GPs’ explanatory models for irritable bowel syndrome: a mismatch with patient models?

Rachel E Casiday, APS Hungin, Charles S Cornford, Niek J de Wit and Mwenza T Blell


Background. Inconsistencies in doctors’ views about causes and treatment of irritable bowel syndrome (IBS) lead to frustration for doctors and in doctor–patient interactions. Diagnosis by GPs does not correspond well to established diagnostic criteria.

Objective. To understand GPs’ explanatory models (EMs) and management strategies for IBS.

Methods. Qualitative, semi-structured interviews with 30 GPs (15 from the UK and 15 from The Netherlands).

Results. Diagnosing IBS in primary care is a complex process, involving symptoms, tests, history and risk calculation. GPs were uncertain about the aetiology of IBS, but often viewed it as a consequence of disordered bowel activity in response to stress, which was viewed as a function of people’s responses to their environment. GPs tend to diagnose IBS by exclusion, rather than with formal diagnostic criteria. They endeavoured to present the IBS diagnosis to their patients in a way that they would accept, fearing that many would not be satisfied with a diagnosis that had no apparent physical cause. GPs focused on managing symptoms and reassuring patients. Many GPs felt that patients needed to take the responsibility for managing their IBS and for minimizing its impact on their daily lives. However, the GPs had limited awareness of the extent to which IBS affected their patients’ daily lives.

Conclusions. GPs’ diagnostic procedures and EMs for IBS are at odds with patient expectations and current guidelines. Shared discussion of what patients believe to be triggers for symptoms, ways of coping with symptoms and the role of medication may be helpful.

Keywords. Explanatory model, GP perception, irritable bowel syndrome, primary care, qualitative.

Introduction

Irritable bowel syndrome (IBS) is an important problem in primary care, with approximately half of all patients seen with gastrointestinal symptoms in general practice suffering from IBS or other functional illness.1,2 There is considerable disagreement between diagnostic criteria,3 and GPs’ diagnoses of IBS do not correspond well to the consensus-based Rome criteria and other published diagnostic guidelines.4,5,6 The cause of IBS is largely unknown, though a number of underlying mechanisms have been proposed, including hypersensitivity, abnormal brain activation from painful stimuli, altered colonic motility, intolerance of specific foods, inflammation and psychological factors and the possibility of overlap with coeliac disease.

Current consensus recommendations for treating and managing IBS emphasize education and support, dietary modification and sparing prescription of drugs including antispasmodics, laxatives, antidiarrhoeals and in some cases antidepressants.6,7,8,9 However, there is limited evidence for the efficacy and tolerability of therapies currently available in Europe for the treatment of IBS.10 Psychological treatments, including cognitive behavioural therapy (CBT), may be of value in some patients with IBS.6,11 The lack of
effective treatment options makes IBS a frustrating condition for doctors and patients alike, with many GPs describing IBS as an ‘unrewarding’ condition to treat.12

Given the empirical ambiguity about the nature and aetiology of IBS and the high frequency of consultation for IBS in primary care, it is important to understand the models that practitioners employ to explain the condition to themselves and to their patients. Explanatory models (EMs) for disease are notions about an illness addressing such questions as aetiology, pathophysiology, illness course and treatment.13,14 Some work has begun to shed light on doctors’ EMs of IBS. A survey of views of GPs and patients with IBS showed agreement about the symptoms but differences in beliefs about aetiology and management.15 One qualitative study found that doctors hold a ‘public’ definition (derived from textbooks) and a ‘private’, sometimes pejorative, definition of IBS.12 They distinguished between ‘good’ and ‘bad’ IBS patients and managed them accordingly. Inconsistencies in doctors’ views about the causes and treatment of IBS led to frustration for doctors as well as in doctor–patient interactions. There remains a current knowledge gap about GPs’ views of the factors responsible for IBS and treatment strategies.

We undertook a qualitative study in the UK and The Netherlands aiming to elucidate GPs’ EMs and management strategies for IBS.

Methods

Interviews were conducted with 30 GPs (15 from the UK and 15 from The Netherlands). The Netherlands were chosen alongside the UK because of similar structures of primary care, with GPs in both locations providing general medical care, and because of our prior links in collaborative research. This was important because we needed to conduct this qualitative research in settings which would not pose fundamental variations in data collection and analysis.

Given the qualitative study design, we followed a purposive sampling strategy to maximize representation of age, gender, practice size and relative affluence of patients in the practice. The total sample comprised nine female doctors (UK two and Netherlands seven); mean span since qualification in the UK sample was 20 years (range 10–28 years) and in The Netherlands 21 years (range 6–33 years).

A semi-structured interview protocol was developed for use in both countries, covering understandings of the underlying pathology and causes of IBS, diagnosis, management and treatment and views about the impact of IBS on patients’ lives. The interviews were held in the doctors’ surgeries and lasted 30–60 minutes. The interviews were recorded and transcribed for qualitative analysis. Interviewing continued until theoretical saturation was reached.

Following a modified grounded theory approach,16 we simultaneously undertook the complementary processes of coding and categorization of data and developing analytical questions and a conceptual framework. The grounded theory approach was modified insofar as themes were identified both as emergent from the data and in response to a priori research questions. Data analysis took place over four stages: (i) preliminary identification of key themes and data categories, conducted independently by the two research teams by reading transcripts and generating codes whenever new concepts emerged; (ii) halfway through data collection, meeting of all the researchers to agree categories and a provisional thematic structure; (iii) coding of transcripts using NVIVO version 2.017 (a software package to aid qualitative research) to identify passages relevant to the agreed categories, with passages relevant to each theme read and reread in relation to one another and to their individual contexts, seeking both to confirm and to identify counterexamples for emergent findings; and (iv) summary of findings under each heading by the two research teams and final meeting to compare findings and develop the theoretical, conceptual and explanatory frameworks that now lie at the heart of this paper.

Findings

Aetiology of IBS

GPs defined IBS as a combination of symptoms with no explained organic cause, focusing on changed defaecation pattern and abdominal pain. Many described the condition as a defect of the bowel, referring to the organ as ‘angry’ or ‘disordered’ in its reaction to stimuli such as food and stress. GPs in both countries frequently used squeezing gestures to depict the abnormal motions of the IBS bowel.

It is a normal bowel but for some reason it just decided to misbehave, is the sort of understanding I have of it. Even if you were to analyse the bowel and do a biopsy of you wouldn’t be able to find very much wrong with it but for some reason it malfunctions, so produces areas of bowel that are obstructed and other areas that have become distended, possibly as a result of the constriction in other areas. (UK O)

I think IBS is a wrongly programmed bowel that reacts over sensitively to all kinds of stimuli. A kind of hyperactivity as can exist in the lungs. (Netherlands A)

Most doctors realized that they did not know what causes IBS, although they named factors they
associated with the disease. Stress and tension were named by every GP but the exact relation was unclear. British GPs also named infection, food and travel. Dutch GPs mentioned smoking, caffeine, diet, ‘hasty lifestyle’ and lack of exercise. These factors were typically seen as aggravators rather than underlying causes.

The putative psychosomatic nature of IBS was particularly important in the GPs’ accounts. Some spoke of disordered bowel motions as a natural response to stressful situations, noting that ‘exam nerves’ can trigger diarrhoea even in people without IBS. Most viewed their patients’ strategies for coping with stress as more important than the stressful event itself. In other words, ‘stress’, as it relates to IBS, is an attribute of the person rather than the environment. Some British GPs alluded to ‘a certain type of person’ who suffers from IBS: female, a worrier and a complainer. One Dutch GP described IBS as a way for people to deal with stress.

I think IBS occurs more often in people with a high level of aspiration who have the tendency to ignore their body and feelings. People who are not always aware of what emotions and feelings can do to them. They just keep running and never stop to feel. It can be very busy people who are taken by surprise by the IBS. They often ignore themselves a bit. (Netherlands M)

Many GPs felt that patients did not recognize the role of stress in their IBS and were at great pains to validate the patients’ suffering while persuading them that there was no serious physical problem to treat.

The weird thing is that some patients say that their complaints have nothing to do with stress. Often the connection is not immediate but the complaints develop after a stressful period or event. Not like people who get an immediate headache during a stressful event. (Netherlands C)

You have to get patient to accept that they have a psychosomatic illness, which can be difficult. (UK B)

**Diagnostic processes**

GPs did not typically use positive diagnostic criteria for IBS, but rather spoke of a ‘diagnosis of exclusion’ after ruling out serious conditions (by screening for ‘red flags’). Blood tests were sometimes used to rule out other illnesses, as were specialist referrals. Although the GPs usually carried out at least some form of physical examination, several expressed uncertainty about when to perform additional tests.

When asked about positive diagnostic criteria for IBS, most GPs were aware that such criteria existed but were unable to list them. Despite their unfamiliarity with the diagnostic criteria for IBS, most GPs were comfortable with their diagnoses. Although they admitted that there is always some fear of missing a serious illness (and a few could point to instances when this had happened to them), they generally felt confident that they minimized the likelihood of this by performing tests to rule out other concerns.

RC: Do you ever have any worries about the patients that you think have IBS, whether it should have been diagnosed as something else?

GP: If I have that worry I usually act on it so I try not to go home with any of it. (UK O)

Some doctors relied on particular symptoms to confirm an IBS diagnosis; for example, several indicated that an alternating bowel habit (as opposed to constipation or diarrhoea alone) was necessary for an IBS diagnosis. GPs also spoke of certain ‘triggers’ that suggest the type of patient likely to suffer from IBS: female sex, episodic complaints and frequent consultation (especially for complaints like headache and fatigue).

**Treatment**

In line with current recommendations, GPs said their chief concern in dealing with IBS patients was explaining the condition and reassuring them that they did not have a life-threatening disease. They offered simple and non-specific explanations, describing the gut as sensitive or disordered motion and sometimes sought to ‘match up’ their explanations with the patients’ own experience.

So you know it’s the old GP thing by exploring ideas, concerns and expectations that is trying to sort of figure out before you launch into an explanation that might completely miss the mark for what that person’s concern is . . . so I think any explanations to my mind have to take into account what their existing health problems are, what do they think is going on. (UK B)

However, the GPs claimed little knowledge of their patients’ views about the causes of IBS and took few steps to elucidate the patients’ understandings and experiences of IBS. One doctor used IBS as a trigger for more general health education in advising patients about healthy diet and bowel maintenance. Doctors described as ‘challenging’ those patients who were ‘in denial’ about the nature of their IBS and insisted on trying to find an organic cause for the condition.

Patients will vary enormously in their reactions to being told that the underlying mechanism for this may well be stress related and for some patients that’s a conflict and for others then great denial will kick in and they will continue to pursue an
organic route, choose another doctor, seek another opinion, who feel very uncomfortable with that notion that their body is telling them that for all they may feel in control of things actually life isn’t quite as hunky dory as are wanting to present to the world and they will be uncomfortable with that. (UK R)

Generally, the doctors viewed treatment for IBS as a trial-and-error process. GPs pointed out that different patients have different needs, and so some focused more on reassurance and others on finding a treatment that would alleviate symptoms. They assumed that non-returning patients no longer felt ill. Returning patients were offered further reassurance, different medication and occasionally further tests or specialist referral. The inability to treat IBS more definitively was a source of great frustration.

I think in general it’s not too difficult but there certainly are some who we don’t seem to satisfy their hope and they can be naughty. They might be one of the small numbers that might get referred. (UK D)

The role of dietary advice was notably different between the two countries. British doctors were sceptical about diet, believing that it made little difference, because patients’ own accounts of their ‘trigger foods’ varied so much and appeared to lack empirical grounding. However, they recognized that dietary changes did help certain patients and sometimes encouraged patients to try modifying their diets, particularly to incorporate more fibre. Some British GPs mentioned ‘elimination diets’, but felt that they were too difficult for patients to follow. In The Netherlands, by contrast, dietary and lifestyle advice play an important part in the advice GPs said they gave IBS patients. Components of this advice include eating regular, healthy and high-fibre meals, drinking plenty of fluids and managing stress appropriately.

Most GPs in both countries prescribed fibre for patients with IBS, but drug prescription practices varied between the two countries. British GPs readily prescribed a variety of medications, changing to others when patients continued to complain of IBS symptoms. Dutch GPs said that they prefer not to prescribe any drugs unless requested by the patient, and even then for a limited period, mainly because of the lack of scientific evidence for their efficacy. The Dutch GPs claimed to tell their patients that the drugs are not proven to work, but that some people seem to benefit from them.

Depending on which way the symptoms go you might have to vary your management a little bit now and then. I mean if someone has diarrhoea I would probably give them something to stop the diarrhoea and if someone has constipation I would probably give something else like a laxative to try and get their bowels moving a bit. (UK C)

I think there is not much you can offer patients treatmentwise except a good explanation and trying to reassure them. Of course people often want something for their complaints and sometimes I get seduced into giving them something although there is hardly any proof that it works. Of course, I always try to give lifestyle advice like eat healthy, regular and meals rich in fibre but I often have a need to give them something extra. (Netherlands G)

GPs in both countries mentioned psychological treatments like CBT as potentially useful for IBS. None of the British GPs had actually used such treatments, but Dutch GPs did sometimes refer patients—particularly those who continually worried or struggled with their IBS—to a psychologist for CBT. The GPs tended to be dismissive of IBS self-help groups, suspecting that they would make IBS worse by prompting patients to dwell on their symptoms.

GPs’ perceptions and expectations of IBS patients

GPs indicated frustration with their inability to explain the pain of IBS physically or to alleviate it. They implied that this negative view was sometimes transferred to patients, particularly those who consulted frequently. Some GPs distinguished between ‘rational’ IBS patients (for whom there was likely to be some physical cause) and ‘anxious’ patients (for whom no physical cause was likely to be found).

I think given the same level of bowel and distension, different people come out with different stories and different people in different frames of mind come out with different stories. So I guess I think I have to say I have some anxiety patients for whom difficult passings are undoubtedly part of anxiety and some that are perfectly rational people who clearly get belly ache. (UK W)

Many GPs suggested that the impact of IBS varies among individuals, depending on attitudes and circumstances, and thus stressed the importance of reassuring patients that their disease is not life threatening. The most difficult part of living with IBS was seen to be its unpredictability: a patient may be fine for weeks or months and then suddenly experience the pain again, triggering worry in the patients.

I never ask my patients about their quality of life. I’m sure it will have an influence. Patients who visit my practice have a problem and therefore a diminished quality of life. (Netherlands P)
I think patients can really suffer from IBS. But it differs from one patient to another. There are patients whose complaints are minor but there are also patients who can suffer really severe episodes and who can’t go to work during those episodes. (Netherlands C)

Thus, GPs often felt that their patients’ own attitudes or behaviour were the chief problem with IBS. Indeed, when GPs expressed ‘negative’ attitudes towards IBS patients (or towards ‘certain’ IBS patients), their management strategy focused on convincing the patient there was nothing seriously wrong. Sometimes this took the form of offering investigative testing that the physician may consider unnecessary, in order to reassure the patient that all possibilities had been explored, but more commonly GPs emphasized explaining to their patients why no further tests were needed. After the initial reassurance and trying some medications, diet or lifestyle modifications, they had little to offer patients in the way of treatment. They often gave ‘the problem’ back to the patient, suggesting that they have to learn to live with it. Some GPs in the Dutch focus group suggested that for frequently returning patients it is important to make clear that the patient, not the GP, is the holder of the problem, although responsibility for treatment is held jointly by the patient and the GP.

It’s one of these diagnoses no one does much with and even lay people are well enough aware and live with it and get on with it and smile. And eventually they have to decide whether their glass is half full or half empty. If it’s half full you don’t see them again but if it’s half empty, they’ll be back. (UK W)

I usually explain to the patient who is having a lot of complaints, ‘OK, I can give you something for the time being that will reset the balance but I can’t do this forever, eventually you have to do something about the cause yourself’. (Netherlands E)

Discussion

The study was conducted within two systems of health care which are broadly similar in organization and delivery, e.g. with regard to the primary–secondary care interface and referral systems. The study necessitated data collection and analysis in two languages but regular international team meetings ensured that differing linguistic expressions were explored and that the analysis, while retaining national context, followed a coherent, common approach. We believe that this process helped to capture outcomes as accurately as possible given the two national settings. The use of the semi-structured interview process allowed prior concepts to be explored and left open the ability to uncover new perceptions. Reliability was enhanced through respondent validation whereby a sample of the participants provided feedback on the content and analysis.

To our knowledge, this is the first international study analysing GPs’ EMs for IBS. We conclude that although most GPs have a realistic understanding of current knowledge about IBS, the many unresolved questions regarding background and management have a negative impact on their attitudes towards patients suffering from IBS. Diagnosing IBS in primary care is a complex process, in which symptoms, tests, history and risk calculation all play a role.

GPs were uncertain about the aetiology of IBS, but often viewed it as a consequence of disordered bowel activity in response to stress. Stress was often viewed as a function of people’s responses to their environment rather than the environment itself, so that many GPs came to characterize IBS as affecting a certain type of person. This is in contrast with our finding in a study of patients’ EMs that IBS sufferers, while recognizing stress as an important contributor to IBS, viewed it as an attribute of their environment which they may or may not be able to control.

In contrast with current guidelines, GPs rarely used formal diagnostic rules, but rather use tests in an approach of diagnosis of exclusion. Part of this diagnostic workup is explained by the diagnostic uncertainty that GPs feel in the management of IBS-like symptoms. In addition to tests and history, they reported using patient characteristics (family history, psychosocial background and personality) in diagnosing IBS. GPs were at great pains to present the IBS diagnosis to their patients in a way that they would accept, fearing that many would not be satisfied with a diagnosis that had no apparent physical cause. By contrast, our study of patient EMs found that patients were not particularly concerned with the underlying aetiology of IBS, but rather with how to manage the symptoms and minimize its effect on their daily lives. As one patient in that study reported, ‘A diagnosis without a remedy, that’s not very useful’.

In line with current guidelines, the main focus of management was reassuring patients. Dietary and lifestyle advice and drug prescription patterns appeared to differ between the two countries, although the qualitative study design does not allow for a systematic comparison of IBS management strategies. Some GPs distinguished between rational and anxious IBS patients, corresponding to the good and bad patient dichotomy described by Dixon-Woods and Crichtley, but most expressed frustration with the condition rather than with the patients themselves. Many GPs felt that patients needed to take the responsibility for managing their IBS and for minimizing its impact on their daily lives. However, the GPs had
limited awareness of the extent to which IBS affected their patients’ daily lives. Likewise, they had given little thought to what their patients thought was the cause of IBS, other than to distinguish between those who were accepting of their diagnosis and those who demanded a more concrete explanation. Treatment of IBS would be helped by the availability of effective specific therapies.

Despite major advances in understanding of IBS and diagnostic approaches,5,6,18,22 this results illustrate the existing gap between current literature and real-world clinical practice, highlighting the need for better translation of research into general practice. A more provocative interpretation of the GPs’ and patients’ relative disinterest in understanding the aetiology of IBS is that academic research has been underinformned by an understanding of clinical and community practice ‘on the ground’ and that greater understanding of practitioners’ and patients’ concerns (as offered by this study) is needed to make future work more relevant.

This study has demonstrated the need for GPs to match their consultations better to the expectations of patients. Shared discussion of what patients believe to be triggers for symptoms, ways of coping with symptoms and the role of medication may be helpful. As indicated by the findings of this study and our complementary study of patient EMs,18 enhanced training for GPs about IBS may be useful, focusing on (i) effective management of symptoms and (ii) making GPs more comfortable with the diagnosis, recognition and sharing of IBS.

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