Patients’ explanatory models for irritable bowel syndrome: symptoms and treatment more important than explaining aetiology

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Background. Irritable bowel syndrome (IBS) is a common condition associated with no certain organic cause, though diet and stress are widely implicated. The condition is frustrating for both sufferers and doctors, and there are problems in diagnosing and treating the condition. Eliciting explanatory models (EMs) is a useful tool for understanding how individuals relate to their illnesses and their expectations for treatment, particularly for illnesses with uncertain aetiology like IBS.

Objectives. To understand the EMs, experiences and expectations for management of patients with IBS.

Methods. Qualitative, semi-structured interviews were conducted with 51 primary care patients (31 in the UK, 20 in The Netherlands) meeting the Rome II diagnostic criteria for IBS.

Results. Although IBS often had a significant dampening effect on daily life, IBS patients made great efforts not to allow the condition to take over their lives. Triggers of symptoms were more important to patients than understanding the underlying aetiology of IBS. Diet and stress were both recognized as important triggers, but views about which foods were problematic and the extent to which stress was modifiable were inconsistent. Diagnosis and treatment were often a confusing and frustrating process, and patients often expected more diagnostic tests than they were offered before receiving a diagnosis of IBS. However, the often poor outcome of medical interventions does not, in general, appear to have a negative impact on the patient–doctor relationship.

Conclusions. Clinicians should be aware of the extensive impact of IBS on sufferers’ daily life and the frustration that results from repeatedly trying treatments with little effect. Clearly explaining the guidelines for diagnosing IBS and the range of treatment options may help patients to make sense of the diagnostic and treatment processes. The personal EM should be addressed during the consultation with the IBS patient, ensuring that any successive medical interventions match with the patients’ disease perception.

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

Introduction

Irritable bowel syndrome (IBS) is a common condition, with an overall prevalence of 11.5% across Europe, varying from 6.2% in The Netherlands to 12% in Italy and the UK.\textsuperscript{1} It is a little understood condition entailing abdominal pain and changes in bowel habit with no certain organic cause. The condition is frustrating for both sufferers and doctors, and there are problems in diagnosing and treating the condition. A
Research methods

In all, 51 patients with IBS (31 British, 20 Dutch) were recruited from primary care networks in the UK and The Netherlands for interview. In the UK, recruitment was managed through two large general practice surgeries. A letter of invitation was sent to all patients meeting the criteria were randomly selected from the Utrecht University primary care network using the diagnostic search term ICPC code D93 (IBS) and invited to participate.

A semi-structured interview protocol was developed for use in both countries, exploring history of IBS complaints, diagnosis, effects on daily life and coping strategies, understandings of the nature of IBS and expectations for treatment. Interviews were held in participants’ homes and GP surgeries, lasting 30–90 minutes. Participants were given written information and the opportunity to ask questions before providing written consent. Interviews were recorded and transcribed for qualitative analysis. After the interview, participants completed the irritable bowel syndrome Quality of Life (QOL) questionnaire. Interviewing continued until theoretical saturation was reached.

The interviews were conducted in respective languages (English and Dutch), recorded and transcribed accordingly. Linguistic expressions and meanings at variance between the two settings were explored at joint team meetings and utilized within the respondents’ explanations so as to not lose meanings. The team meetings facilitated a common approach to the analysis between the two countries. Ethnic data or educational attainment level of participants within each country setting were not sought and the international comparisons, where they occur, are based on the two cohorts as a whole; differences between participants’ understandings and perceptions were drawn directly into the analysis.

Following a modified grounded theory approach, 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 2.0 (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. The analysis confirmed saturation after the first six or seven interviews.

Findings

Nine participants were male and 42 female, and participant ages ranged from 19 to 67 years with an average of 43 years. The IBS-QOL scores for the sample [UK: mean 61.9, (7.4–91.2), SD 20.4; The Netherlands: mean 73.6, (27.2–93.4), SD 18.7] indicated a reasonable QOL on average, but with wide variation between participants.

Consequences: impact of IBS on daily life

IBS complaints varied among participants in our sample but typically entailed abdominal pain and episodic diarrhoea and/or constipation. The impact on daily life also varied, with most describing the condition as an uncomfortable nuisance but a few being virtually housebound from pain and fear of a public accident.

I try to do the normal things even though my bowels are giving me trouble. I go into work and also attempt to do fun things. I don't want to be influenced by my IBS. If you are in pain and your stomach is giving you trouble then it is quite hard to just get on with things but I really try not to let it bother me. (Netherlands 2J)

Sufferers tended to adopt a stoic demeanour in order to get on with their lives without allowing the IBS to take over. Otherwise, the condition could become debilitating:

I dare not go out of the house on a morning to about dinner time or after because a couple of times I have had accidents in the street and its very embarrassing and the quality of life has gone. I don’t go out anywhere, I don’t go out. If I go down the town I have to have nothing to eat or drink the whole time I’m out. I have to wait until I come back to the house before I dare to have anything to eat or drink and to take my tablets in case I have an accident down the town or anything. (UK 2C)

Many sufferers complained of episodes occurring at awkward times, such as during holidays and at work. In addition to the difficulties negotiating sick days from work, some participants found burdensome the repeated costs they incurred for drugs and fibre preparations.

I have spent pounds and pounds on stuff to make me go but they have said a lot of them are addictive and make your bowel lazy. (UK 4C)

In terms of day-to-day activities and social life, the majority of participants claimed to ‘just get on with it’ despite their IBS. However, the need to take certain precautions—particularly ensuring ready access to a toilet at all times—did limit their activities. A number of sufferers noted that they do not travel long distances by car or train for this reason. Others said that their social life was somewhat limited because they could not eat certain foods.

I have got five in the family and they say, ‘Come on Mum we will go out for a meal,’ and it’s a shame to say, ‘Well, I can’t have this and I can’t have that and I can’t have the other,’ and I feel as though I am spoiling it for them, I don’t deliberately eat stuff that upsets me, only on special occasions. (UK 1S)

Most IBS sufferers, particularly in the UK, tended not to discuss the condition except to inform immediate family members and sometimes work supervisors and close friends and sometimes other IBS sufferers. Few had discussed with their doctors the full extent to which the condition hampered their daily lives. When asked why this was, they cited stigma around discussion of bowel habits in general, so by extension IBS was embarrassing; however, very few participants in either country felt any sense of stigma against them personally.

I was always used to doing so many different things. But now my body will tell me when I take on too much. I’ve got many limitations. I have to adjust to have a normal life but I accepted this. For me it is really important that nobody notices something. Otherwise I feel really forced. People can’t see on the outside what is wrong with me and I don’t talk about it. If it happens in a social situation I tell people I got a stomach bug and I leave. (Netherlands 15J)

Lingering fears of more serious illness were also important. Although most of the participants had been relieved to learn that their diagnosis was IBS and not cancer, a few continued to doubt the diagnosis.

Well you always worry that the doctors have got it wrong and it’s something much more sinister. As I said before, you read that many things about misdiagnosis and all of that, so yes I worry about cancer. (UK 6A)

Anxiety about the possible long-term effects of taking medication for IBS or of irregular bowel activity was also common.

Only that it [frequent constipation] might be doing damage and mainly because IBS is not that recognised. There’s not a lot of research into it and it might do something that they don’t know it does. It can be doing me damage because I’m
constipated. It’s not good for your insides not going to the toilet for 2 days and it could be doing damage in that way as well. I can’t take any laxatives because it says on the laxative packets not to take it for I.B.S. (UK 9C)

**Aetiology and onset**

Most of the sufferers had experienced IBS symptoms for many years, but they varied in terms of how long they had suffered prior to receiving a diagnosis of IBS. Often the onset of bowel problems was attributed to some event, such as pregnancy, an illness or an accident requiring strong pain-relieving medication. A few participants felt that IBS was simply a part of their personal make-up, such as the UK participant who described herself as ‘a constipated person since childhood’.

Most participants in this study had little to say about the underlying causes of the condition. When asked about causes of IBS, they responded in terms of agents that might provoke a flare-up of symptoms. Diet and stress were both cited by nearly all as the principal causes of IBS episodes. Sufferers could readily list their trigger foods, which varied greatly. Dairy products, wheat, citrus fruits and alcohol were frequently mentioned. Several had taken food intolerance tests in order to identify foods to eliminate.

Irregular food and a lack of fibre are two things that can really set off my complaints. If I take enough fibre I can notice it getting better. Eating regularly at exact times is very important. That also explains why it goes wrong on holiday because you eat more irregularly. In another country they also use other ingredients which can often give me constipation. (Netherlands 6J)

Notably, a number of other sufferers felt that fibre was a trigger for their IBS. This observation conflicted with doctors’ advice to eat a diet high in fibre and vegetables, and sometimes contributed to patients’ feeling that their doctors did not understand the condition or how to treat it.

I always eat lots of vegetables and fruit and they say bran, but if I eat bran it has the opposite affect. It just makes it worse even though I drink loads and loads of water. (UK 7C)

Stress, for the most part, was conceived in terms of discrete events rather than as a personality trait, i.e. IBS flares up during stressful times. In relation to stress, some sufferers also mentioned depression and found relief from their IBS by taking antidepressants; one UK participant said that she only has IBS during the winter when she also suffers from seasonal affective disorder.

Every time I have high stress levels, money problems, family problems then my IBS complaints appear in a big way. It is not just stress related but also when I take too much on, when I’m too busy. (Netherlands 20J)

**Diagnosis**

IBS symptoms were typically present for several years before they were formally diagnosed. Sufferers eventually approached their doctors for one of two reasons: concern that they had a more serious illness (particularly cancer), often triggered by a case of stomach or bowel cancer in a family member, or an awareness about IBS (usually from a magazine article or family member) prompting a desire for treatment to alleviate the symptoms.

I think it started about six years ago. The first time I consulted the GP I wanted to know if I didn’t have any scary diseases or something. It is just so painful. (Netherlands 11J)

So it wasn’t until I came to the doctors here and the doctor actually said to me, ‘Well, what do you think it is because it’s been there for a while,’ and I had mentioned to him that my auntie had I.B.S … I kind of felt that I had diagnosed myself to be honest. (UK 9C)

Whether they had approached the GP for reassurance or for alleviation of symptoms, patients tended to find the diagnosis of IBS a confusing process. In describing this process, they tended to focus on tests (e.g. colonoscopy) or lack of tests, but did not understand how their doctors had actually determined that their condition was IBS.

A few participants were not convinced that IBS was the right diagnosis or found the diagnosis to be unhelpful because they still could not find an effective treatment.

On the one side it has a name but on the other side it does not really help much. The complaints stay. It is not like ‘ok, we now know what it is, here is a pill or a prescription and it will all go away‘. There is no remedy. A diagnosis without a remedy, that is not very useful. At least it has a name and I’m not the only one who suffers from it. That reassures me a bit. (Netherlands 3J)

When I say I don’t feel too good they do this test and that test. Nothing wrong with you, that’s all they keep saying, nothing wrong with you, nothing wrong with you, but why do I feel ill inside if there’s nothing wrong with me? That’s what gets me. (UK 2C)

Others felt a clear sense of recognition upon receiving an IBS diagnosis and suddenly could make sense of their symptoms. Patients who had consulted because they worried about more serious illnesses found
the IBS diagnosis to be a relief, provided they were convinced that the diagnosis had been made on the basis of sufficient information.

**Treatment**

Even though nearly all the participants recognized the role of stress in IBS, few sufferers in the UK attempted to alter their lifestyles to decrease stress and relieve their IBS. Stress was something external to the sufferer, over which he or she had little control, so IBS became something they ‘just have to live with’. By contrast, a number of Dutch sufferers used the severity of their IBS complaints as indicators for when their lives had become too busy and stressful. When their complaints started playing up or became more severe, this was a signal to take a step back.

Busyness can set off my complaints . . . I mean I can deal with pressure and I don’t mind if things are busy but when I think ‘oh, I’m losing control’ even if it is for a minute. My work at the moment is very busy. We are reorganising and I work in the human resource department which gives me the job to decide who has to go and who can stay. That is very difficult and I notice that I have to take it easy a bit. I notice that immediately in my stomach. (Netherlands 12J)

Treatment of IBS was often frustrating, as it seemed to rely on an endless process of trial and error. Participants felt their suffering was unfair, especially when they took great care to follow medical advice and control their diet:

I am always on a diet and I eat plenty of fibre. I have Weetabix or porridge for my breakfast; I eat lots and lots of fruit. There isn’t a reason on this earth why I should be constipated, no reason on earth. (UK 4C)

On the other hand, some people expressed feelings of guilt about their IBS because they did nothing to treat it:

Maybe that’s what it is. I hardly drink any water. Maybe one or two glasses a day. I know they say you should drink at least six glasses a day but I tried that once. Maybe it’s the water. Maybe it’s the way my diet is. (UK 5C)

Although the qualitative research design did not allow for a statistical exploration of the relationship between patients’ frustration with their symptoms and their QOL scores, it is apparent that those interviewees who expressed the most frustration had experienced great impacts of IBS on their QOL and had found little relief in the treatments that they had been offered.

More members of the British than the Dutch sample were taking prescribed medication for their IBS, though patients in both countries adopted various strategies for using their medications: roughly half claimed to take them every day faithfully, while the others took them only as needed to cope with a flare-up. A few used their medication preventatively, for example, to pre-empt an episode when they indulged in a spicy meal. Patients also described the need to use their medication carefully to balance symptoms: taking too much was likely to ‘make you go the other way’ and be just as bad as no treatment.

In addition to the prescribed medication, self-management of IBS was very important for the participants in this study. Diet was a great consideration: as discussed above, most sufferers knew which foods would trigger an episode. They were careful to avoid these foods or, if they did indulge, to plan to be near a toilet the following day (often spending the day at home).

**Patient–doctor interaction**

Despite their confusion about the diagnostic process and their frustration with the lack of effective treatments available, most patients that we interviewed spoke well of their GPs. They were grateful when drugs helped to alleviate the condition, but even when the drugs did not work patients generally felt that the GPs were doing all that they could. Most were also grateful for the reassurance that their GPs could offer that the IBS was not a life-threatening condition:

Q: Once they did the examination and they found out it was I.B.S, how did you feel about that?

Chuffed to hell. It wasn’t of a serious nature so you put up with things. Likewise I am going to get the results and the blood and urine samples now and see how the medication is controlling things. It was good news. (UK 8S)

Some patients did feel that there had been too few tests performed to rule out serious illness. Others were frustrated that GPs appeared to blame them for the condition, not taking seriously their efforts to modify their diet or lifestyle. Furthermore, the GPs’ emphasis on reassurance sometimes led to dissatisfaction that the doctors did not understand how much IBS affected the sufferers’ day-to-day lives:

I don’t think they understand the condition. I have been before and I came to see a doctor . . . and I said it’s food related and he said don’t be so stupid what do you think you are talking about; I just turned round and said I’m the one that is suffering. If you read everything you get from doctors, it’s not food related. It’s that you need more fibre in your diet; it’s not; I think it’s to do with food. (UK 3U)
I told the GP that I did not find those sachets [Metamucil] a great success but he gave them to me again anyway and told me I had to continue with them for a bit longer. I went back a later time because it really did not help and then he gave me magnesium tablets which didn’t help either. Then I thought to myself that I didn’t want to take drugs every day anyway and I stopped with everything. I didn’t go back to my GP. We’ll see how things will go now. (Netherlands 4J)

The nature of physician–patient interactions did not necessarily appear to correlate to the severity of the patient’s IBS complaints. In many cases, patients with very severe complaints clearly stated that their doctors were ‘doing all they can’. The overall quality of the relationship and communication was generally more important to how patients spoke of their GPs’ management of their IBS than the success or failure to offer an effective treatment.

Discussion

Summary of findings

Although IBS often had a significant dampening effect on daily life, IBS patients made great efforts not to allow the condition to take over their lives. Such efforts included dietary and lifestyle modification, auto-regulation of medications and adopting a stoic demeanour to ‘just get on with it’.

The sample had a preponderance of females but no gender-associated differences were discovered.

Despite the often expressed feelings of guilt (that they had brought their symptoms on themselves) or of frustration (that, despite their best efforts, they still suffered from IBS), IBS patients generally maintained a reasonable QOL (mean IBS-QOL scores were 61.9 and 73.6 in the UK and The Netherlands samples, respectively). However, as has been demonstrated for other chronic conditions, IBS did entail serious re-orderings of daily life, which patients did not always reveal to their doctors, and high QOL scores may in some cases reflect the stoicism some patients displayed in dealing with their IBS complaints. Furthermore, lingering worries about cancer or long-term effects of IBS also detracted from sufferers’ QOL. Our qualitative findings give greater depth to recent survey results indicating that a significant percentage of IBS patients believe the condition turns into cancer and increases the risk of inflammatory bowel disease.

For IBS sufferers, triggers of symptoms were far more important than causes of disease. Participants had given little thought to the underlying aetiology of IBS, but viewed it as a long-term condition that was either a personal attribute or had appeared to begin with some discrete event in the past. As has been shown elsewhere, diet and stress were both recognized as important triggers, but views about which foods were problematic and the extent to which stress was modifiable were inconsistent between sufferers and sometimes also with standard medical advice. Although the scientific understanding of IBS pathology has advanced significantly, this knowledge appears to be of very limited importance to IBS sufferers. Although the reasons for this were not asked explicitly in the interviews, a likely explanation is that IBS sufferers do not perceive the current medical knowledge as contributing to effective relief.

This study examined patients’ EMs for IBS in a primary care setting. In general in this setting, poor outcome of medical interventions does not appear to have a negative impact on the patient–doctor relationship. Diagnosis and treatment of IBS were sometimes a source of relief, but more often a confusing and frustrating process. In particular, many felt that they should have had more tests. Dissatisfaction with the often unclear explanation by the GP and the lack of effective treatment may not be so much a criticism of the GP’s skills but rather the lack of current knowledge about IBS and the lack of effective treatments. In short, the dissatisfaction of the patient may primarily reflect the dissatisfying diagnosis, not the quality of communication. Our companion study of GPs’ EMs for IBS enables a comparison of patient and physician perspectives to understand more fully the nature of the doctor–patient interactions.

This finding differs from a study of IBS in secondary care, in which IBS patients felt they were labelled as neurotic by the medical profession and this difference maybe explained by differences between patients treated for IBS in primary and secondary care.

The international patient group in this study enabled a preliminary view of how cultural context informs IBS sufferers’ EMs. For instance, different views expressed in the UK and The Netherlands about the extent to which stress is a modifiable trigger of IBS may reflect broader cultural notions about stress and lifestyle. On the whole, the views and experiences in the two countries were more similar than different, and future cross-cultural comparisons of more divergent cultures than these (e.g. non-Western cultures) would be useful. The apparently greater use of prescribed medication in the UK than The Netherlands maybe an artefact of the different sampling strategies used in the two settings, as UK participants were initially identified by medications listed in their medical records.

Clinical implications

Patients’ expectations for diagnosis of IBS (relying on tests to rule out more serious diseases) were often at odds with clinical guidelines, which recommend diagnosis on the basis of symptoms rather than by exclusion. However, more recent evidence suggests that inclusion of absence of alarm indicators (e.g. age of
onset > 50 years, persistent daily diarrhoea, rectal bleeding, unexplained weight loss) with Rome II criteria increases diagnostic certainty and maybe more reassuring to patients if this is clearly explained.

Clinicians should be aware of the extensive impact of IBS on sufferers’ daily life and the frustration that results from repeatedly trying treatments with little effect. Explaining the range of treatment options and encouraging patients to return if their treatment is not helping may help patients to make sense of the trial-and-error process of IBS treatment. In addition, clinicians should be aware of and address concerns that patients may have about IBS causing long-term damage.

Patients care more about triggering factors than aetiology. Therefore, it is probably more efficient in daily consultation to invest in exploring personal disease triggers than trying to explain complex diseased pathways to the patient. Doctors should also be aware that—in the absence of clear pathophysiological explanations for IBS—the patients’ views of provoking factors and disease background are an important starting point for medical intervention, even if it may not seem rational to the clinician. Ideally, the personal EM should be addressed during the consultation with the IBS patient, ensuring that any successive medical interventions match with the patients’ disease perception.

A further implication of this research relates to the way in which the patient–doctor interaction is affected by the new mobility of both patients and clinicians across Europe. The fact that the Dutch and English patients’ perceptions of IBS and what they sought from clinicians was broadly similar supports the concept of a common understanding of this problem and, probably, the need for a management approach which is uniform across both settings. Whether this can be translated across to other countries and cultures is an interesting question.

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