# Clinical Implications of Diagnosing Irritable Bowel Syndrome

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# Clinical Implications of Diagnosing Irritable Bowel Syndrome: Do All Roads Need to Lead to Rome?

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**Abstract: Irritable bowel syndrome (IBS) is one of the most common diagnoses made by healthcare providers. Yet the majority of patients with IBS are undiagnosed. The study by Sayuk *et al.* allows insight into the characteristics of different patient groups, e.g., with and without a formal diagnosis of diarrhea predominant IBS (IBS-D). We discuss the questions raised by this study regarding the importance of making a confident diagnosis, conveying it to patients and their implications for clinical practice.**

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Abdominal pain and diarrhea are the leading gastrointestinal (GI) symptoms prompting ambulatory visits in the United States with more than 27 million ambulatory, emergency department, and hospital outpatient clinic visits per year. Abdominal pain and diarrhea are also common leading GI diagnoses in the ambulatory setting, with "abdominal pain" being the most common (over 16.6 million per year) and "diarrhea" the ninth most common (over 2.6 million per year). Interestingly, the diagnoses of abdominal pain and diarrhea are more common than the diagnosis of irritable bowel syndrome (IBS; tenth most common diagnosis with 2.4 million diagnoses per year) (1). The fact that these diagnoses are so often made does not come as a surprise when considering the high prevalence of GI symptoms in the general population. Although epidemiological data are scarce (2), the available numbers indicate that a significant portion of the US population—42% of adults (3) and 23% of children and adolescents (4) —experience GI symptoms that correspond with at least one of 20 functional GI disorders (FGIDs), including IBS. However, more than half of the individuals with functional bowel symptoms do not seek medical care for their symptoms (5). These individuals are often referred to as non-patient individuals with FGIDs.

In this issue of the journal, Sayuk *et al.* report their findings from an online survey conducted in 1,924 individuals from a general US population who had previously participated in various surveys and had indicated having GI symptoms. Individuals were excluded if they reported having habitual constipation or rectal blood loss in the month prior to participating in the survey. The authors found that 1,094 (56.9%) of the respondents met the Rome III criteria for IBS-D and received a formal diagnosis from their health care provider. The other 830 (43.1%) individuals fulfilled the Rome III criteria for the disorder (IBS-D), but had never received a formal diagnosis. Furthermore, over half (53%) of these undiagnosed individuals have never spoken to a physician about their abdominal symptoms, and therefore, have never received a formal diagnosis (6). Given this considerable proportion, the question arises what factors drive individuals experiencing abdominal symptoms compatible with IBS to consult their health care providers about these symptoms? While most studies have repeatedly shown that abdominal symptom severity is an important determinant in this regard, discrepant findings have been reported for the exact role for psychological factors (7–11). This category of non-patient individuals therefore may represent a population characterized by mild severity of IBS symptoms. These individuals are probably able to cope and manage their symptoms adequately without any additional involvement of the health care system. For this group of non-patients, education via non-formal routes (lay media, family, and peers etc.) seems appropriate and probably sufficient. A formal diagnosis therefore does not appear to be necessary.

In addition, the study by Sayuk *et al.* (6) allows further insight into another category of patients: those whose symptoms were compatible with IBS-D who had sought the advice of a healthcare professional, but have not received a formal diagnosis. This population represents 47% (390/830) of all subjects surveyed without a formal diagnosis. This number seems surprisingly

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high. After all, an individual with IBS-symptoms seeking advice from a healthcare professional, for instance due to the severity of their symptoms, would rightfully expect to receive a diagnosis and appropriate advice in terms of treatment and management of their symptoms. Such a formal diagnosis helps initiate a dialogue between patient and healthcare provider with regards to insight into triggering factors and treatment options—so argue Sayuk *et al.* (6). With regards to treatment options, a variety of non-medicinal approaches (e.g., dietary and behavioral interventions) have shown to be effective treatments for IBS symptoms and many of the patients prefer and do well with these approaches. In addition, it is important to remember that demonstrated therapeutic effectiveness with a specific intervention in IBS patients does not guarantee similar effectiveness in non-patients or patients without a formal diagnosis of IBS (12). Above all, IBS patients often simply ask for explanations and expect to be educated about their disease, rather than a prescription for medication to cure or alleviate their symptoms (13). Furthermore, with regard to medications, a multinational study has shown that, although over 60% of patients with abdominal cramping and pain use some form of medication, the majority of the patients prefer over-the-counter medicines over prescription drugs (14). Thus, decisions regarding therapeutic approaches and specifically pharmacotherapy should be done on an individual basis, based on patients' predominant symptoms, illness severity, and patients' preference.

Another intriguing finding by Sayuk *et al.* (6) sheds light on an apparent disconnect between the treating physician and the patient having symptoms compatible with IBS-D; 45% of patients without a formal diagnosis who have had their symptoms for over 10 years and have seen a gastroenterologist, report that they have indeed never received the diagnosis of IBS-D. How is this possible? Are gastroenterologists not confident in making the diagnosis of IBS-D? Were patients given an alternative diagnosis? Or is it a failure to explicitly communicate the diagnosis to patients? In fact, a small study from Iceland using telephone interviews showed similar findings: only one out of five individuals with IBS symptoms was formally diagnosed with IBS, even though more than half of them saw a physician because of their GI symptoms. Remarkably, these results were irrespective of whether the patients fulfilled the Manning or Rome III criteria for IBS (15).

From the providers' perspective, we know from earlier studies that general practitioners generally do not use the Rome criteria for IBS diagnosis but rather rely on a pragmatic approach based on clinical experience, judgment, and knowledge about the patient (16–18). We also know that there is considerable difference between the various symptom-based diagnostic criteria (e.g., Rome III and the less inclusive Rome IV), and that this has significant effects on the prevalence numbers for IBS (19). While the use of new and improved Rome IV criteria should be encouraged among all health care providers, certainty and confidence in making a positive diagnosis of IBS is definitely warranted, regardless of which diagnostic criterion one is most accustomed to using. Indeed, the revised Rome criteria were adjusted by clarifying the language, updating the definition, and including the option of minimal laboratory testing, with the intention to make it easier for doctors to diagnose IBS (20). However, uncertainty is almost inherent to a symptom-based diagnosis and most community providers still believe that IBS is a diagnosis of exclusion rather than using positive symptom-based criteria to support the diagnosis (21). This approach—or lack of one—is time consuming and costly for the health care system. In regard to this, a recent study suggests that when gastroenterologists use uncertain language in diagnosing patients with FGIDs, this can contribute to patient discard of diagnoses and leads to unnecessary additional studies, endoscopic investigations and repeat consultations (22).

From the patients' perspective, previous studies have shown that the majority of IBS patients felt that they are insufficiently informed on their condition, and were not provided with an adequate explanation for their symptoms (23). This seems particularly relevant since patients may often have considerable misconceptions about IBS. For instance, in a study by Lacy *et al.*, 40.6% of IBS patients thought that colonoscopy can diagnose IBS, and one in seven patients stated that IBS turns into cancer (24). Therefore, in addition to making a clear and confident diagnosis, an effective management strategy must also involve addressing disease-specific fears and concerns and tailoring individual therapeutic approaches while setting mutually reasonable goals and expectations. Indeed, it has been shown that only satisfaction with the physician-patient relationship discriminated between IBS subjects who sought continued consultation with a physician vs. those who did not (8).

What does this all add up to? Apparently we are not doing a good job at diagnosing IBS—or at least communicating and explaining the diagnosis to patients. If so, it could be due to the lack of time for effective communication with the patient, but it could also be due to lack of understanding of IBS or feeling uncomfortable making the diagnosis by the providers themselves. Regardless of the source of the problem, there is still work to be done, by gastroenterologists and their general practitioner colleagues, on improving ways to make a confident diagnosis of IBS and explaining IBS to patients in an effective and convincing way. Given the current restraints on health care systems and limited time in terms of consultations, attempts should be made to establish patient self-help measures for development of better coping and self-empowerment techniques using comprehensive multimedia education material. These approaches have indeed been shown to be efficacious therapeutic tools (25). Digital technology approaches can offer solutions for providing information and insight, engaging patients with or without formal diagnosis into being more health-conscious and potentially improving effective communication between patients and their providers (26).

The broader implications of the findings by Sayuk *et al.* (6) are that they highlight the importance of (i) educating non-patients and patients about IBS (and other FGIDs) symptoms regardless of whether they have sought medical attention, in order to increase common knowledge and clear misconceptions; (ii) and indeed when medical help is required, physicians need to feel confident in making the diagnosis and conveying it effectively to their patients. This should increase our ability to identify patients who are likely to gain from consultation and tailoring of an appropriate

diagnostic and symptom management plan, while avoiding long-term suffering from chronic GI symptoms and/or entering endless rounds of investigations and explanations.

## CONFLICT OF INTEREST

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