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RESEARCH ARTICLE

# How individuals with the irritable bowel syndrome describe their own symptoms before formal diagnosis

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**ABSTRACT**

*Aim*. To investigate how individuals fulfilling the Rome II criteria for irritable bowel syndrome (IBS) spontaneously described their symptoms. *Method*. From a general population, 1,244 randomly sampled adults were asked to describe their gastrointestinal symptoms (if any) verbally, in their own words, at a semi-structured interview. Their own descriptions were sorted into five symptom clusters. The participants independently completed a written questionnaire (the Rome II Modular Questionnaire (RMIIMQ)). *Results*. A total of 601 participants reported at least one gastrointestinal symptom, and 128 had IBS according to the RMIIMQ. After exclusion of organic causes, previously diagnosed IBS, or additional gastrointestinal diagnosis, 81 participants with IBS according to RMIIMQ remained. Five participants (6%) described symptoms included in the full definition of IBS, but none fulfilled the Rome II criteria completely. Abdominal pain or other IBS-related symptoms were reported by 64 (79%), and 12 (15%) did not report any IBS-like symptom. *Conclusion*. Previously undiagnosed individuals, who fulfil criteria for Rome II-IBS, often express their complaints in words that do not fit into the current diagnostic criteria.

**KEY WORDS**
Diagnosis, digestive symptoms, irritable bowel syndrome (IBS), layman's wording, medical history--taking, questionnaires

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## Introduction

The irritable bowel syndrome (IBS) is a functional chronic disorder characterized by abdominal pain and/or discomfort in combination with bowel disturbances, but in the absence of organic abnormalities (1). IBS is thus a clinical diagnosis based on symptom criteria.

IBS criteria were originally suggested by Manning et al. in the 1970s (2) but were revised to the Rome I criteria in the early 1990s (3) and then further developed through the years to Rome II (4) and Rome III (1). However, an 'intuitive diagnosis' based on the medical history is often used in general practice, while specialists tend to rely more on the exact Rome criteria (5–8). Consequently, a diagnosis of IBS in primary care is often less exclusive than that according to the Rome criteria (9,10).

Only a fraction of sufferers with functional gastrointestinal disorders seek care annually, and many never consult (11). Concerns and fears about serious causes of the symptoms drives consulting (12), which may bias the spontaneous reporting of 'most prominent' or most bothersome symptoms.

The Rome classification system is based on the premise that for each disorder there are clusters of symptoms that have been reported both in the general population (according to surveys) but also by patients (4). Very little is known about how a person with IBS, as defined by the Rome criteria, spontaneously describes his or her symptoms.

We hypothesized that individuals from the general population who fulfil the Rome II criteria for IBS might complain about symptoms not captured by the Rome II criteria according to the Rome II Modular Questionnaire (RMIIMQ) (4). We thus performed a study where such individuals were asked to describe their symptoms in their own words during an open interview.

## Methods

In this previously reported population-based Swedish epidemiological study on gastrointestinal symptoms (13), 2,293 participants (mean age 46.8, 45.2% men) were randomly sampled from the general population. Of these, 1,244 (55%, mean age 48.7, 42.7% men) accepted an invitation to a research centre (Ersta Hospital, Stockholm) for clinical evaluation by a gastroenterologist.

The gastroenterologists performed a semi-structured interview, asking the participants to describe their gastrointestinal complaints (if any) in their own words. All gastrointestinal symptoms described were documented with the key words as

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expressed by the participants and in the same order if more than one symptom was mentioned. No follow-up questions were asked in order not to bias subject responses, and thus we did not ask if any symptom was predominant. The symptom descriptions were independently separated into logical medical clusters and translated into English by a Swedish-speaking assistant whose native language was English.

The participants independently completed the RMIIDQ (4) after the interview, and those who fulfilled criteria for IBS were included in the study. For an IBS diagnosis according to the questionnaire, the participants had to have the key symptom of abdominal pain or discomfort 'often' during at least 3 weeks (at least one day per week) over the last 3 months.

The study was approved by the local Committee of Research Ethics. All participants gave written informed consent.

## Results

Of the 1,244 participants visiting the research centre, 601 (49.2%, of whom 64.1% women) reported at least one gastrointestinal symptom in the interview. Of those, 128 (mean age 55.9, 63.3% women) fulfilled criteria for IBS by the Rome II questionnaire. Forty-seven (36.4%) were excluded: nine reported that they had IBS already diagnosed and were thus possibly biased by prior information, 13 had evidence of organic gastrointestinal disease in a follow-up part of the study, and 25 were given an additional diagnosis by the questionnaire, namely gastroesophageal reflux ($n = 18$) and functional dyspepsia ($n = 7$). Thus, 81 participants fulfilled Rome II diagnostic criteria for IBS but had no further functional or organic gastrointestinal disorder. By definition, all 81 participants reported at least one gastrointestinal symptom, 29 of them (36%) reported two symptoms, and eight (10%) reported three symptoms. According to the anticipated reason/background for their complaints, the symptom descriptions all fitted into one of five contextual medical clusters:

(1) Gastroesophageal reflux disease (GERD)-like symptoms: 'heartburn' and 'reflux'.
(2) Dyspepsia-related symptoms: 'nausea', 'gastritis', 'dyspepsia', 'disturbed/upset stomach', 'bad stomach'.
(3) IBS-defining symptoms: pain and concomitant constipation or diarrhoea (bowel habit disturbances (BHD)).
(4) IBS-related symptoms (symptoms given alone, and when considered individually did not fulfil the Rome II definition of IBS, are listed as 'supporting symptoms' according to Rome II (4)): 'urgency', 'swollen', 'bloating/flatus', 'upset', 'constipation', 'diarrhoea', 'loose stool', 'constipation and diarrhoea', 'hard stomach', 'irregular or frequent movements/stool', 'sensitive stomach', 'sensitive bowel', 'troubled stomach', 'distressed stomach', 'stress-related stomach', 'pain/discomfort', 'distressed bowel'.
(5) Abdominal pain without BHD.

The second or third symptom (if more than one was mentioned) fitted into more than one of the symptom cluster in four cases. The distribution over the five symptom clusters therefore resulted in a total of 85 symptom constellations (Table I).

Table I. The number of participants reporting symptoms per symptom cluster. As four cases reported symptoms that fitted into more than one cluster, 85 participant cluster constellations are recorded for the 81 participants.

| Symptom cluster | Participants/ cluster (*n*) |
|---|---|
| GERD-related symptoms | 7 |
| Dyspepsia-related symptoms | 9 |
| IBS-defining symptoms | 5 |
| IBS-supporting symptoms | 60 |
| Abdominal pain without BHD | 4 |

Thus, only five subjects (6%) stated symptoms according to the definition of IBS (cluster 3). They reported pain or discomfort together with constipation ($n = 2$), loose stool ($n = 2$), or diarrhoea ($n = 1$). No one spontaneously reported onset or pain relief in combination in any way with BHD. Thus, no one reported symptoms fulfilling the *complete* Rome II IBS definition, which includes two out of three of 1) pain relieved by defecation, onset of pain associated with 2) changes in stool frequency or 3) changes in stool form.

The most common individual symptom reported was BHD, expressed as constipation or diarrhoea ($n = 32$), followed by sensitive stomach or bowel ($n = 19$).

Among the four cases reporting symptoms within more than one symptom cluster (all in clusters 1 and 2) one participant with IBS also complained of acid stomach (dyspepsia-related), one participant reporting GERD-related symptoms also reported loose stool and diarrhoea (BHD), one participant reporting GERD-related symptoms also reported abdominal pain, and one with suggested dyspepsia also reported diarrhoea. Thus, altogether 12 individuals (15%) did not spontaneously report any symptoms that adhere to IBS.

## Discussion

In the present study we analysed how individuals from the general population who fulfilled the Rome II criteria for IBS described their primary gastrointestinal complaints in an open interview. The participants were confirmed to be free from organic gastrointestinal disease, and they did not have any additional functional gastrointestinal disorder. Judging only by their own description of symptoms, without directing follow-up questions, none of the 81 participants would be diagnosed with IBS by the commonly accepted criteria. Being conscious of the Rome criteria, a doctor might ask leading questions, but the interview in our study was not conducted in that way. We report, to our knowledge for the first time, how subjects (non-patients) with IBS by Rome criteria spontaneously describe their disorder.

One strength of this study is that the participants were asked to describe their symptoms (if any) in their own words. We interpret this to mean they most likely mentioned the 'worst' or most bothersome symptom first, if they had more than one. A weakness of the methodology applied is that any fluctuations of symptoms over time would not be revealed. Notably, none of the participants described meal-related symptoms, and yet dietary advice is common in modern IBS therapy (14).

Pain or discomfort is one of the key symptoms in IBS. However, discomfort in Swedish is understood as a more embracing expression. Thus, the symptom wordings used by some of the participants do not necessarily fit into the IBS 'pain and discomfort' expression. This raises the issue of whether discomfort should be retained as an IBS criterion when the Rome criteria are next revised.

The literature about patients' own descriptions of their symptoms is sparse. A prior Swedish thesis has shown that laymen seldom use medical terminology to describe their complaints. The symptoms that impact on daily habits and quality of life are more often given prominence (15).

Lacy and co-workers investigated 261 IBS patients, defined according to the Rome II criteria, who completed a questionnaire to evaluate their knowledge, attitudes, and fears regarding IBS (16). Most patients believed that anxiety, dietary factors, and depression caused IBS, and few (28.7%) recognized that abdominal pain is the main criterion for the diagnosis. This patient-centred study is in line with the study by Lydeard and Jones (12) who compared consulters and non-consulters with dyspepsia. The consulters did not differ from the non-consulters in terms of severity or frequency of symptoms, but in their fear for a serious disorder as a cause, and, importantly here, in the possible seriousness of their symptoms. Moreover, DiMatteo has shown that despite the importance of taking a complete medical history by listening to the patient very little time is spent listening to the patients' transmittal of information (17), and the ability to focus on an holistic communication seems to decline over time in a doctor's career (18). We suggest this may be caused by 'more experienced' clinicians tending to adhere to more preconceived diagnostic symptom clusters and becoming less open-minded in an attempt to be more evidence-based. As the most experienced doctors and researchers construct the diagnostic tools, the patients' and above all the non-patients' view of the wording and weight of their symptoms may not be considered. A meta-analysis of studies concerning the interaction between IBS-diagnosed patients and their physicians (19) showed that many patients experienced dissatisfaction and negative attitudes to their doctors. One reason for this might be lack of agreement on priority in the description of their symptoms. The importance of a more patient-orientated approach in further versions of the Rome criteria for IBS has recently been pointed out by the Rome Foundation (20). These findings may be a part of the explanation of the discrepancy between the outcome of the Rome II questionnaire, based mostly on assumptions from patients, and the subject's primary description in this study. This interpretation is supported by validation studies of the Rome criteria for IBS, which has shown suboptimal accuracy, with sensitivity between 47% and 73% and a specificity of 66%–73% for Rome II (21). Introduction of the Rome III criteria does not seem to have improved the validity (22,23).

It should be noted that the IBS definition from Rome II used here also fits closely into the Rome III criteria, both by the combination of the key symptoms and the three-month timeframe asked for in the RMIIMQ (4) and in the Rome III questionnaire (1), and thus our results most probably are valid also for Rome III. Moreover, it was recently shown in primary care patients with IBS that the diagnostic agreement according to their general practitioner between the Rome II and Rome III criteria is 86% (24), and it seems reasonable that the same is valid in a general population sample. Thus interpretations made here likely also apply to the current Rome III definition of IBS.

## Conclusion

For a symptom-based diagnosis of IBS, a standardized protocol is commonly used (Rome criteria). However, the expression of complaints by subjects from the general population who are diagnosed with IBS largely fails to fit into these standard descriptions. This has to be taken into account when developing diagnostic tools for epidemiological research and clinical practice in the future. More patient-centred symptom clusters based on focus group research should be considered when revising the Rome criteria in the future.

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H.M. wrote the manuscript and did the analysis together with L.A. and H.N.; L.A. and H.N. with N.J.T. were also responsible for the study concept, design, and supervision. L.K. conducted the study (as part of a large population-based colonoscopy study, the PopCol study); S.W. and N.J.T. revised the manuscript for important intellectual content; and A.A., the research coordinator for the PopCol study data repository, extracted the data and participated in the writing of the manuscript.

## Declaration of interest

No author has any disclosures or any potential conflicts of interest relevant to the manuscript.

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