



What Patients Know About Irritable Bowel Syndrome (IBS) and What They Would Like to Know

By: Alben Halpert, M.D., Co-Director, Functional GI Program, Center for Digestive Disorders, Boston Medical Center, Boston, MA

At a Glance

The right information can help patients with IBS feel better. Knowing this can help doctors and patients.

Wrong beliefs about IBS may lead to distress, more doctor visits, and unneeded tests. For example, patients need to know that IBS:

- Does *not* put them at risk for cancer,
- Does *not* get worse with age, and
- Does *not* shorten life spans.

Patients most often want to know:

- If foods and diet have an effect on IBS,
- The causes of IBS, and
- How best to treat and cope with the disorder.

More and more the Internet is a useful learning tool. (Always choose a trustworthy source.)

Doctors usually use a physician-centered approach to patient education. They provide information they believe to be most important for patients to know. This approach often does not include patients' own ideas and beliefs about their illness. In contrast to just providing information, a learner-centered (or patient-centered) approach uses prior knowledge and experience as a starting point to help people learn. This learner/patient-centered education model has been shown to help patients better manage their disease, and to improve quality of life and patient satisfaction in a variety of long-term illnesses. Examples include diabetes, arthritis, and heart disease. What are the educational needs of patients with irritable bowel syndrome (IBS)? We believe it is important to understand what patients know and do not know, and how they prefer to obtain their information, as a first step in developing a true patient-centered educational standard.

Irritable bowel syndrome is a common disorder, affecting 15 to 20 % of the adult U.S. population. Some aspects of IBS are "education responsive." Examples include stigma attached to bowel functions, lack of public awareness about IBS, and high rate of psychological distress. Thus, the potential benefits of improved patient education in regard to IBS are large. Looking at and defining educational needs of patients with IBS may aid in developing more meaningful, patient-centered educational strategies that improve IBS management.

Researchers from Boston University and the University of North Carolina at Chapel Hill, in collaboration with IFFGD, surveyed a national sample of patients with IBS to determine what they already know about the disorder and what they need to know. This information allowed us to begin the process of developing patient-centered, effective educational programs. In the first step of the study, we conducted several focus groups of patients with IBS to obtain information we needed to develop a patient educational needs questionnaire. The questionnaire was then completed by 1,242 IBS patients nationwide. Between the years 2003 and 2005, 871 qualifying subjects living in 49 U.S. states completed the study online. Three hundred and seventy-one qualifying subjects recruited via non-online sources completed the survey by mail. Those who took part in this study were mostly females (85% female and 15% male) and in their 30's with some education beyond high school. Almost all of those taking part in the study had used the Internet in the past in order to find information about IBS. In the prior 6 months, a doctor had treated most for IBS.

Mistaken beliefs can affect symptoms

Our survey identified what IBS patients in the U.S. know about their health problem and what they need to know in regard to IBS. Patients were able correctly to identify the main IBS symptoms and triggers.

Many (up to 70%) connected their symptoms with psychological distress. We learned that patients often mistakenly believe that IBS will develop into cancer, colitis, malnutrition, get worse with age, and even shorten life span. Such mistaken beliefs may lead to unnecessary concerns and contribute to anxiety, which often co-exists in patients with IBS. This kind of distress may cause patients to seek more medical care and to demand more testing.

What patients want to know

The information patients most often seek about IBS includes learning about:

- What foods to avoid
- The causes of the disease
- Treatment choices
- Ways to best manage living with IBS

Patients mainly want to know about the role of food in IBS (“What foods to avoid”). Yet there is a lack of strong evidence in the medical literature for the effects of specific foods in causing IBS. Doctors usually are not able to offer specific advice on what to eat. Nevertheless, given the patients’ need for this type of information, it is important for patients and doctors to discuss this subject to help maintain healthy eating habits. Patients may benefit from understanding the basics of how the gut works. For most people with IBS, oral intake of foods in general, rather than specific foods, (except in conditions like milk intolerance, gluten sensitivity, etc.) may bring on symptoms. Information from a doctor to a patient that is aimed at addressing specific concerns, instead of general data, is most useful.

The study also found that IBS patients who use the Internet have better knowledge about IBS in general. They have fewer mistaken beliefs about IBS, and are aware of the psychosocial connection with symptoms. They also seem to have the most current knowledge of commonly used medications and interest in learning ways to manage the disorder. Most of those who took part in our study used the Internet, suggesting the acceptance of web-based education.

Summary

The study worked to define the educational needs of a large national sample of IBS patients. We found that many patients hold mistaken beliefs about the condition. Some beliefs may negatively influence patients’ emotional well-being and increase their health care needs. According to our data, patients are mostly interested in dietary modifications, the causes of IBS, and treatment and coping strategies. Patients better informed about the disease use the Internet. They may have different educational needs than non-web users. The results of the study can be useful to doctors who treat patients and as a basis for developing a variety of patient-centered IBS educational approaches.

Acknowledgment

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Additional Reading

Halpert AD, Thomas AC, Hu Y, Morris CB, Bangdiwala SI, Drossman DA. A survey on patient educational needs in irritable bowel syndrome and attitudes toward participation in clinical research. *J Clin Gastroenterol*. 2006 Jan;40(1):37-43.

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