

ORIGINAL PAPERS

## The irritable bowel syndrome care process from the patients' and professionals' views

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### ABSTRACT

**Background and purpose of the study:** This study assessed the experiences of irritable bowel syndrome patients with the healthcare system. Specifically, this study focused on the barriers that patients found.

**Methods:** Three focus groups were conducted with the participation of 19 patients and 10 healthcare professionals. From this information a script of questions was designed and 33 structured interviews were conducted. Finally, a scale for evaluation of the perception of patients was designed for primary care (14 items) and gastroenterology (13 items). Internal consistency and construct validity were calculated.

**Results:** The difficulties of accessibility, to clarify doubts, concerns regarding uncertainty, reduced information about prognosis and its social and labour effects were the most cited by patients. Low adherence and persistence in the treatment plan were the problems cited most often by professionals. The items of the scale for primary care were grouped into 4 factors (explained variance, 73%), while those for gastroenterology were grouped into 3 factors (explained variance, 67%). The internal consistency was 0.84 and 0.82, respectively. A total of 29 (88%) patients were satisfied with the care provided in gastroenterology, while 24 (73%) declared themselves satisfied with the primary care physician (Chi-square 2.4,  $p = 0.21$ ). This study was carried out from November 2013 to July 2014.

**Conclusions:** This study describes the most relevant problems in the assistance received by these patients.

**Key words:** Irritable bowel syndrome. Care quality. Care path. Perception.

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### INTRODUCTION

Irritable bowel syndrome (IBS) is a highly prevalent disorder, affecting 3-10% of the Spanish population. Women are more frequently affected than men (ratio 2-2.5/1) (1), and about 40% of all patients seek medical help at some point during the year (2). It has been estimated that IBS accounts for 2-15% of all consultations in primary care (PC) and up to 30% of all specialized consultations in gastroenterology (digestive diseases). Although a clinical guide on the management of IBS has been published (the AEG guide), the fact is that the diagnostic and therapeutic approaches to the disease vary among both gastroenterologists and PC physicians (3).

Irritable bowel syndrome has a strong impact upon patient quality of life. In effect, patients with IBS suffer disturbances in their social and professional life, and feel ashamed of their symptoms. They often change their eating habits and frequently resort to the healthcare services in a futile search for effective medical care (4,5). These are patients for which no concrete answer is available, and their medical care is conditioned by psychosocial factors, the attitudes of the professionals and patients themselves, the comorbidities and severity of the symptoms, and mistaken concepts about the disease (6-8).

The information received by the patients, the coordination among different healthcare levels, and the diagnostic response capacity are key factors in the care process, since the physicians and patients tend to disagree on their perception of the influence of psychological variables in IBS (9). Patient scepticism characterizes the relationship with the medical professionals. Patients with IBS normally are not satisfied with the treatment they are receiving and actively seek information on other possible alternatives. They perceive no clear benefit from the prescribed therapy and complain about significant shortcomings in the information they receive (10). Previous studies have evaluated patient perception referring to colonoscopy (11),

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and a 38-item questionnaire has been developed to assess patient satisfaction with the care received in the context of the management of IBS (12). In this latter study satisfaction was positively correlated to a quality of life measure (IBS-QOL) (13) and negatively to the level of psychological stress reported by the patient. Some years earlier, this same research group (14) conducted a study on the symptoms most frequently reported by patients with IBS. They found that 47% were dissatisfied with the care provided, though 73% of the patients had a positive opinion about the treatment they were receiving at that time.

Studies have been made of the quality of the patient-physician relationship (15), with the identification of a larger number of negative (n = 106, 54%) than positive comments (n = 22, 11%). The evaluation of patient reported outcome measures (PROMs) and of patient reported experience measures (PREMs) can contribute to introduce changes in patient care, when such data is used by clinicians in their decision making processes (16,17). However, we do not know the perception of patients with IBS regarding the healthcare process applied to them, and there are no Spanish population based studies on the perception of patients with IBS regarding the medical care they receive. The present study evaluates the opinion of patients with IBS regarding their experience with the healthcare system in Spain, and conducts a specific analysis of the difficulties these patients commonly face both in primary care and in specialized gastroenterological consultation.

## METHOD

A phenomenological, observational study based on qualitative investigational techniques (focus group technique and structured interviews) was carried out. The focus group technique (18) was used to analyze patient and professional opinion regarding the way in which the patients experience the medical care they receive for IBS, the main difficulties they find, and their most frequent mistakes in relation to treatment or diet. Structured interviews, with the application of scales specifically designed for this study, were used to gain insight to the aspects of medical care in patients of this kind and which were identified as key elements by the participants in the focus groups.

We established three focus groups with a duration of about two hours each [one with 10 professionals (PC physicians, specialists in gastroenterology, psychiatry, clinical psychology, medical inspection and nursing) and two with 8 and 11 patients, respectively]. This allowed triangulation of the contributions, with identification of the salient common ideas. No personal information or clinical data from any source was collected. Consent was obtained from all the participants, following the indications of the Project Evaluating Body of Universidad Miguel Hernández in Elche (Alicante, Spain) (2014.305E.OEP).

The field work was conducted in Alicante (Hospital General Universitario de Alicante, Spain) and in Madrid (Hospital Clínico San Carlos, Madrid, Spain) between November 2013 and July 2014. In the case of the professionals, we applied the following

inclusion criteria: At least 5 years of experience in the care of patients with IBS, with an even (50%) distribution between males and females. In the case of the patients the inclusion criteria were: Functional disorders with a diagnosis of IBS, a disease duration of at least 5 years, a possible history of psychiatric, mental health or rheumatologic consultations, and a male/female ratio of 2/3. Since age is positively correlated to satisfaction (19), we included patients belonging to different age groups, in order to compensate this possible effect.

The focus groups were conducted by two professionals with experience in the technique (JJM and MG). A list of key questions and cluster questions was developed by consensus among the members of the research team, with the purpose of exploring the following study parameters: Information on IBS (nature, prognosis, treatment and aspects relating to hygiene and diet), information sources, accessibility to diagnostic tests, delays in diagnosis, patient strategies for coping with the symptoms, identification of reference professionals, integral care between healthcare levels, accessibility to clinical information and professionals, healthcare delays, coping with changes in family relations, friends and the occupational setting, and safe use of medicines. The group sessions were ended when information saturation was evidenced by similar or repetitive contributions on the part of the participants. Discourse analysis was made through reorganization of all the ideas of the participants in a script answering each of the key questions of the study, followed by classification of the ideas into mutually excluding categories –extracting examples from the discourse that unequivocally represented the meaning of each of these categories. This triangulation process was carried out by consensus among the authors JJM, MG and EIG. Analysis of the information for highlighting the salient ideas also considered the following: Within-group consistency, between-group consistency and relevance (considering the agreement observed among the participants).

Furthermore, all the participants (patients and professionals) individually scored the importance of a series of barriers against good care in patients with IBS, based on a scale from 0-5. This list of barriers was defined by consensus among the members of the research team. Such assessment on an ordinal scale was used to rank the relative position of the difficulties which in the opinion of the participants affected patients with IBS in key moments of the care process or in moments of transit between different healthcare levels. The coefficient of variation was included as a measure of consensus among the participants.

Based on the above information, we designed a series of questions for conducting structured interviews, and developed a scale for assessing patient opinion about the care received in the PC (14 items) and specialized digestive diseases setting (13 items) (Annex 1). Designing the scale involved the participation of 8 patients who scored comprehension of the questions and evaluated whether the questions explored relevant issues (apparent or face validity). In addition, a convenience sample of 33 patients with a profile similar to that of the patients participating in the focus groups was interviewed on an individual basis, answering the questions on the scales, following the obtaining of consent. The scales were available on the internet using the Survey Monkey application, in order to facilitate response and guarantee confidentiality. Principal components analysis, followed by varimax rotation, was used to determine the validity of the scales construct, with application of the Cronbach's alpha statistic to assess internal consistency.

The results of the interviews and scales included frequency (percentage) data to describe the experience of the patients with IBS. The chi-squared test was used to analyze the relationships between qualitative variables. The IBM SPSS Advanced Statistics 20.0 package was used throughout.

## RESULTS

A total of 60 patients and 10 professionals participated in the study.

### Focus group results

The main difficulties experienced by patients with IBS in their relationship with the healthcare system are (Table I): Accessibility of specialized gastroenterological consultation from the PC setting, with doubts regarding the capacity of the PC physician to identify the disorder, and fear that the disease may be serious (e.g., cancer); limited information on the probable course of the disease and on how it affects social and occupational life; incomprehension often due to insufficient information on the criteria used for referral to mental care; the briefness of visits in PC; and insufficient coordination between healthcare levels, reflected in patient perceived difficulties for receiving integral care.

In turn, the professionals (Table II) emphasize that these patients are difficult to handle, because of low adherence to therapy and poor persistence with the management plan and follow-up. The main “bottlenecks” in the IBS management route for patients (Table III) are a lack of information on the disease—particularly as regards diet recommendations—and incomprehension on the part of the PC physicians, who sometimes take several months in establishing a first diagnosis.

In the opinion of the professionals, the different manifestations of IBS are one of the problems that account for the broad variability in the assessment and referral criteria used in such patients. For the patients, the day to day limitations are the main cause of concern, and in their opinion the existing treatment options are not always effective. The most common patient mistakes are related to continuous changes in eating habits.

### Results of the interviews

Ten males (31%) and 23 females (69%) completed the interviews and care scoring scales. The mean patient age was 43.31 years. Twenty patients (62%) were working, though 17 (52%) had experienced problems at work because of the disease. In turn, 14 patients (44%) described their health as good or very good, while 8 (25%) considered their health to be poor. The most common symptoms

at the time of response were: Lack of energy, tiredness ( $n = 14$ , 44%), fear of going out to have lunch or dinner ( $n = 11$ , 33%), abdominal pain ( $n = 9$ , 27%), diarrhoea ( $n = 9$ , 27%), libido loss ( $n = 9$ , 27%) and irritability ( $n = 7$ , 23%).

The items of the scale for PC focused on four factors (explanation of 73% of variance), while the scale for digestive disease focused on three factors (explanation of 67% of variance). The internal consistency was 0.84 and 0.82 for PC and digestive disease, respectively.

At the time of the interview, 12 patients (36%) regularly visited nursing care in PC, and 6 (18%) were attended in mental health in addition to being seen regularly in PC and digestive disease. Six patients (18%) combined public and private medical care.

The main source of information for knowing about IBS and how to deal with the disease was the gastroenterologist ( $n = 24$ , 73%), the PC physician ( $n = 10$ , 31%) and the internet ( $n = 7$ , 23%).

Twenty-two of the interviewed patients (67%) knew the indication of the prescribed medication and the dosing regimen. Fourteen (42%) claimed to have received instructions on what to do at home or at work to control the symptoms, together with advice on eating, physical exercise and coping with stress. Twenty patients (62%) agreed short- and middle-term treatment objectives with their physician. Thirty (40%) claimed to have received specific counselling from the physician on how to prepare for going out to dinner, and on the required precautions. In turn, 14 patients (42%) reported improvement with the treatment received, while four (12%) claimed to have stopped taking the medication because of tolerance problems or because it was regarded as ineffective.

The gastroenterologist was better rated than the PC physician in relation to the verbal information given on treatment alternatives ( $n = 21$ , 64% versus  $n = 9$ , 27%), accessibility for asking questions and clarifying doubts ( $n = 30$ , 91% versus  $n = 24$ , 73%), and the patient impression of having been listened to ( $n = 30$ , 91% versus  $n = 22$ , 67%). Twenty-nine patients (88%) claimed to be satisfied with the care received by the specialist in digestive diseases, while 24 patients (73%) claimed to be satisfied with the PC physician (chi-squared 2.4,  $p = 0.21$ ).

## DISCUSSION

This study broadly examines the problems which patients with irritable bowel syndrome (IBS) have with the primary care physician and specialist in digestive diseases, from the time of diagnosis and establishment of the treatment strategy, in the context of the Spanish public healthcare system. These are patients who are sceptical about the treatment received, and this scepticism is reinforced by having to undergo tests that yield no significant findings, changes in treatment in search of increased effectiveness, and unsatisfied expectations.

**Table I. Principal difficulties in the care process of patients with IBS in the primary care setting**

<i>Barriers in primary care</i>	
<i>Professionals</i>	<i>Patients</i>
<ul style="list-style-type: none"> <li>– Patients expect to be listened to and want the physician to understand their problem and how they feel</li> <li>– They are afraid that the disease may be cancer</li> <li>– Little time is usually spent on each patient. In such individuals this does not allow a global approach to the problem and produces patient distrust of the PC physician</li> <li>– This lack of time lies at the root of many inappropriate referrals to the gastroenterologist that could be avoided</li> <li>– The patient expectations regarding treatment are not adequately dealt with</li> <li>– A correct explanation is required of what IBS is and how to deal with it. If an antidepressant is prescribed, clear explanations are needed, since patients normally see such prescription as a sign that the physician does not believe their symptoms</li> <li>– Patients clearly feel a lack of information on the disease</li> <li>– The professional must be convinced that treating such patients in PC is not a “waste of time”</li> <li>– The approach used and the healthcare education provided by the nursing professionals are essential for allowing the patient to cope with the disease</li> <li>– Strategies should be developed to allow the patient to accept the diagnosis and trust the PC physician</li> <li>– There is pressure to refer patients to gastroenterology, and for invasive complementary techniques such as colonoscopy</li> <li>– Dietetic recommendations by the nursing professionals are not registered in the electronic case history</li> <li>– No websites where the patients can gain further information are recommended</li> </ul>	<ul style="list-style-type: none"> <li>– Confirming the diagnosis takes too long, with important variability depending on the attending professional. First referral to gastroenterology can even take years</li> <li>– Patients want tests requiring shorter attendance times</li> <li>– There are many suspected diagnoses before the diagnosis of IBS is confirmed. One of the demands of these patients is “<i>I want my doctor to give me a clear diagnosis</i>”</li> <li>– Patients would like more interest on the part of the physician. “<i>I want the family physician to inform be better on the subject and become more involved. I don't want to be told that it's all a matter of nerves, without offering me any solution</i>”. “<i>I feel frustrated and helpless, because the professionals who have seen me offer no solutions. I have had to inform myself in order to have better quality of life</i>”. “<i>There's no medication, no solution</i>”. “<i>Professionals need to be more delicate with the patients</i>”</li> <li>– Needless variability in the patient follow-up regimen</li> <li>– The sensation is that patients only complain, and that their description of the symptoms is not trusted</li> <li>– Primary care physicians are too variable in their diet recommendations. Patients want more information regarding diet recommendations</li> <li>– There are no group consultations, mutual assistance groups, etc. “<i>I would like to have follow-up, with talks among patients</i>”. “<i>It would be a good idea to have an association of patients with problems of this kind, since sharing this type of information can help us</i>”</li> <li>– Patients prefer to be treated by specialists, and trust them more</li> <li>– The physical symptoms condition daily life, are experienced intensely, and require a convincing explanation</li> </ul>
<i>Barriers in specialized care</i>	
<i>Professionals</i>	<i>Patients</i>
<ul style="list-style-type: none"> <li>– Diet specifications every 4 months, and every 6 in case of improvement. There is variability in the discharge criteria</li> <li>– Unrealistic expectations regarding the disease, with doubts as to whether it hides cancer</li> <li>– Many patients do not accept antidepressants or inter-consultation or referral to psychiatry</li> <li>– Little time available per patient, which limits the chances for exploring the case history and for helping the patient to better cope with IBS</li> <li>– Early treatment dropout – an aspect that is not always foreseen in the patient interview. Frequent failure to adhere to therapy in patients with antidepressants (especially if they do not consider themselves to have comorbidities)</li> <li>– No websites where the patients can gain further information are recommended. Self-assistance groups are not encouraged</li> </ul>	<ul style="list-style-type: none"> <li>– In the case of specific consultation in gastroenterology, patient satisfaction changes, the information on the disease is better, and the expectations on how to cope with the disease are modified</li> <li>– Patients do not want a change in doctor, since they feel that professionals who always treat the same patients are much more concerned about them. “<i>I always want to be treated by the same doctor and would like him or her to be more concerned about us</i>”. “<i>I always would like to be seen by the same specialist in digestive diseases</i>”</li> </ul>
<i>Barriers in mental health care</i>	
<i>Professionals</i>	<i>Patients</i>
<ul style="list-style-type: none"> <li>– The patient profile ranges widely from people who want to be seen in mental health to learn how to deal with their emotional problems, depression, etc., to patients who deny the situation and fail to visit once they have been referred</li> <li>– There is a need to understand why antidepressants are prescribed. Treatment in mental health needs to be accepted</li> </ul>	<ul style="list-style-type: none"> <li>– Most patients do not understand why mental health care or antidepressants are needed</li> </ul>

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**Table I (Cont.). Principal difficulties in the care process of patients with IBS in the primary care setting**

<i>Barriers in the home</i>	
<i>Professionals</i>	<i>Patients</i>
<ul style="list-style-type: none"> <li>– Patients expect to be listened to and want the physician to understand their problem and how they feel</li> <li>– They are afraid that the disease may be cancer</li> <li>– Little time is usually spent on each patient. In such individuals this does not allow a global approach to the problem and produces patient distrust of the PC physician</li> <li>– This lack of time lies at the root of many inappropriate referrals to the gastroenterologist that could be avoided</li> <li>– There is distrust of drug treatment, changing the diet without following the instructions of the physician or nurse, and with doubts about the existence of psychiatric problems. Trust in alternative approaches (herbal remedies, homeopathic treatments, advice of neighbours and friends, etc.)</li> <li>– Experimentation with home remedies. Use of strategies such as suppressing dairy products, restrictive diets, oats, etc. They do not go out to dinner or eat out of the home</li> <li>– Inappropriate demands for emergency care. Inappropriate demands for tests</li> <li>– Patients resort to private care which is often combined with public health care. After different tests and visits to private centres it is common practice to return to public care to continue treatment</li> <li>– Patients occasionally report to inspection, requesting attention, with disorientation as to what is actually happening, and demanding a firm diagnosis. Of greater concern are the problems associated with working absenteeism caused by IBS</li> <li>– A small percentage of patients ask for a change in specialist</li> <li>– Frequent non-compliance and scant adhesion to the visiting protocol, depending on the evolution and severity of the symptoms</li> </ul>	<ul style="list-style-type: none"> <li>– Confirming the diagnosis takes too long, with important variability depending on the attending professional. First referral to gastroenterology can even take years</li> <li>– Patients want tests requiring shorter attendance times</li> <li>– There are many suspected diagnoses before the diagnosis of IBS is confirmed. One of the demands of patients is “I want the doctor to give me”: Faster intolerance testing, faster testing of all kinds to detect intolerances, information on what I can and cannot eat, and more information</li> <li>– Patients are of the opinion that the care provided in the emergency service is quite deficient in their concrete case (“They pay no attention in the emergency service”)</li> <li>– Innumerable occupational problems requiring changes in jobs</li> </ul>

During the focus group sessions, and in line with the findings of other studies (20), the patients described the following principal problems related to the care process: Incomprehension and unresolved doubts on how to cope with the disease on a day to day basis. Specifically, the patients complained of delays in confirming the diagnosis (a problem that was found to decrease among patients under 35 years of age compared with earlier years, thanks to improved resolution capacity among PC physicians), unnecessary changes in the follow-up protocols once the diagnosis was established, and the quality of the relationship with the PC physician. In this regard, two groups were identified: Those patients who claimed to be trustful and considered that the PC physician understood their problems, and a second group expressing distrust of the capacity of the PC physician. The most demanded information was regarding the prognosis of the disease and the clarification of doubts referring to the diet and kinds of food that could be consumed. The patient findings were consistent with those of other studies in that more information was

called for in order to overcome difficulties in the workplace, program leisure activities (21) and evaluate alternative medicine options (22). In the case of our healthcare system, such difficulties related to the patient-physician relationship were accompanied by delays in diagnostic tests as a further barrier facing patients in the care process associated to IBS. In contrast to other studies, our patients were reluctant to be referred to mental health units, complained of incomprehension if they reported to the emergency service, and expressed their preference for having a specialist in digestive diseases as reference physician. This study also considered the opinion of the professionals. A lack of adherence to therapy and persistence in the established follow-up protocol, along with constant changes and mistakes regarding eating habits on the part of the patients, were the factors that worried the professionals most.

In this regard, the interviews confirmed the data obtained in the first phase of the study, with 7 out of 10 patients having received enough information about their disease. These findings are very similar to those published by Ring-

**Table II. Professional opinion regarding the main "bottlenecks" facing patients in the care process in IBS**

<i>Criterion</i>	<i>Mean</i>	<i>Variance</i>	<i>CV</i>
	CV	0,2	0,1
Treatment non-compliance	4.7	0.2	0.1
Diet errors	4.3	1.6	0.3
Patients with very different manifestations	4.2	1.1	0.2
Poor adherence (follow-up)	4.0	0.9	0.2
"Rotating door" patients	3.8	1.1	0.3
Excessive variability in clinical practice	3.5	1.6	0.4
Passive role of the patient	3.5	1.2	0.3
Difficult patient-physician relationship	3.5	0.3	0.2
Unrealistic treatment expectations	3.5	1.4	0.3
Patient information on the disease	3.4	1.8	0.4
Scant effectiveness of the treatment alternatives	3.4	0.5	0.2
Care of psychiatric comorbidity	3.3	2.2	0.5
Criteria for identification and referral to PC	3.1	1.2	0.4
Delays in diagnostic tests	2.7	2.2	0.6
Scant coordination between healthcare levels (PC and specialized care)	2.6	1.4	0.5
Inadequate use of practice guides	2.2	0.8	0.4
Access to drug treatment	1.8	0.4	0.4

ström (23) in Sweden. However, the patients expressed a wish for more information regarding the diet and how it affects them, together with recommendations on how to cope with the symptoms in daily life (particularly at work), information related to the prognosis of the disease, and greater empathy and understanding on the part of the professionals. This data corroborates the findings of a study carried out in the United Kingdom (20) and in Boston in the United States (24), involving similar methodology. Self-care in IBS contributes to improve patient quality of life (25). This data is relevant, since it underscores the information shortcomings that make it difficult to implicate patients in their own care.

Patients do not want their symptoms to be trivialized, and call for greater treatment resolution in PC. This situation is similar to that found in other healthcare systems with organizational models similar to our own (19). According to the literature, one of the main problems is failure to adequately appreciate the patient discomfort, and this has a negative impact upon the patient-physician relationship, thereby complicating correct diagnosis and treatment (26,27).

The percentage of patients in this study who claimed to be satisfied with the care received was greater than the 13% satisfaction rate reported by Olafsdottir et al. (21). In this regard, the percentage of patients who claimed to be satisfied with the care received was more similar to that published by Drossman et al. (14). The data trend suggested slightly greater satisfaction with the gastroenterologist, though statistical significance was not reached. In this case the scale used was briefer and therefore easier to apply in the clinical context than the 38-item IBS-SAT (12), and the validity and consistency data were adequate in this respect.

The symptoms of the patients in our study were similar to those described in other publications (28). Nevertheless, the present study has some limitations. Although we attempted to ensure representation of the different patient profiles, the number of subjects was limited, in the same way as in most studies on IBS patient perception published to date. We did not codify age, gender or educational level for ensuring anonymity of the participants. Likewise, we did not contemplate access to the patient case histories. As a result, we did not have information on comorbidities, diagnostic tests or treatment. Since the patients had been attended in the PC setting at least 5 years ago, their assessments do not reflect the current state of primary care practice.

Patients with IBS question the resolution capacity of PC physicians and wish to receive more information on eating habits and on how to deal with the symptoms of their disease in the workplace. Future studies could determine whether the activation of these patients can contribute to reduce the characteristic symptoms of IBS.

In conclusion, our study summarizes the care problems found in IBS from the patient perspective. The incorporation of these data to the management of patients with IBS must be considered from both the individual clinical perspective (patient-physician relationship) and the organizational point of view.

**Table III. Patient opinion regarding the main "bottlenecks" they face in the care process in IBS**

<i>Criterion</i>	<i>Mean</i>	<i>Variance</i>	<i>CV</i>
Information on the disease supplied to patients in PC	4.1	0.9	0.2
Daily life limitations (personal and professional) because of IBS	4.1	1.0	0.2
Insufficient information on proper diet	3.9	1.4	0.3
Criteria used in PC for IBS identification and referral to specialized care	3.8	1.8	0.5
Delays in diagnostic tests from PC	3,8	2,4	0,6
Delays in specialized consultation	3.6	2.0	0.6
Incomprehension of the problem on the part of the PC physician	3,5	1,7	0,5
Scant effectiveness of the treatment alternatives	3.5	1.7	0.5
Visits spaced too far apart in time (digestive diseases or mental health)	3.4	2.1	0.6
Scant coordination between healthcare levels (PC and specialized care)	3,0	1,7	0,6
Delays in diagnostic tests from specialized care	3.1	2.9	0.9
Difficult patient-physician relationship (PC, digestive diseases, mental health)	3.0	1.7	0.6
Excessive variability between PC and specialized care in the information supplied to the patient	3.0	2.4	0.8
Information supplied to the patient from specialized care	2.9	1.8	0.6
Unclear criteria for referral to mental health	2.8	5.4	1.9
Time spent on the patient by the PC professionals (physician or nurse)	2.8	2.8	1.0
Excessive variability between PC and specialized care in the way of treating patients with IBS	2.7	2.8	1.0
Time spent on the patient by the gastroenterologist	1,9	5,5	2,8
Fear of serious illness (e.g., colon cancer)	2.8	2.8	1.1
Difficulties in following treatment on a continuous basis (forgetfulness)	1.9	2.8	1.4
Care received in mental health (information, alternatives, visiting regimen)	1.9	5.5	2.8
Insufficient information as to why the patient is referred to mental health or is treated with antidepressants	1.4	4.1	3.0

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### Annex 1.

#### QUESTIONNAIRE FOR THE EVALUATION OF PATIENTS WITH IBS (PC)

1. Can you ask your general practitioner and clarify all your doubts about your illness and its treatment?:  
 Yes       No
2. Are you regularly asked in the primary care clinic about how the illness affects your daily life, with the aim of helping you to find alternatives that make you feel better (foods you can eat, exercise, work conditions, etc.)?:  
 Yes       No
3. Do you have the impression that your general practitioner listens to you and takes what you say into account?:  
 Yes       No
4. The level of coordination between primary care and digestive diseases care (degree of agreement regarding indications, requests for tests, knowledge of what is happening) in your case is:  
 Very good     Good       Fair       Poor       Very poor
5. How would you rate the explanation given in any of the public primary care centres you visit regarding which medicines, foods, etc. you must take and what you must not do or must avoid?:  
 Very good     Good       Fair       No explanation
6. How would you rate the explanation given in any of the public primary care centres you visit regarding what to do at home or at work in order to control the symptoms (advice on food, physical exercise, coping with stress)?:  
 Very good     Good       Fair       No explanation
7. Have you been given written information referring for example to your diet or other indications designed to help you feel better and correctly follow the treatment?:  
 Yes       No
8. How would you rate the explanation given in any of the public primary care centres you visit regarding the nature of your illness, how to treat it and what to expect from the treatment?:  
 Very good     Good       Fair       No explanation
9. Is your treatment effective in reducing the gastrointestinal symptoms?:  
 Very effective       Quite effective       Somewhat effective       Not effective
10. How would you rate your current knowledge of your illness?:  
 Very good     Good       Fair       Poor
11. Has your regular general practitioner explained what the concrete aims of treatment are?:  
 Yes       No



12. Have you received an explanation of the treatment alternatives?:  
 Yes       No
13. Have you been asked about your health and lifestyle habits?:  
 Yes       No
14. Have you been given the chance to participate in deciding which treatment to use? Has your family doctor listened to your opinion and preferences regarding treatment?:  
 Yes       No

### QUESTIONNAIRE FOR THE EVALUATION OF PATIENTS WITH IBS (GASTROENTEROLOGIST)

1. Has your gastroenterologist given you written information referring for example to your diet or other indications designed to help you feel better and correctly follow the treatment?:  
 Yes       No
2. Has your doctor explained the possible treatment alternatives and allowed you to give an opinion?:  
 Yes       No
3. How would you rate the explanation given in any of the public digestive diseases clinics you visit regarding the nature of your illness, how to treat it and what to expect from the treatment?:  
 Very good     Good       Fair       No explanation
4. Have you received an explanation of the treatment alternatives?:  
 Yes       No
5. Are you regularly asked in the digestive diseases clinic about how the illness affects your daily life, with the aim of helping you to find alternatives that make you feel better (foods you can eat, exercise, work conditions, etc.)?:  
 Yes       No
6. The level of coordination between primary care and digestive diseases care (degree of agreement regarding indications, requests for tests, knowledge of what is happening) in your case is:  
 Very good     Good       Fair       Poor       Very poor
7. How would you rate the explanation given in any of the public digestive diseases clinics you visit regarding what to do at home or at work in order to control the symptoms (advice on food, physical exercise, coping with stress)?:  
 Very good     Good       Fair       No explanation
8. How would you rate the explanation given in any of the public digestive diseases clinics you visit regarding which medicines, foods, etc. you must take and what you must not do or must avoid?:  
 Very good     Good       Fair       No explanation
9. Does your doctor ask you about your diet and comment on whether it is correct or needs to be modified?:  
 Yes       No
10. Has your doctor given you advice to allow you to go out for lunch or dinner?:  
 Yes       No
11. Is your treatment effective in reducing the gastrointestinal symptoms?:  
 Very effective     Quite effective     Somewhat effective     Not effective