


# Do Patients' and Physicians' Perspectives Differ on Preferences for Irritable Bowel Syndrome Treatment?

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## Abstract

Irritable bowel syndrome (IBS) is a highly prevalent disorder of gut–brain interaction and poses a significant burden to patients. Pharmacotherapy, diet, and psychotherapy all have largely comparable clinical efficacy. Therefore, factors outside efficacy can have an important impact in determining preferences for a specific therapeutic entity. The aim of this study was to compare the patient and physician perspectives and identify important treatment characteristics regarding the management of IBS. Semistructured interviews were performed among IBS patients ( $n = 8$ ), fulfilling the Rome IV criteria, and surveys were sent to physicians involved in IBS care ( $n = 15$ ). Nine important treatment characteristics were revealed: effectiveness, time until response, cessation of response, side effects, location, waiting period, treatment burden, frequency of healthcare appointments, and willingness to pay. Time to response, location, and waiting time were less important for patients compared to physicians. This study assessed important IBS treatment characteristics and provided context to preferences from a patient and physician perspective. These data could be relevant during shared decision-making in clinical practice.

## Keywords

irritable bowel syndrome, qualitative research, semistructured interviews, treatment preferences, patients' perspective

## Introduction

Irritable bowel syndrome (IBS) is a highly prevalent disorder of gut–brain interaction. It is characterized by recurrent abdominal pain and altered bowel habits and is diagnosed according to the Rome IV criteria (1,2). Prevalence ranges from 4% to 14% worldwide. IBS bears a negative impact on quality of life of patients and imposes a significant burden on the health care system (3). It is, therefore, imperative to employ effective management strategies that not only reduce symptom burden but also increase quality of life (4). All therapies, diets, psychologic therapy, and pharmacotherapy have comparable efficacy with a number needed to treat from 4 to 5 (5–7).

However, IBS patients constitute a clinical heterogeneous population and no single treatment will suit all patients. Therefore, apart from the efficacy, other treatment characteristics such as risk of side effects, length of therapy, or method of administration are important when recommending a specific therapy. Previous studies showed that patients were willing to accept higher risks of serious adverse effects of

the therapy, if their symptoms improved (8,9). Besides, they were willing to pay significant monthly costs (10).

Thus far, the treatment preferences and their specific characteristics in IBS have not been addressed, neither from patients' nor from physicians' perspective. In this study, we examine from both patient and professional perspective which treatment characteristics of IBS are considered important.

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## Method

### Study Population

Patients diagnosed with IBS, fulfilling the Rome IV criteria, were recruited from the outpatient clinic of the Gastroenterology and Hepatology division of Maastricht University Medical Center+ (MUMC+). Written informed consent (for audio recording as well) was obtained from all patients prior to being included in the study. The recruited experts were registered gastroenterologists all over the Netherlands, both from Dutch academic and nonacademic teaching hospitals, specialized in the field of neurogastroenterology, and were all members of the Neurogastroenterology Committee of the Dutch Association for Gastroenterologists (n = 16). Also, general practitioners (GPs) from South-Limburg participated in this research based on the network of the investigators (n = 3).

### Methodology

First, a screening of the literature was performed to select possible treatment characteristics and levels. The result from this screening was used to develop the patient and physician (interview) topic guide, to provide consistency between interviews. Before the semistructured interviews, the irritable bowel syndrome symptom severity scale (IBS-SSS) questionnaire, Rome IV criteria, and the IBS subtype were assessed by the participants (2,11,12). In the first part of the interviews, the participants answered open questions about their (treatment) experience and wishes. In the second part, participants were asked to rank aspects of treatment on level of importance (Likert scale 1-5), using the topic guide and treatment aspects suggested by the participants during the interview (13). The overall sample size of the interviews was determined by saturation point, as per guideline recommendations (14).

To investigate the important characteristics of physicians in advising therapy for IBS patients, a survey was sent by email. This survey consisted of open questions about the work experience of the clinical expert, their perspective on different characteristics of therapy, and a ranking exercise for the level of importance of the same treatment characteristics as used in the patient interviews.

### Data Analysis

Interviews were audio-recorded and transcribed. Qualitative analyses of the interview data were performed by using a software tool, NVivo Release 1.2 QSR International. These data were coded, as themes and subthemes, to reflect the interviews in an iterative process.

Descriptive statistics in software program IBM SPSS Statistics version 27.0 for Macintosh (SPSS Inc) was used to analyze background characteristics. The median was used to calculate central tendency for the Likert scale data,

because of the categorical data and the non-normal distribution (15).

Details regarding the patient selection, literature screening, the topic guide, and the coding process of the interviews are available in the supplementary files online (Appendix 1-4).

## Results

In total, 8 patients were included between August and September 2020. The mean age was 44.0 years (SD 18.18) and 6 out of 8 were female. All patients met the Rome IV criteria for IBS. The mean length of IBS diagnosis was 9.56 years (SD 6.73). The mean IBS-SS score was 256.25 (SD 69.68), indicating a moderate severity of IBS.

Saturation was reached after 6 interviews, after which 2 more interviews were conducted for confirmation. No new relevant treatment aspects were reported. All patient characteristics and discussed IBS (sub)themes and sample patient quotations are shown in Online Appendices 5 to 6.

Most of the patients had received multiple IBS therapies. The mean amount was 3.63 (SD 1.51) therapies per patient (see for details Appendix 5). All patients would like to have an effective therapy. Four patients mentioned the therapy should possess none/few minor side effects. One mentioned additionally a preference toward low costs. One patient said that the ideal therapy should be easy to complete with minimal effort in time. Two patients reported the need for guidance and sufficient number of healthcare appointments. One patient wished for therapy with a quick response. One patient would like to have a combined therapy of diet intervention and psychotherapy.

Moreover, patients preferred a professional who pays enough attention and listens carefully. Patients would like to gather enough information about the different available therapies from professional. A few patients mentioned “trust” to be an important feature in the professional-patient relationship. Also, one patient preferred the same doctor during the whole treatment, not several doctors.

### Results Survey Physicians

Nineteen experts were contacted to take part. The response rate was 78.9% (n = 15). Twelve gastroenterologists and 3 GPs completed the survey. The mean practice time treating IBS patients was 20.4 years (SD 8.95). The number of prescribed therapies is summarized in Appendix 7 online. Ineffectiveness, adverse effects, too much time for a response to occur, high costs, high treatment burden, and distant location of therapy, were all reported as reasons to discontinue therapy for patients, according to the perception of physicians. The professional preferences for therapy depended on treatment characteristics, IBS subtype, the opinion of the patients about the treatments, experience with previous treatment, and additional psychological complaints.

## Ranking of Treatment Characteristics by Patients and Physicians

The results of the predefined therapy characteristics, on level of importance, are shown in Figure 1. According to patients, effectiveness, duration of response, side effects, and treatment burden were considered important to very important. Waiting period and location of therapy were classified as “not important” to patients. No differences in results were seen between male or female and the level of education of the patients. Table 1 presents patient quotes about the different treatment characteristics. According to physicians, important characteristics of treatment were effectiveness, duration of response, side effects, treatment burden, and willingness to pay.

## Discussion

Results of our study show that the effectiveness of treatment appears to be the most important factor with regard to treatment preference, as described by both patients and physicians. Duration of response, side effects, and treatment burden were scored by patients and physicians as important, too. Time to response, location, and waiting time for an appointment were not important for patients (scored as not important) compared to physicians (scored as neutral). Patients reported these aspects to be minor details during the interviews because they were suffering from these symptoms for many years and were, therefore, willing to wait for treatment to start and response to occur. Physicians believed

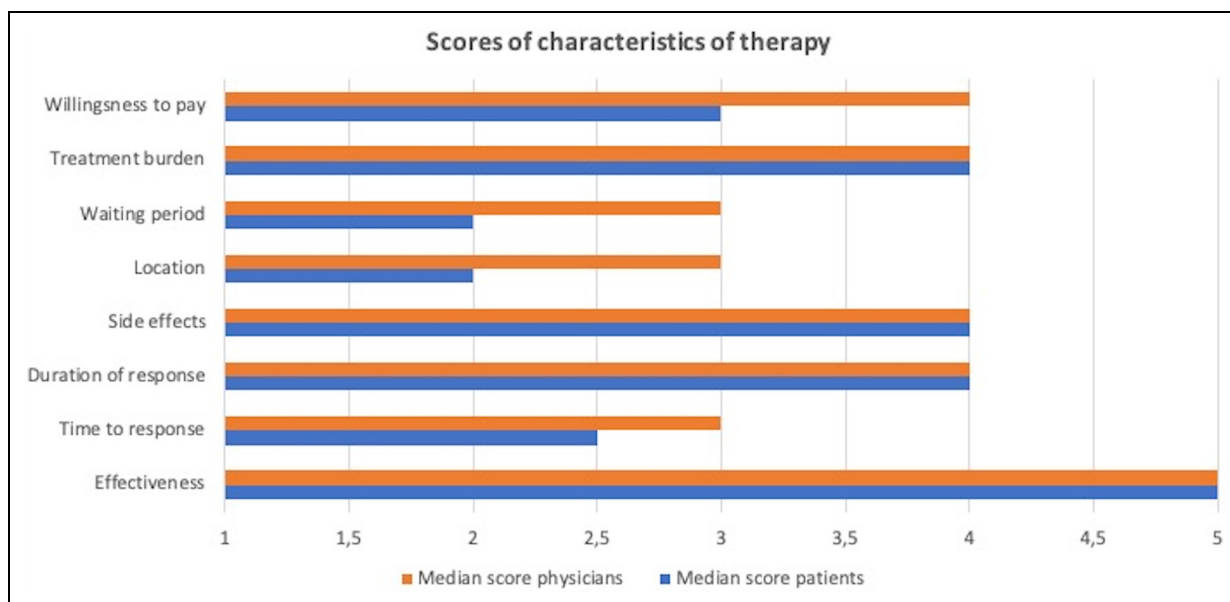
that the willingness to pay or costs of treatment is an important characteristic of patients. However, patients valued this as less important (scored as neutral). These findings provide insight into the difference in treatment perspective between patients and physicians and can be used during shared clinical decision-making.

The ideal therapy, according to IBS patients in our study, would consist of a therapy that is effective, contains no or few side effects, and includes frequent health care appointments for guidance. By involving patients’ needs and preferences, treatment adherence and management success could be improved (16,17).

## Limitations

Patients were recruited from outpatient clinics in an academic hospital which has a combined secondary and tertiary care function. No patients from primary care or patients from other hospitals were included. This could have resulted in a selection bias because patients from the (academic) hospital do not necessarily represent the whole IBS population. Due to schedule difficulties and time investment of health care professionals, the form of a survey was chosen. In-depth interviews with physicians may have provided us with more detailed information but were not considered feasible.

Although the number of patients included ( $n = 8$ ) may appear limited, the sample size in qualitative research is determined by the saturation point. Saturation in our study was reached after 6 interviews which mean that no new



**Figure 1.** Scores of characteristics of therapy. The bars represent the median scores of level of importance\* of the treatment aspects, among physicians and patients. \*The Likert scale is a 5-point scale (1-5) to rank the level of importance, where 1 displays very unimportant, 2 not important, 3 neutral, 4 important, and 5 very important.

**Table 1.** Sample Patient Quotations About the Different Treatment Characteristics.

Characteristics	Sample quotations
Effectiveness	<p>“Effectiveness is the most important to me. That’s the first thing I inspect when choosing a therapy.” (Male, 64 years old)</p> <p>“If the therapy will provide 50% symptom reduction, then I already think it is worth to try. The therapy must ensure a significant difference in symptom reduction.” (Female, 63 years old)</p>
Time until response	<p>“I have been dealing with bowel problems for years, so it doesn’t matter if the treatment takes months to work”. (Female, 28 years old)</p> <p>“I would invest up to a year in the therapy, if the treatment is effective” (Female, 26 years old)</p>
Cessation of response	<p>“This aspect is very important to me. Because I have been dealing with the complaints for several years, it is important to me that the effects are long-term. This period should be at least two months.” (Female, 26 years old)</p>
Side effects	<p>“It is very important to choose a treatment with few side effects.” (Female, 28 years old)</p> <p>“Side effects are more important than the effectiveness when choosing a therapy. Imagine having a constant headache as a side effect, I wouldn’t choose that therapy. It’s the balance between these two aspects, that is important” (Female, 63 years old)</p> <p>“Minor side effects are no issue at all.” (Male, 64 years old)</p> <p>“There may be side effects, but they should not cause any harm. They must be reversible.” (Male, 54 years old)</p>
Treatment burden	<p>“Maximum time I would like to spend on a therapy would be one or two hours per week. This time would be more if my complaints were worse.” (Female, 22 years old)</p> <p>“One hour per day would be acceptable for me.” (Female, 63 years old)</p> <p>“Eight hours or one day a week would be okay for me to spend on therapy sessions, including homework.” (Male, 54 years old)</p>
Waiting period	<p>“I don’t mind waiting a few months, because I know that these symptoms are long term that will continue my whole life.” (Female, 22 years old)</p>
Location of therapy	<p>“The maximum distance I would like to travel to therapy depends on the frequency of the therapy session. If the therapy is weekly, then 40 km is the maximum distance I would like to travel. If the therapy is once in six weeks, then 200km is acceptable.” (Female, 26 years old)</p> <p>“The location of therapy is not important to me. It doesn’t matter to me if I have to travel 30km to the location every two weeks during six months. If the therapy is effective, then it’s worth the effort.” (Male, 54 years old)</p>
Willingness to pay	<p>“I earlier paid €3 000 per month, that was okay for me. Because I am a student, I am not able to pay more for a treatment.” (Female, 22 years old)</p> <p>“If the therapy is effective for my bowel pain, then I am willing to pay € 200–400 euros per month for a therapy.” (Female, 63 years old)</p>
Frequency of healthcare appointments	<p>“I would like to have more doctor visits during therapy for guidance. Once in six weeks would be optimal.” (Female, 26 years old)</p> <p>“Regular telephone contacts with the doctor of therapist would be important to me. Five or ten minutes will be enough.” (Female, 34 years old)</p>

information was discovered. However, 2 more interviews were conducted to assure no additional content was missed.

## Conclusion

Our results provide context as to why patients consider some aspects such as waiting time or location of therapy less important. This information might facilitate shared decision-making and personalized treatment in clinical practice.

## Authors’ Note

All procedures that followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1964, as revised in 2013. The study was reviewed and approved by the ethics committee at the Maastricht University Medical Center (2020-2212). Written informed consent (for audio recording

as well) was obtained from all patients prior to being included in the study.

## Declaration of Conflicting Interests

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## Supplemental Material

Supplemental material for this article is available online.

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