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IRRITABLE BOWEL SYNDROME

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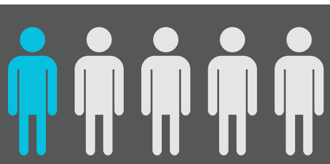
IRRITABLE BOWEL SYNDROME

The elephant in the waiting room

As we reflect upon the issues brought to the fore during irritable bowel syndrome (IBS) awareness month, we're taking a look at how the interplay of different perspectives come together to shape the healthcare experience of patients with IBS.

But what can we hope to glean from exploring the perspectives of patients living with the condition, and also the perspectives of healthcare professionals (HCPs) involved in the care of patients with IBS? Why is it important to explore these perspectives? And how will it contribute to improving the current state of play? Well we'll tell you… but first of all, what is the extent of the problem?



one in five people

in the UK suffer from IBS[1]

A staggering one in five people in the UK suffer with IBS.[1] Continual abdominal pain that is related temporally to going to the toilet, and that is associated with a change in bowel habit and/or a change in stool appearance are the textbook symptoms associated with IBS. However there are many other physical symptoms reported, including tiredness, nausea, backache, and bladder symptoms.[2,3] The Rome IV criteria[3] are a helpful set of consensus diagnostic criteria aiding the effective management of patients with functional gastrointestinal disorders.

However, as is the case with many chronic diseases **the extent to which the disease impacts upon a patient's quality of life is inadequately represented by considering the symptoms alone.**

Rome IV Diagnostic Criteria[a] for IBS[3]

Recurrent abdominal pain

Occurring, on average, at least 1 day per week in the last 3 months

Associated with 2 or more of the following criteria:

Related to defaecation

Associated with a change in frequency of stool

Associated with a change in form (appearance) of stool

[a] Criteria fulfilled for the last 3 months with symptoms onset at least 6 months before diagnosis

Patients with IBS suffer disturbances in many aspects of their lives and negative experiences and feelings are often internalised, resulting in patients feeling ashamed and embarrassed.[4] Frequent alterations to eating habits in an effort to alleviate symptoms are common among those patients with adequate levels of self-efficacy to make lifestyle changes, whilst others retreat into a form of learned helplessness.[4]

The scale of the problem for patients is huge and touches most aspects of their lives. But what is going on behind the scenes for the HCPs that are seeing these patients when they do present for help?

We were interested to find out what HCPs' experiences are and what factors might influence actions (or inactions) when seeing patients with IBS. So we did some digging and thought we'd share what we found.

You may well be asking, 'why explore these issues at all?' and, 'what difference does it make?' Well, we think that key to affecting positive change in the healthcare journey of patients with IBS is:

- **understanding patients' and HCPs' experience**
- **acknowledging the apparent disconnect between the perspectives of patients and HCPs**
- **providing education to both groups**

In order to:

- **raise levels of patient activation**
- **raise levels of public awareness**
- **improve the HCP–patient relationship**
- **improve patients' health outcomes and healthcare experience**

So what can we learn from the patients themselves?

Insights from patients suffering with IBS

Three themes have been identified to describe the healthcare experience of patients with IBS[5]:

- **feelings of frustration from lack of control**
- **a sense of isolation**
- **dissatisfaction with available treatments, information received, and the healthcare system in general**

The frustration appears to be, at least in part, borne out of a perceived inability to anticipate, prevent, or control the symptoms of IBS. This leads to **social anxiety, feelings of not being understood, and a state of dependency as individuals struggle to preserve their dignity.[5,6]**

Clinically this experience further lowers levels of self-efficacy, and in the context of a condition where a large portion of management is assigned to the patients themselves, this may negatively affect health outcomes.

More personally for the patient with IBS, as negative feelings become entrenched this leads to low self-esteem, withdrawal, and ultimately social isolation.[5]

Publicly there certainly seems to be a stigma surrounding IBS. Patients worry about public perception, and almost preempt a negative experience when approaching HCPs; the **unhelpful construct that IBS does not qualify as a bona fide physical condition may be at the heart of the issue.**

Compounding this problem is our relative unease in discussing issues relating to bowel function, which leads to a propensity to keep bowel symptoms to ourselves.

All of this adds up to create an environment in which societal awareness and open discussion of IBS is lacking when compared to other chronic illnesses such as asthma or diabetes.[7,8]

Resultantly, patients choose to suffer in silence, with only half of IBS patients informing family and friends about their diagnosis.[5]

Only **half of IBS patients** inform family and friends about their diagnosis[5]

Interestingly, in an expressive writing study, when asked about their illness experience, 70% of patients gravitated to discussing their relationship with HCPs.[9] This highlights the importance of said relationship in the context of patients' overall experience.

The Calgary–Cambridge guide to the medical interview[10] encourages effective two-way communication between HCP and patient and is seminal reading for all clinicians; however the art of effective communication in the context of healthcare is far from straightforward.

In relation to IBS, HCPs have been criticised for not being sufficiently empathetic in probing the patient's perspective and for not providing enough information or guidance relating to the management of IBS symptoms. This leaves some patients feeling dismissed and undervalued.[11,12]

IBS patients consider listening and showing empathy the most important, currently underutilised, elements intrinsic to forming a more functional HCP–patient relationship.[5]

Furthermore, it seems less than one-third of patients are satisfied with medications they use for IBS, with more than one in ten patients stating that they would accept a one in a thousand chance of death in exchange for a treatment which would free them from IBS symptoms.[13]

If patients are made to feel passive in their healthcare journey, they are less likely to consult with their HCP; instead they may simply stop taking medications. When asked, GPs generally suggest that patients do not return because symptoms have settled, rather than due to patients being dissatisfied with their care.[14]

In addition, the level of information imparted by HCPs has been criticised:

IBS patients state that they are insufficiently informed, with many holding misconceptions relating to their illness that actually fuel their anxiety.[5]

Patient education surrounding the condition is vital to increasing patient activation and improving health outcomes. Areas of interest where patients would welcome further education include[5]:

- **medically appropriate dietary modifications**
- **some insight as to the actual causes of IBS**
- **relevant strategies for preventing 'attacks' of IBS**
- **coping strategies for when symptoms do flare**

Now we know a little more about the struggles facing patients with IBS, what are the corresponding perspectives of the HCPs involved with caring for these patients?

Insights from HCPs caring for patients with IBS

HCPs have been found to[5]:

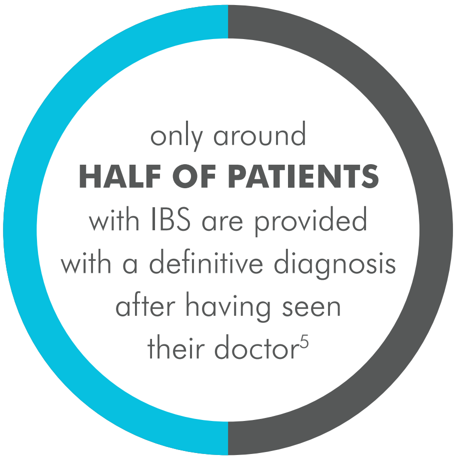
- **underestimate the severity of IBS symptoms**
- **understate global effect on quality of life**
- **consider diagnosis as tentative and iterative**
- **overstate psychological causes**

IBS does not have a fully elucidated aetiology, but despite the existence of robust diagnostic guidelines[2,3], recent evidence[5] shows that over half of HCPs still consider IBS a diagnosis of exclusion. From experience, no HCP relishes the prospect of dealing with patients with *functional* diagnoses, as opposed to *organic* ones; uncertain aetiologies and relatively less-consistent treatment recommendations lead to a discomfort that further breaks down the HCP–patient relationship and translates into increased patient anxiety. In fact, such is the aforementioned discomfort, only around half of patients with IBS are provided with a definitive diagnosis after having seen their doctor.[5]

So, IBS itself causes unease in HCPs by virtue of it's relatively poorly understood aetiology, and this can negatively impact the patient. But is there a means by which, through effective communication and further education, HCPs and patients can understand where each other are coming from and work together for improved outcomes?

Can we break the stalemate?

over
HALF OF HCPS
still consider IBS as a diagnosis of exclusion



only around
HALF OF PATIENTS
with IBS are provided with a definitive diagnosis after having seen their doctor[5]

A case of never the twain shall meet?

At the interface of patients' and HCPs' experience of IBS we see that patients suffer from low self-efficacy and low self-esteem, which likely has an effect upon adherence to medication.

We also see that HCPs practically manifest the medical profession's bias regarding *organic* versus *functional* diagnoses, whilst they are also being called out for not displaying enough empathy, not being a conduit for appropriate patient education, and for not fully utilising available guidelines.[14]

We at IGNIFI feel there is scope for the provision of educational materials, to both patients and HCPs, which for patients would increase their level of activation, empower them as participants in their healthcare journey, and enable them to more effectively self-manage.

For HCPs, improving awareness surrounding the availability of, and contents of, clinical guidelines such as NICE Clinical Guideline 61 (CG61)[2] and the ROME IV Diagnostic Criteria[3], may aid in HCPs forming an appropriate IBS diagnosis and providing the recommended management earlier, thus reducing repeat attendance. Then, by providing education to HCPs around patients' illness experience, this may improve the quality of the HCP–patient relationship in the context of IBS.

Finally, through raising public awareness of IBS, we can challenge the stigma facing IBS patients and promote more open discussion of the condition.

For now, and as a parting gift, let us share with you some educational points[5] that have been deemed of potential benefit to most IBS patients. Insights such as these, we hope, will go some way to greasing the wheels of effective HCP–patient dialogue and may improve outcomes for stakeholders involved with, or affected by, IBS.

Key educational points that could benefit most IBS patients

Conversational points	Importance
IBS is a real gastrointestinal condition; it is not 'in your head'. IBS can significantly affect one's life.	Provides validation and demonstrates empathy.
IBS is a chronic medical condition, although the symptoms can come and go. There is no magic pill for IBS.	Helps patients set realistic expectations.
There are many things we can do to help you better manage IBS symptoms. You may have long periods of time (sometimes years) without experiencing any symptoms.	Provides hope to the patient, while implying the need for self-management.
IBS does not cause cancer, colitis, or any other problems. It does not shorten your life.	Helps to clarify potential common misconceptions and reduce disease-related anxiety.
For some people with IBS, stress can trigger symptoms or make them worse.	Can be used to further explore the role of psychological factors in IBS.
We need to work together to help you manage your IBS.	Emphasises the need for a collaborative approach.

Adapted from: Halpert A. Irritable Bowel Syndrome: Patient–Provider Interaction and Patient Education. *J Clin Med.* 2018;7(1):3.

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About the author

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Michael is a trained biomedical scientist who went on to read medicine at Durham University.

Choosing not to pursue a career in medicine, Michael began working in medical writing; first in medical information and, upon joining IGNIFI, medical copywriting.

Michael draws on first-hand clinical experience and ongoing research to explore issues facing patients, the pharmaceutical industry and the healthcare sector.

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