Medical and lay views of irritable bowel syndrome

Mary Dixon-Woods and Sophie Critchley


Objectives. The purpose of this study was to investigate doctors’ and patients’ views of irritable bowel syndrome (IBS) in order to assess why problems in the doctor–IBS patient relationship seem to occur.

Methods. A qualitative study was undertaken involving in-depth, semi-structured interviews that were tape-recorded, transcribed verbatim and analysed using the constant comparative method. The subjects comprised 12 doctors, including six GPs and six gastroenterologists, and 14 patients with IBS.

Results. Doctors hold two definitions of IBS, one ‘public’ and akin to a textbook definition, the other ‘private’ and including experiential knowledge and absorbed prejudices about IBS patients. Doctors are not universally hostile towards IBS patients, although the views of gastroenterologists may tend to be more pejorative than those of GPs. Most doctors experience frustration with IBS, and this is due as much to medical uncertainty and shortage of effective interventions as to intolerance of the personal characteristics of IBS patients. Doctors distinguish between ‘good’ and ‘bad’ IBS patients and manage them accordingly. Many patients tend to find their IBS symptoms very troublesome. Patients are more satisfied if they are taken seriously and helped to manage their symptoms, but many feel that they are labelled as neurotic by the medical profession. They tend to feel stigmatized and let down by doctors.

Conclusions. Better partnerships could be created with patients, and better outcomes for IBS might be achieved, if doctors recognized the impact of medical beliefs about IBS on patients. Doctors should offer IBS patients empowering explanations for their disorder.

Keywords. Doctor–patient communication, irritable bowel syndrome, patient participation, qualitative.

Introduction

Irritable bowel syndrome (IBS), a chronic disorder of bowel habit, is a significant problem in terms of prevalence and demand on health services, and is thought to be the gastroenterological condition encountered most frequently by GPs and by hospital specialists in gastroenterology. It is argued increasingly that a strong doctor–patient relationship is vital to the successful management of IBS, and patients frequently report that the medical profession tends to be unsympathetic and hostile towards them, and doctors are often characterized in the medical literature as being intolerant of IBS patients. The reasons for these apparent problems could be better understood by directly accessing the views of both doctors and patients.

Methods

Our study intended to explore the views of doctors and patients on IBS, and therefore seemed especially well suited to a qualitative approach using semi-structured interviews. A strategic theoretical sampling approach was used to recruit participants to the study. This form of sampling does not aim for representativeness in a statistical sense; the adequacy of the sample is assessed instead by the extent to which it permits the development or confirmation of emerging themes. Interviewing therefore ceased when no new major themes were being identified with each new interview. This point of ‘theoretical saturation’ was reached when 12 doctors and 14 patients had been interviewed. The doctors included six GPs and six gastroenterologists (identified by the symbol HS below), varying in seniority from SHO to consultant. The patients were selected from two gastroenterology clinics in Leicestershire and all had a confirmed diagnosis of IBS. All patients were aged 20–55 years, English-speaking, experienced typical...
IBS symptoms and had no evidence of other gastrointestinal morbidity. Because of a strong theoretical prior belief about the significance of being female and having IBS, all patients interviewed were women.

A topic guide based on themes generated through a review of the literature was used in the interviews, but participants were also encouraged, through use of open-ended questions, to pursue other topics. All interviews were tape-recorded and transcribed verbatim. The resulting data were analysed using the constant comparative method to discover recurring and patterned ways of talking about IBS. Analysis began with *in vivo* codes and eventually major organizing themes were identified.

**Results**

**Defining IBS**

**Doctors.** Many doctors seemed to hold two definitions of IBS. One was a ‘public’ definition involving a symptom list that contained elements of textbook definitions. GPs, in offering these public definitions, were usually happy to make a positive diagnosis of IBS based on presentations that they felt to be typical of the condition, but gastroenterologists were much more cautious, referring to “the times when you’ve been horribly caught out” (HS2). A ‘private’ definition, on the other hand, focused on what were perceived to be typical IBS patient characteristics, almost always including a reference to women. The private views of hospital specialists seemed to be more pejorative than those of GPs:

“Patients tend to be women, middle-aged, worriers, analy retentive people who think a lot about their health and bowels”. (HS4)

“They tend to be women, younger rather than older . . . reasonably articulate, not necessarily married, probably before having children . . . those are the defining characteristics”. (GP4)

However, several doctors, while they held private, non-textbook definitions of IBS, were more reluctant to commit to attempts to stereotype IBS patients, arguing that “there is a danger in lumping them all in together” (HS1).

**Patients.** IBS was defined for patients by their perception that their symptoms were abnormal. Some saw their symptoms as nothing more than an inconvenience, but others experienced significant interference with normal functioning:

“I’m desperate, I’m legging it to the loo every five minutes but it’s just mucousy and bleeding . . . I’m in absolute agony”. (P28)

For most patients, the significance of the symptoms lay in the constraints imposed on everyday life: several emphasized the need to be near a toilet at all times, and fear of an attack of diarrhoea limited activities such as shopping, holidays, and work.

“I felt I daren’t go anywhere, I was restricted to the house, never off the toilet”. (P25)

**Views about the aetiology of IBS**

**Doctors.** Most clinicians in our study agreed that “IBS has no clear structural or pathological explanation” (HS2), but all nonetheless held their own views on the aetiology of IBS. Some emphasized pathophysiological factors:

“(There is) a neurological explanation for why we’re not aware of our guts moving but some may feel theirs . . . colonic pressures and whatever in motility disorders all have family histories”. (GP6)

Psychological factors and ‘stress’ were emphasized in all of the doctors’ accounts, albeit in different ways. Some saw these as initiating and perpetuating IBS, arguing that IBS patients are “very stressed, obviously twitchy, quite neurotic” (HS4). Others saw psychological problems as a consequence of IBS symptoms, suggesting that if a patient had physical symptoms then “you’re going to have psychological problems—anxiety, depression—centering on that” (GP3). Still others described a circular effect:

“I’m a great believer in IBS being a vicious circle of stress causing symptoms or symptoms causing stress causing further symptoms . . . a positive feedback mechanism”. (HS3)

A few doctors expressed concern that psychological factors had taken the blame for IBS because medical science had failed to come up with a more credible physiological explanation:

“All diseases have gone through being psychosomatic in origin until physicians come up with some demonstrable cause. This is where IBS is now . . .”. (HS2)

**Patients.** Patients were, in general, well aware of medical explanations for IBS symptoms that emphasized the role of psychological precipitants such as stress or neurotic personality, but none was aware of a physical explanation other than food intolerance. Some patients did accept the role of psychological triggers in their condition, and admitted to excess anxiety about health or identified specific stressors such as divorce.

“Last week I’d convinced myself I’ve got breast cancer but I haven’t . . . there again when I had diarrhoea I’d convinced myself I’d got bowel cancer”. (P4)

Others rejected psychological explanations, commenting that they were “not your obvious neurotic”
(P18), or reiterated the circular effect described by some of the clinicians:

“We’re patients OK, then got IBS and became neurotic? Or were they neurotic, got IBS and became more neurotic? I wasn’t neurotic about my health until I got IBS”. (P24)

Patients who did not accept that stress caused their symptoms tended to favour a food intolerance explanation, and many could identify specific foods that appeared to trigger symptoms.

Managing IBS

Doctors. All the GPs in our study aimed to diagnose and manage IBS by themselves in the first instance, providing reassurance and symptomatic pharmacological relief. Reasons for referral included uncertainty about diagnosis, presence of potentially sinister symptoms, treatment failure or inability to reassure patients. Overall, gastroenterologists’ management was very similar to that of GPs, including a heavy emphasis on reassurance, but was more likely to involve attempts to rule out organic disease. For some clinicians, the decisions to investigate were based on objective criteria, such as the patient’s age, while others based their decisions on more subjective factors such as need for their own ‘peace of mind’ or pressure from ‘demanding’ patients, including those who were “pushy . . . cancer phobics” (HS1).

However, despite the perception that many IBS symptoms were neurotic in origin, there was a reluctance among several doctors in the sample to enquire into psychosocial aspects of patients’ lives.

“It’s not particularly valid. What I’m concerned about is making sure there’s no other diagnosis”. (GP5)

“You’re treading on GPs’ territory. Social issues are usually community issues, not to do with hospitals. We’re here to give you opinions on your GI symptoms, medicines, further tests, etc.”. (HS6)

Doctors expressed widely varying views on interventions for IBS patients, with many referring to the problem of finding effective treatments, especially for a ‘hard core’ of patients. Many referred onwards to a variety of other specialists, including dieticians and clinical psychologists. There was particular debate over the role of psychological therapies:

“There’s good evidence from small trials that cognitive behavioural therapy improves patients’ symptoms”. (GP2)

“If my heavy reassurance and advising that stress is causing the problem doesn’t cure them, then I doubt a psychiatrist or psychologist would”. (GP4)

Patients

All patients in the study had consulted their GP in the first instance, prompted by triggers such as a particularly severe episode of symptoms, by symptoms interfering with social function or by fears about the significance of the symptoms.

“I’m a hairdresser. You feel the cramps and think ‘crikey, I’ve got to leave this client, and say ‘excuse me, I need the toilet’”. (P18)

“I thought I’d got cancer, it seemed too severe for just diarrhoea”. (P25)

All patients had tried a range of first-line treatments including anti-spasmodics and stress avoidance. While two patients were reluctant to be referred to a specialist, others felt that they had to ‘push’ for a referral:

“Eventually he gave in and referred me”. (P17)

Once in the care of a consultant, patients underwent a range of investigations. Following the IBS diagnosis, patients were usually prescribed drugs. Over half the patients were referred to other specialists, and those who had been referred to clinical psychologists had mixed views. One was very enthusiastic (P19), but others felt that it was ineffective:

“She just taught me how to breathe . . . I thought, ‘it’s my day off. I’ve got better things to do’”. (P23)

“He talked about embarrassing things like sex . . . nothing I could pin IBS down to. Things never got better”. (P17)

Overall, while some patients were satisfied with the medical management of IBS, many were disappointed, feeling that they had not been given a clear “way forward” (P15) and had been left to find out about triggers for symptoms and devise a management plan by themselves.

“You expect the GP to sort everything out like an infection, antibiotics and that’s it. As time passes you realise (doctors) don’t know everything, it takes your rose-coloured glasses off”. (P21)

Patients were also frustrated by advice that did not work, and by conflicting advice:

“All-Bran made the constipation worse but the GP wouldn’t listen. According to him it couldn’t make it worse . . . One GP prescribed laxatives, another said don’t touch them so I was lost about what to do and not getting any help”. (P28)

The doctor–patient relationship

Doctors. Most doctors were at pains to stress the need to deal with IBS patients in a sensitive and sympathetic way, notwithstanding their own ‘private’
views about IBS patients in the case of gastroenterologists:

“If you treat people with a troublesome illness as if it’s not serious . . . they feel devalued, that they’re not being helped, and they fear they’re being a nuisance”. (HS2)

All doctors had developed strategies for dealing with IBS patients, often involving forms of communication. Doctors described how they developed their “own patter, you know what goes down well” (GP3).

“Sometimes it means using fairly vernacular terms. Some have no idea what flatus is but they know what a fart is”. (GP2)

However, all doctors mentioned aspects of IBS that they found frustrating. Frustration centred on the workload imposed by IBS, the feeling that it was an unrewarding condition to treat because of poor understanding of the condition and the absence of effective treatments, or the perceived problematic characteristics of IBS patients:

“Anyone gets frustrated with patients banging out symptoms, saying medication makes them worse, nothing makes them better, and ‘what are you going to do, doctor?’ You’re racking your brains and often catch yourself because you’re thinking of ways to get the patient out of the clinic rather than genuinely help them”. (HS6)

It became apparent that, rather than treating all patients in the same way, doctors distinguish between ‘good’ and ‘bad’ IBS patients. ‘Bad patients’ were recurrent attenders who would not accept the IBS diagnosis, demanded expensive and lengthy investigations, and failed to cope or respond to treatment.

“There are some patients who are very easy to speak to and there are some who are unaccepting of anything you say and it can be very difficult to talk to them . . . ”. (HS6)

“What can be frustrating is patients who complain a lot about seemingly very small symptoms . . . it’s difficult after looking after sick patients on the wards to sympathise”. (HS4)

‘Bad’ patients were seen to resent the ‘IBS’ label and to reject psychological explanations for their symptoms:

“A few take the diagnosis very badly, saying ‘there must be something wrong’. If you say ‘there it is, you have IBS’, it’s not good enough. It’s almost like they’re seeking a more serious diagnosis”. (HS3)

“Sometimes patients go all defensive when you suggest psychological factors, saying ‘I’m not depressed, there’s nothing wrong with my mental state’”. (HS4)

‘Good’ patients, on the other hand, welcomed the diagnosis:

“They’re relieved to know they’ve got a label attached to their illness because they’ve done the rounds . . . finally someone says ‘I think it’s this’ and gives an explanation”. (GP4)

For ‘bad’ patients, doctors may decide to discard the overtly sympathetic and caring approach, and instead try a different tack:

“They’re heartsinkers, and labelled as such. Sometimes you have to be brutal and say ‘no drug will take these symptoms away. We’ve tried them all, now we’re going to try a different aspect and learn to live with it’”. (HS6)

Patients. Patients themselves seemed to be very conscious of negative medical views of IBS, and perceived themselves as a very stigmatized group who were discredited in the eyes of the medical profession:

“They put all patients into one bag, saying ‘she’s neurotic, send her off with tranquillisers’”. (P24)

“He actually said ‘there’s nothing wrong, go away, it’s all in the mind dear’”. (P18)

Patients’ reactions to the diagnosis of IBS appeared to fall into the two groups identified by the doctors: those who accepted it—“I was happy” (P27)—and those who found it bad, fearing that their symptoms signalled something sinister that had remained undiscovered, or rejecting the validity of the label altogether. Patients were “left thinking perhaps it’s something else” (P24) that “they’d diagnosed me wrong” (P25) or that:

“It has a label for me that it’s not a proper illness, it’s saying ‘it’s psychological’”. (P28)

Patients praised doctors who treated them as if they’d got “something worth treating” (P19), and who were sympathetic to their fears (P18). Dissatisfied patients perceived that doctors trivialized their symptoms, saw IBS as a ‘dustbin diagnosis’, did not offer them enough time and failed to recognize the impact of the symptoms on their quality of life.

Discussion

The value of accessing the views of both doctors and patients on problematic issues in the doctor–patient relationship is now being recognized and is especially important in IBS, where a strong doctor–patient relationship may be linked to reduced consultations. Our study confirmed that the doctor–IBS patient relationship is prone to problems, and identified some of the reasons for
These by enabling an understanding of the frameworks within which clinicians interpret patients’ symptoms and behaviour, and the meanings of IBS for patients themselves.

**Doctors’ views**

The incomplete medical nature of medical knowledge about IBS meant that, for doctors in our study, IBS was not a single rational scientific entity with a clearly understood aetiology, nor were universally effective treatments available. Therefore, while most doctors were able to produce a textbook-type list of symptoms that defined IBS, they also drew on other resources, including experiential knowledge and absorbed prejudices, in their private ‘definitions’ of the condition. This experiential, personal knowledge results in doctors holding conflicting views about the value of everything from bran to enquiring about the psychosocial aspects of the condition. Doctors’ informal private theories may be quite different from the more official doctrines of published reviews and textbook summaries of research on IBS,18–22 but they formed the basis for the ‘rules of engagement’ governing their relationship with IBS patients. It is thus vitally important that private views are recognized and acknowledged, given that they may be far more influential in determining doctors’ behaviour than publicly acceptable views.

These informal theories and views about IBS are especially important in understanding the ways in which doctors perceive IBS patients. The study demonstrated that it would be wrong to characterize doctors as being universally hostile towards IBS patients, although some gastroenterologists may express more negative views. IBS was certainly a source of frustration for many doctors, but this appeared to be fuelled as much by the absence of effective treatments and poor medical understanding of the condition as by the perceived personality characteristics of IBS patients. It is important to note that several doctors were reluctant to accept a negative stereotype of patients, and felt that IBS was inappropriately understood as neurotic in origin.

Many doctors in fact distinguish between ‘good’ and ‘bad’ IBS patients, rather than being ill-disposed towards all or any IBS patients. Earlier qualitative work in accident and emergency departments23 and other settings24 has shown how patients are characterized by staff into such categories, and that these categories have consequences for how patients are managed. IBS patients who are ‘good’ may be protected by doctors’ strategies or implicit ‘rules’ for dealing with IBS patients, but IBS patients who are ‘bad’ violate these rules and they therefore risk experiencing medical hostility by activating a ‘heartsink’ reaction. Doctors who experience this reaction are likely to feel helpless in the face of a demand for a medical resolution which is not currently within their power to offer.25

**Patients’ views**

There was a tendency for IBS patients to be unhappy with their relationship with the medical profession. Patients were unaware of doctors’ rules of engagement for the conduct of the doctor–IBS patient relationship and, since these rules drew so heavily on experiential, personal knowledge, they were very difficult to elicit. Patients who were reasonably content were those who, usually unknowingly, obeyed the rules set by their doctors: they accepted their diagnosis, came to an accommodation with their condition and did not demand further investigations or treatment. These ‘good’ patients were helped to comply with the implicit rules by doctors who encouraged them to feel that they had been taken seriously and that they had been helped to maintain control over their IBS.

Patients who might be deemed ‘bad’ by doctors, on the other hand, transgressed the implicit rules laid down by doctors. These patients perceived IBS as having a very negative impact on their quality of life, but ‘pushing’ for referral and investigations, finding it hard to accept that there was ‘nothing wrong’ and continuing to complain of severe and troublesome symptoms meant that they unwittingly placed themselves at a disadvantage. Their behaviour resulted in them being labelled as neurotic: because their symptoms were ‘all in the mind’, they felt that their fears were ridiculed, their symptoms were trivialized and the search for relief from symptoms was transferred from the medical profession back to them. The transformation of a failure of medical science to find an explanation for their symptoms into a personal failing on the part of patients meant that many patients felt deeply stigmatized and let down by the medical profession. Patients wanted a legitimate medical explanation for their symptoms, and to be offered effective treatments rather than a confusion of opinions.

**Conclusions**

IBS represents a significant demand on health service resources and is often a source of frustration for both doctors and patients. The reasons for this frustration lie in the ambivalent and poorly understood status of IBS as a disease category and the absence of universally effective treatments, which encourage doctors to evolve their own personal, experientially based views about IBS. Recognition of the impact of medical views on patients, including an understanding of the significance of the label of ‘neurosis’ for IBS patients, is essential in building successful doctor–patient partnerships. The adoption of a more all-encompassing view of the aims of medical services,25 and acceptance of the need to provide ‘empowering’ explanations26 that encourage patients to see IBS as a legitimate disease for which a clear pathogenesis has not yet been found, could offer a way forward.
References