [3]. The third part of the questionnaire included questions on expectations in joining a patients' organization for IBS. The questions were then validated by two members of the APSSII and the medical advisor to the APSSII, to simplify understanding of all the issues in order to receive adequate replies. All questions related to

expectations were scaled using a 5-point scale ("strongly disagree", "somewhat disagree", "neutral/not sure", "somewhat agree" and "strongly agree'). At the end of the questionnaire, participants were able to add a small commentary (5 lines) on other needs and expectations not included in the questionnaire.

STATISTICAL ANALYSIS

Baseline demographics and relevant clinical information were calculated and compared between participants who completed the survey online and those who completed the survey by mail. Means and standard deviations were calculated for continuous variables and comparisons were performed using t-tests and ANOVA. Frequencies were calculated for categorical variables, and comparisons were performed using Chi-square tests. To simplify the presentation of the results on expectations, we classified the responses in three categories: "agree", "disagree", and "neutral". These categories were obtained from the original responses by grouping ''strongly disagree,'' ''somewhat disagree,'' into ''disagree;'' and ''somewhat agree,'' and ''strongly agree'' responses into ''agree.'' The response ''neutral'' remained ''neutral/not sure''. In a sub-group analysis, we compared the mean responses between the subjects who completed the study online and those who responded by mail. Correlations between variables were made using the Pearson correlation test. In all cases, $p <$ 0.05 was considered significant. All the statistical analyses were carried out with SPSS software, version 24.0 (IBM).

RESULTS

Patients' characteristics

At the time of the study, the organization had 330 members; 222 of these (67%) answered the questionnaires: 164 by mail and 58 via internet. Participants were mostly women (n=152,

68.5%), with a mean age of 46.8 ± 17.3 years and a mean disease duration of 8.8 ± 0.7 years (IQR [1.6-12.56]). First symptoms of IBS occurred at a mean age of 29.6 ± 15.8 years (median 26.6; IQR [18.9-38.5]) while the mean delay between the first symptoms and IBS diagnosis was 3.4 years IQR [0.77-10.1]. The characteristics of the participants in the survey are given in Table 1.

The proportion of the different IBS subtypes was no different between women and men (IBS-C 30.3% vs 20.3%; IBS-D: 31.0% vs 40.6%; IBS-M: 38.6% vs 39.1%; respectively; p= 0,224). According to IBS-SSS, IBS was severe (IBS-SSS > 300) in 52.8 % of the patients, moderate (IBS-SSS between 175 and 300) in 39.2%, and minimal (IBS-SSS < 175) in 6.8% of participants;   two participants could be considered to be in remission (IBS-SSS <75). The mean IBS-SSS was not influenced by gender or transit pattern and was correlated neither with disease duration (r = -0.002; p=0.97) nor with age at onset (r = -0.093; p=0.23). Forty five percent of the patients suffered from severe depression (global HAD >19). QoL was altered in each of the eight dimensions (figure 1) and more severely impaired in women than in men (FDDQL global score 40.2 ±14.4 in women vs. 44.9±14 in men; p=0.039). There was no difference for the global QoL between IBS subtype (p=0.662) while FDDQL score was correlated with both disease severity (r = -0.707; p<0.0001) and HAD score (r= -0.484, p<0.0001).

At the time of the study, 53.7% of the patients were in active employment. Participants by mail were older than those who participated online (48.3 ± 16.8 vs 42.5 ± 18.3 years old; p = 0.028). There was no difference in other clinical (gender) or diseases characteristics (disease duration, HAD score, IBS-SSS, FDDQL) for those who participated in the study by mail and those who participated online.

Healthcare pathway

The initial diagnosis of IBS was made by a physician in 88% of cases, based in most cases on an analysis of symptoms and a normal colonoscopy (87 % of cases). In about 10% of the cases, this diagnosis was not given to the patient. At the time of the survey, 65 % of the participants were being followed up: by a general practitioner in 38 % of cases, a gastroenterologist in 57 %, or another specialist (psychiatrist, neurologist, acupuncturist, naturopath, nutritionist) in 5 %. Eighty-two percent of the participants in the survey had consulted for their IBS in the previous 12 months.

Past or current treatments and percentage of treatment cessation are presented in Table 2. Among the 222 participants, 219 (98.6%) had already been treated once. The mean number of therapeutic options tried since diagnosis was 5.3 ± 2.33 (up to 11) and was correlated with the IBS-SSS (r=0.287; p<0.001), HAD global score (r=0.158; p=0.03) and FDDQL, r = -0.276; p<0.001), but not with disease duration (r=0.0.79; p=0.272).

The mean number of treatments per participant at the time of the survey was 2.04 ± 1.64 (22% of participants underwent no further treatment: neither medical, dietary, nor alternative therapies; 16.8% underwent one treatment; 25.7% underwent two treatments and 35.5% of participants underwent 3 or more treatments (up to 8) at the same time; 64.5% of participants were currently under medical treatment), and was correlated with QoL (FDDQL, r =-0.244; p=0.001) but not with HAD score, IBS-SSS or disease duration. Diet and/or alimentary exclusions concerned 78.3% of participants (Table 3).

Laxatives were taken or had been taken by 74.2% of participants classified as IBS-C and 43.4% of IBS-M. Anti-diarrheal drugs (loperamide) were taken by 3.7% or had been taken by 3.3% of the 222 participants, by 17.8 % of participants classified as IBS-D (10.9% as past

treatment and 6.8% as current) and by 3.6% of IBS-M (2.4 % as past treatment and 1.2 % as current).

Previous expectations and experiences with HCPs in relation to IBS

The main expectations of patient relating to IBS were "improved health compared to their current state" in 94.2%, "a better knowledge of the causes" in 93.7%, "better knowledge of treatments" in 94.7% and "better disease recognition by family circle, colleagues and society" in 86.3%.

Expectations of patients concerning HCP and their previous experiences are given in Table 4. Patients also thought that their doctor had "a good knowledge of IBS" in 18.4%, "believed in their symptoms" in 46.8%, "was concerned by their symptoms" in 40.5%. HCPs had suggested to 65.3% of the patients that "symptoms were in their mind" and said to 82.6% that "they must learn to live with their symptoms". Globally, only 16.3% of the participants were satisfied by the health care system for IBS management, while 68.4% considered that a better management of symptoms would have had an impact on the overall IBS cost. The expectations of the 222 participants, compared to their experiences with previously chosen sources of information on IBS, is presented in Table 5.

Participant's expectations of an IBS patients' organization

Patients' expectations were "to feel less isolated" in 87.2% of cases, "to get information on the disease and treatments" in 100 %, "to participate in research on this disease" in 93.6%, "to obtain better recognition of the disease" in 94.1%, and "to reduce the out-of-pocket costs" in 82.4%. Table 6 supplies additional expectations, for the 222 survey participants, on joining a patient organization, as described in the free comments part of the survey.

DISCUSSION

This prospective cross-sectional qualitative survey, conducted on members of the French Association of IBS patients, highlights several important unmet needs in IBS management. In particular, it emphasizes an imperfect patient-HCP relationship, whereas an effective patient-physician relationship is essential to IBS care [9]. It further shows strong expectations for the IBS patients' organization. This data is likely to be representative of the expectations of the group, due to an answer rate to the questionnaire of 67 %. The participation of two-thirds of the members in the survey after only one request (online or by mail) is probably due to the fact that patients often feel poorly considered; only a third felt that their concerns had been heard by HCPs, the remaining HCPs not taking this unrecognized disease into consideration.

The characteristics of the participants are comparable to previous French studies on IBS: two-thirds of sufferers are women, with an average age of around 47 years [10,11], but also to studies on IBS patients from other parts of the world [12–14]. The distribution of the different subtypes according to the predominant transit disorder is also in accordance with the results of the most recent and largest study, carried out in France on more than 35,000 people [11]. Apart a small difference in age with younger participants in the online version of the study, there was no difference either in clinical factors such as gender, or in diseases characteristics such as disease duration, HAD, IBS-SSS and FDDQL between those who participated in the survey by mail or the online survey.

The severity of the disease, with severe IBS present in 52.8 % of the patients, is a noteworthy characteristic of the population who answered the questionnaire, whereas in the general population, it is estimated that only 20-25% of IBS patients have a severe disease [15]. The number of treatment options tested prior to doing the survey, and the percentage of patients who had already been treated by alternative, non-pharmaceutical options, are indirect

arguments to confirm the severity of IBS [1]. One might intuitively deduce that members of a patient's association have a more severe form of the disease and are more invested in the management of their disease.

However, in this survey, the frequency of severe IBS does not appear to be overestimated. This frequency was calculated in patients who had received a diagnosis; studies have reported that IBS is often more severe in diagnosed than in undiagnosed patients [16].

In addition, this frequency was very close to that calculated in a previous French study in consecutive patients recruited in private practice by a representative sample of 400 doctors among 2000 [10]. The percentage of depressed patients, with almost half of them suffering from severe depression according to HAD scores, is also unsurprising. The results of most studies indicate that IBS patients seen in outpatient treatment settings have high rates of psychiatric disorders and psychological distress (between 40 % and 60 %) [17]. We also confirmed that all the dimensions of QoL are impaired in IBS, that QoL was inversely impacted by symptoms severity and that QoL impairment is greater in women than in men [17]. Therefore, we can assume that most of the answers to this survey are those of a population representative of the overall IBS population and not only those of more severe and dissatisfied patients.

Our results demonstrate high expectations rates in French IBS patients for all the items listed by Halpert et al [3], with no differences between US and French patients. Unsurprisingly, sufficient information on the disease was one of the main expectations, IBS patients feel insufficiently informed, in particular with bowel cancer risk and diet [18]. As in the Halpert study [3], prior experiences of patients with their healthcare provider differed from their ideal expectations, but the percentage of patients who met these expectations was about two times

lower in France, particularly concerning sufficient information on IBS (only achieved in 16 % of participants), and concerning support from the physician: only present in one of four participants. In addition, patients received more information on the disease from gastroenterologists than from general practitioners.

Our methodology does not provide a definite explanation for these discrepancies. They could be explained either by differences in the organization of the health care system leading, for instance, to more limited time for patient consultation [19], or by cultural differences concerning both patients and health care providers between the US and France [20]. This relatively better patient-healthcare provider relationship in the US could also be explained as a consequence of all the work done by US patient organizations, which have over 25 years of existence, compared with the situation in France, where the organization is very recent. In addition, comprehensive information on IBS may be difficult to deliver when research provides more and more arguments for a multifactorial disease, depending on the subtype. As shown in the US, we also found that the preferred source of information is doctors [21].

This low satisfaction level concerning information from HCPs [22] and anxiety could explained why many patients seek information via the Internet [23]. The second main point of this survey is that interaction between French patients and the medical community seldom clarified the patient's understanding of the condition or improved its management whilst supportive social relationships, including a positive patient-practitioner relationship, have been associated with positive health outcomes [1]. The severity of the disease, reflected by the high number of treatment strategies tested in our study, could be one explanation for the difficult patient-practitioner relationship and for the sense of frustration and isolation reported by patients. Frustration is a result of the perceived inability to control symptoms, to prevent episodes, to identify episode triggers, and to obtain medical validation of the condition, gastroenterologists and general practitioners underestimating symptoms in about 50 % of the

cases [23]. The frustrations of frequently inadequate treatment could also explain high members' expectation for a patients' organization and the willingness to participate in the research [24].

This data from the French nationwide IBS patients' organization shows a high frequency of severe IBS among members, a significant psychological impact, impaired QoL and many unsatisfied expectations with respect to the disease and healthcare professionals. Implementing a therapeutic education programme [25] and improving the patient-physician relationship [26] have demonstrated efficacy in patient care and should be an independent objective in the future, apart from that of improving the armamentarium.

Contribution to the study

SABATE JM : designed the study, collected the data, analyzed the data, wrote the paper
DUCROTTE P: collected the data, analyzed the data, wrote the paper
PICHE T: collected the data
ZERBIB F: collected the data
DAPOIGNY M: collected the data
BRULEY DES VARANNES S: collected the data
BONAZ B: collected the data
MION F: collected the data
IGLICKI F: collected the data
DENEZ D: collected the data
FACON S: president of patients' organization, co-designed the questionnaire.
GOURCEROL G: collected the data
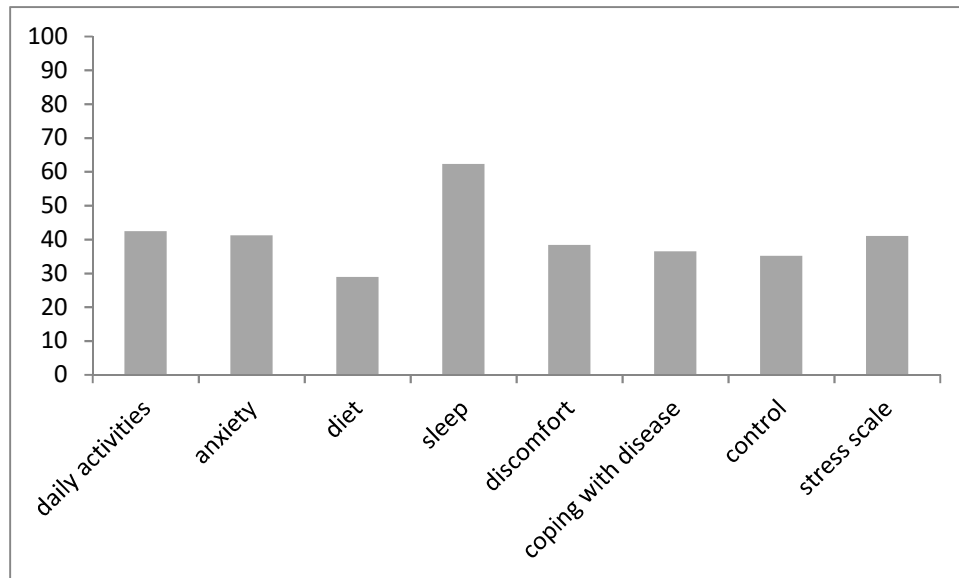JOUET P: designed the study, collected the data, analyzed the data , wrote the paper.

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Figure 1

Mean FDDQL sub-scores in the 222 participants to the survey.

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The score for each dimension of the QoL ranges from 0 (poorest quality of life) to 100 (best quality of life).

Table 1: Characteristics of the 222 patients who participated to the survey

Symptoms	Mean ± SEM
Abdominal pain	97.7 %
Abdominal pain relieved by defecation	71.3 %
Pain associated with modification of stool frequency	82.2 %
Pain associated with modification of stool consistency	72.4 %
Bloating	93.1 %
Mean IBS-SSS	305.7 ± 92.4
Mean pain intensity	46 ± 27
Mean number of days with pain during the last 10 days	6.3 ± 3.1
IBS subtypes	
IBS-C	26.7 %
IBS-D	33.6 %
IBS-M	38.2 %
Psychological status	
Mean HAD score	17.8 ± 6.7
Quality of life	
Mean FDQOL	41 ± 14
Educational level	
Higher educational	72 %
High school	18 %
Middle school	9 %

Table 2

Past or current treatments received by the 222 participants to the survey

Type of treatment	Past or current	Past	Treatment Interrupted (%)	Current
Diet with alimentary exclusions	78.3%	32.4%	41.38%	45.9%
Anti-spasmodics	85.1%	46.4%	54.05%	38.7%
Laxatives	42.7%	25.2%	59.02%	17.5%
Anti-diarrheal	7%	3.3%	47.14%	3.7%
Antidepressants	41.8%	24.8%	59.33%	17.0%
Probiotics	66.4%	38.3%	57.68%	28.1%
Homeopathy	47.2%	33.8%	71.61%	13.4%
Osteopathy	38.9%	27.9%	71.72%	11.0%
Hypnosis	16.7%	14.9%	89.22%	1.8%
Relaxation	38.4%	30.6%	79.69%	7.8%
Acupuncture	34.4%	24.8%	72.09%	9.6%

Participants can have more than one treatment at the same time explaining why the sum of each column is superior to 100%. As past or current were exclusive responses, the column past or current gives the percentage of participants who have tried this modality of treatment.

Table 3

Diet and main alimentary exclusions of the 222 participants

Diet	Patients (%)	Patients (%) of those following a diet or exclusion
Lactose- free	22.07	27.53
Gluten-free	11.71	14.61
Low-FODMAPs	7.21	8.99
Fibers-free	0.90	1.12
Other exclusions		
Cabbage	21.62	26.97
Legumes	9.91	12.36
Raw vegetables	10.36	12.92
Fatty foods	9.46	11.80
Fruits	7.66	9.55
Eggs	1.80	2.25
Bread	4.95	6.18
Alcohol	2.25	2.81
Soft drinks	2.70	3.37

Participants can have more than one diet or alimentary exclusion explaining why the sum of each column of percentages is superior to 100%.

Table 4.

Comparison between the expectations of the 222 participants concerning HCPs and the satisfaction of these expectations after their experience with HCPs

Expectations about HCPs	Patients (%) with this expectation	Patients (%) who met this expectation during previous experiences with HCP
To provide comprehensible / sufficient information on IBS	95.00	16.00
To explain where informations about IBS are available	91.10	
To inform about clinical studies on IBS	94.20	
To answer my questions about IBS	92.10	36.30
To provide careful listening/empathy	97.30	36.30
To provide support	90.00	25.80
To provide hope	84.70	8.90
To improve my health status relative to the current state	94.70	15.30

Table 5.

Comparison between the expectations of the 222 participants about preferred sources of information about IBS and their experiences.

Source of information	Expectations about this source of information	Experiences
Gastroenterologist	91,1 %	47,9 %
General practitioner	90,5 %	31,6 %
Written documents (brochures, books, print press)	90,0 %	62,1 %
Internet	87,4 %	83,7 %
Television, broadcasting	82,6 %	23,2 %

Table 6

Main verbatim about additional expectations when entering the Association of IBS patients.

Verbatim
• To get a recognition of their disability by health and occupational health authorities • To better communicate about the disease with their relatives • To get access to a professionals network for alternative treatments • To get access to "shared experiences" to help them in managing IBS on a daily basis • To find health professionals more aware about IBS and with a better knowledge about the disease. • To get "a kitchen help group" to learn how to better manage daily the diet.