

Patients' perspectives on their interactions with general practitioners in the context of cognitive behavioural therapy for refractory irritable bowel syndrome

A qualitative study

Abstract

Background

Previous studies have identified issues with the doctor-patient relationship in IBS, which negatively impact symptom management. Despite this, little research has explored interactions between GPs and patients with refractory IBS. National guidelines suggest CBT as a treatment option for refractory symptoms.

Aim

To explore perceptions of interactions with their GPs in individuals with refractory IBS after receiving CBT for IBS or treatment as usual (TAU).

Design

This qualitative study was embedded within a trial assessing CBT in refractory IBS. Fifty-two participants took part in semi-structured interviews at post-treatment.

Method

Inductive thematic analysis.

Results

Two themes were identified: Perceived paucity of GP's IBS knowledge and Lack of empathy from GPs, but acknowledgment this has improved in recent years. These perceptions were described through three stages of care: reaching a "last resort" diagnosis; searching for the right treatment through a trial and error process, which lacked patient involvement; and unsatisfactory long-term management. Only CBT participants reported a shared responsibility with their doctors concerning symptom management and an intention to reduce health-seeking behaviour. TAU participants reported a need for reassurance from doctors.

Conclusion

In this refractory IBS group, specific doctor-patient communication issues were identified. Increased explanation of the process of reaching a positive diagnosis, more involvement of patients in treatment options (including a realistic appraisal of potential benefit) and further validation of symptoms could help. This study supports a role for CBT-based IBS self-management programmes to help address these areas and a suggestion that earlier access to these programmes may be beneficial.

Introduction

Irritable bowel syndrome (IBS) is a chronic and relapsing disorder of the gastrointestinal tract characterised by abdominal pain, bloating and change in bowel habit. IBS is not explained by an organic abnormality and it is defined as a functional disorder (i.e. disorder of the gut–brain interaction). IBS affects between 10–25% of individuals in community samples and approximately 11% of the global population (1, 2). The national annual projected costs for treating IBS patients in the UK range from £45.6 to £200 million (3).

Current diagnostic criteria (4) and the National Institute for Health and Care Excellence (NICE) guidelines (5) encourage: 1) a positive diagnosis of IBS, minimising the need for unnecessary investigations after assessing “red flag” symptoms and relevant blood test results; 2) treatment concentrated in primary care, referring patients into secondary care only if “red flags” are identified; and 3) cognitive behavioural therapy (CBT) or psychotherapy for those patients who do not respond to medications and dietary/lifestyle advice after 12 months. CBT has been shown to decrease IBS symptom severity, improve quality of life and promote patients’ ability to cope with their illness (6, 7).

Previous qualitative studies have identified issues with the doctor-patient relationship, with patients perceiving doctors to show lack of empathy during IBS related consultations, dismiss or undervalue IBS symptoms, and provide insufficient information about the nature of the condition and symptom management (8-11). Patients from the UK described the diagnostic process as confusing and the lengthy search for successful medications as frustrating, affecting their trust in the National Health Service (NHS) (12, 13).

Although previous studies have interviewed long-term sufferers (12, 13), little research has explored specifically the interactions between primary care doctors and individuals with refractory IBS (i.e. ongoing symptoms after 12 months despite being offered appropriate medications and lifestyle advice). Patients with ongoing symptoms may be different in severity and beliefs, and are worthy of study. These patients can represent a particular challenge for doctors due to their poor response to treatments and frequent use of healthcare services (14). Hence, the identification of aspects that either promote or hinder these interactions can provide useful resources to GPs to communicate more effectively.

As described above, the available body of literature highlights insufficient person-centred care during IBS consultations. In contrast with this, CBT for IBS is based on an individual conceptualisation of the patient problems aimed to improve self-management of physical symptoms and stress, and promote a healthy lifestyle (15). Thus, exploring if CBT for IBS affects the attitudes of patients towards their GPs will generate insight into whether this approach has an impact on interactions with doctors in the context of managing refractory IBS.

The current qualitative study was embedded within a multicentre randomised controlled trial (RCT) assessing the clinical and cost effectiveness of CBT in refractory IBS (16). Participants were interviewed after having received one of three treatments: therapist-delivered CBT (TCBT) plus treatment as usual (TAU), web-based CBT self-management (WCBT) plus TAU, and TAU only. The aim of this nested study was to explore through qualitative interviews the perceptions that individuals with refractory IBS hold of the interactions with their GPs and how they view the impact of these interactions, after receiving either CBT for their IBS or TAU.

Methods

Design

Five hundred and fifty-eight participants were recruited into the broader RCT from primary and secondary care in the London and Southampton areas over 23 months (see (16) for details on the main study). Before entering the ACTIB trial (assessing cognitive behavioural therapy in irritable bowel syndrome), all participants completed an online consent form and agreed to be contacted regarding an interview at 3 months post-baseline (i.e. post-treatment) and one at 12 months. This study included all 3-month interviews.

The qualitative study was granted approval by the relevant NRES Committee on 11 June 2013 and the interview topic guide of the semi-structured interviews was approved on 4 February 2014 (REC reference: 13/SC/0206). The topic guide was developed collaboratively by the research team and it included open-ended questions to explore: participant experiences during the trial; participant experiences with past IBS treatments and the care received for their IBS; and participant emotional experiences (see Appendix 1 for interview questions and prompts). Participants' reports regarding their views of interactions with GPs emerged naturally while conducting the interviews due to the inductive nature of the analysis. Only data relevant to the current study aim were analysed for this paper.

Participants and recruitment

We approached sequentially via email 100 of the 558 participants in the ACTIB study. Fifty-two of the 100 invited agreed to take part; when one participant declined the invitation/did not respond, another person with similar characteristics was contacted to achieve a final sample with a mix of clinical and demographic variables (i.e. gender, age, ethnic background, geographical location, study arm, symptom severity and recruitment site). Analysis of the interviews, participant selection and data collection proceeded in an iterative process until data saturation was reached (i.e. no new themes emerged from the data and each theme was refined within a diverse sample).

Overall, 52 interviews were conducted by two members of our research team; ten face-to-face and 42 over the phone based on participants' preferences. Data collection lasted between September 2014 and July 2016. Interviews were digitally recorded, transcribed verbatim by a professional transcriber, and anonymised. Interviews lasted between 23 and 116 min (mean = 56 min).

Data analysis

An inductive/data-driven thematic analysis was conducted (17-20) to identify themes in the data, rather than applying a pre-existing theoretical framework. Table 1 contains a detailed description of the analytical steps implemented (21-23). NVivo 11 software was used to facilitate data management and increase the transparency of the findings.

The researchers worked within a contextual constructionist epistemology, which sustains that individuals interpret the world within particular cultural values and meanings (24, 25). Researchers following this epistemology ground the findings in the participants' actual descriptions and triangulation is used to get a fuller picture to increase the validity of the analysis (26). In the current study, a combination of perspectives from different disciplines (i.e. medicine, health psychology) enriched the interpretation of the findings by the research team.

Results

Table 2 shows that the three trial groups had a similar number of participants and comparable demographic and clinical variables. This mix of characteristics within each group and of the overall sample was achieved through purposive sampling. The baseline symptom severity mean scores (27) show that on average participants had moderately severe IBS symptoms. There were no significant differences between those participants who took part in the qualitative interviews and those who did not respond (see Appendix 2 for results).

Overall description of main themes and sub-themes

Frustration and helplessness were identified as the main emotional responses elicited by at least half of the interviewees. These emotions seemed to link to two key themes: 1) Perceived paucity of GP's knowledge of IBS and its treatment and 2) Lack of empathy and support from doctors.

The perceived paucity of GP's knowledge was described in the context of three main stages in participants' experience of IBS:

- reaching a diagnosis of IBS (IBS as a “last resort diagnosis”, lack of informational support);
- finding the right treatment, defined as an exhausting trial and error process lacking patient involvement and significant symptom improvement;
- long-term management, mainly focused on the notion that long-term sufferers know more about IBS than doctors, although they still need to receive reassurance.

Differences between participants recruited from primary and secondary care were not identified. The themes and sub-themes are summarised in Figure 1 and described in detail below, paying particular attention to the differences between the CBT and the TAU groups.

Theme 1: Perceived paucity of GP's knowledge of IBS.

Sub-theme 1a: During the diagnostic phase.

“IBS is a last resort diagnosis.”

The fact that an IBS diagnosis was reached by the presence of specific physical symptoms, the assessment of red flags and, in several cases, the exclusion of organic problems through diagnostic tests, was often perceived by participants as the result of lack of understanding of the real physical cause triggering their symptoms, a “last resort diagnosis.” Interestingly, patients were not aware that these steps followed by many GPs were necessary to reach a correct diagnosis, according to national guidelines.

“Because I know that the doctors can't find anything else wrong with you, so what they put on your results is IBS. And I find that really irritating that they sort of call it that as a last resort.” (38591, TAU, female, diagnosed in 1999)

“You're in hospital, you've got a camera shoved up your bum and then the doctor says, ‘no, it's just classic IBS symptoms’, then you kind of think that's just a term they use when they haven't got any other diagnosis.” (21339, WCBT, female, diagnosed in 2008)

"I had an endoscopy to check if I had Crohn's disease and I didn't. So they were pretty much like 'well, there's nothing particularly wrong with you.'" (20071, TAU, female, diagnosed in 2009)

Lack of informational support.

Interviewees from all groups felt that GPs provided little to none informational support after giving a diagnosis of IBS, often leading to a lack of acceptance of the received diagnosis.

"I was just desperate [...] I didn't feel that I was getting enough support from actual GPs. I didn't want to accept that I had IBS because my GP was telling me that I had IBS, but he actually failed to explain to me what it meant and how it would affect me." (10074, WCBT, female, diagnosed in 2013)

"I haven't had a lot of feedback from my doctor about it or advice from them [...] You would be given a prescription at the doctor's and you're given, maybe, a bit of paper that tells you what it is, but that is it, you've got to go off yourself and do your own research to find out about it." (21049, TAU, female, diagnosed in 2011)

CBT participants frequently reported how the information provided during therapy session(s) increased their understanding of IBS. Self-learning supported by the CBT programme appeared to promote an improved sense of control over symptoms (discussed in "Shared responsibility with doctors").

"Every time I've been to the GP, he just says 'oh you suffer from IBS', but nothing explained. So reading the sessions [...] has been really good because it removed that anxiety about IBS. It is completely new information that you read [...] an alternative way to manage the symptoms." (38910, TCBT, male, diagnosed in 2010)

"I found [CBT] helped me understand what's going on, both from a physiological and psychological side of it, as well as dealing with the symptoms." (25044, TCBT, female, diagnosed in 2004)

Some CBT participants acknowledged that time constraints during GP consultations led to poor provision of informational support. These interviewees suggested that offering patients earlier access to the CBT programme could actually help GPs to promote patient understanding about IBS and management options.

"I don't believe GPs have enough time to deal with the various issues that the study has addressed. I think that it should be an integral part of the service offered to patients with IBS." (10074, WCBT, female, diagnosed in 2013)

"So everything that we worked through in the first section, I think it would be great if doctors could start sort of mentioning that. Or if there were guidance sheets on a website that you can look up. You could work through those sorts of things yourself." (24547, TCBT, female, diagnosed in 2005)

Sub-theme 1b: Finding the right treatment.

"Trial and error process"

Several participants reported anger or frustration when trying different unsuccessful treatments for their IBS, particularly soon after the diagnostic phase, describing this iterative phase as

an exhausting “trial and error process.” Frequently, this process was perceived as the result of lack of medical knowledge from their GP as opposed to a necessary transition phase to find the right fit for them. GPs did not seem to discuss the fact that there is no “one size fits all” treatment.

“I was actually expecting it to work, because it had been prescribed by the doctor I had assumed that they would know what they were prescribing me and that it should work [...] I was quite livid [...] I tried quite a few things, if the doctor can't get it right – what hope have I got.” (20071, TAU, female, diagnosed in 2009)

“I think it's a trial and error. From my experience of doctors, with IBS, they will prescribe you something, then that's it [...] Then you go back and you say it didn't work, so they try something else.” (25119, TCBT, female, diagnosed in 2014)

Poor tailoring and patient involvement.

The absence of a tailored treatment seemed to have a detrimental effect on the active role of patients during this phase. Furthermore, participants often felt that GPs prescribed medications without sufficient explanation of how these might work.

“If a GP doesn't know how to deal with it and just sends me away, what am I supposed to do? It's kind of like trying to drill down into what is for that person.” (45322, WCBT, female, diagnosed in 2004)

“A lot of doctors want to put you in one box and treat you for one specific thing, they don't look at you as an individual, they say ‘oh, you take that medication’.” (45017, TAU, diagnosed in 2007)

Shared responsibility with doctors.

CBT seemed to promote a sense of shared responsibility with doctors in terms of their IBS management. Specifically, CBT participants felt capable of coping with their IBS symptoms in a more independent way compared to individuals from the TAU group, who still relied on their doctors to look for ongoing solutions.

“The next phase for me would be to go back to the doctor, see a different doctor to get a different take on it.” (29998, TAU, male, diagnosed 2014)

“And I think the difference the CBT can make is that if we really learn to change our bad habits, it can be forever. We can control the problem always.” (40496, WCBT, female, diagnosed in 2015)

“You can go to the doctor, they could do lots of different things but at the end of the day, you've got to do it for yourself. That's one thing that this study has actually made me do is I've been in control at all times. I've been able to take charge of my own learning.” (28570, WCBT, female, diagnosed in 2002)

More importantly, a few participants explicitly reported that the CBT received during the trial had changed how frequently they intended to consult their GP. A sense of empowerment appeared to be the main reason underlying the patients' intentions.

“It's a solution which is always in your mind and it will help cut the cost to the health service, which are too high, let's face it. We've all got to do our bit to try not to go to the doctor's so many times [...] I revert to everything I've learnt, instead of going to the doctor.” (20822, TCBT, female, diagnosed in 2013)

Sub-theme 1c: Long-term sufferers know more than doctors.

Participants who labelled themselves “long-term sufferers” usually expressed the belief that they had more knowledge about IBS symptoms and their management compared to GPs and consultants. Despite this perception, participants from the TAU group tended to report seeking for reassurance from doctors, whilst CBT participants reported receiving reassurance when discussing their symptoms with a therapist or when reading the content of the programme.

“I really lost total confidence with my first GP [...] As a long time sufferer with several GPs I've been through quite an exhaustive list of things that I can do [...] often to the point where I feel I've known more about it than my doctors [...] I've seen two consultants– it's reaffirmed what I know.” (20774, TAU, male, diagnosed in 1999)

“And when I was saying to [therapist] about symptoms, he was sort of very reassuring.” (28849, WCBT, female, diagnosed in 1987)

“I think the CBT course can be quite reassuring; that's why I've downloaded things.” (29023, WCBT, female, diagnosed in 2000)

Theme 2: Perceived lack of empathy and support from doctors.

Sub-themes 2a and 2b: “IBS is not serious” and “Just get on with your life.”

Regardless the length of the diagnosis, interviewees from all groups reported that GPs tended to embrace a dismissive and distant attitude during consultations due to the functional nature of IBS and the poor understanding of the actual impact IBS has on patients' quality of life.

“I went to see my GP, they just dismissed all my symptoms and just said I just need to learn to live with it, get on with my life, even though it was like absolutely devastating, my whole life was like falling apart.” (40024, TAU, male, diagnosed in 2013)

“I think basically the biggest frustration was being [ignored] about your own symptoms– I mean it took a good six years to find a doctor that didn't.” (33561, WCBT, female, diagnosed 2003)

Some long-term sufferers from all groups reported a positive shift in doctors in recent years in terms of the empathy shown during IBS consultations as well as an increased validation of their symptoms.

“I feel medical science is gaining awareness of it. Going back 10 years ago, I don't think it was treated by GPs seriously at all.” (20774, TAU, male, diagnosed in 1999)

“My experience of GPs has been mixed. The first GP I went years ago didn't seem to think it was that big an issue [...] The most recent GP was very good and she was very sympathetic...” (16045, TCBT, female, diagnosed in 2003)

Discussion

Summary

Two main themes emerged from exploring the views of patients with refractory IBS: perceived paucity of GPs' knowledge of IBS, and perceived lack of empathy and support from doctors. These negative perceptions seemed to be present during the entire patient journey and impacted on patients' beliefs and expectations of their IBS and its treatment. Participants reported feeling frustration and helplessness as they neither understood their condition, nor experienced significant symptom relief. Despite these negative experiences, participants from all groups recognised a positive shift in recent years in terms of empathy shown by doctors. Differences were identified between trial groups. Only CBT participants reported a shared sense of responsibility with doctors concerning symptom management. Some mentioned how CBT shaped their intention to reduce future healthcare seeking behaviour as they felt more capable of coping with their IBS. Only TAU participants tended to report needing reassurance from doctors. Participants from the CBT groups suggested that offering CBT self-management to IBS patients sooner after the diagnosis could function as a valuable option for GPs to provide additional information regarding the condition and potential treatments, reassurance and resources to self-manage symptoms (see table 3 for a summary of main findings and differences between groups).

Strengths and limitations.

To our knowledge, this is the first interview study, with the largest sample of individuals with refractory IBS, to explore perceptions of interactions with GPs. Our systematic qualitative methodology had strong purposive sampling, a robust audit trail, good coding rigour and various perspectives in data interpretation. This rigorous analysis enhances validity and transferability of the findings.

It is worth noting that participants for this study had refractory IBS and had volunteered to take part in a CBT trial. Furthermore, participants were recruited from both primary and secondary care and possibly differ from a pure GP population. This group of individuals with refractory IBS is important to study due to their ongoing symptoms and use of healthcare resources, but they may hold different views compared with patients with non-refractory IBS. Lastly, the sample was mostly composed of White British females, which resembles the sample recruited to the main trial.

Comparison with existing literature.

Our findings resonate with previous qualitative research conducted with both individuals with IBS (11, 28, 29) and GPs. Studies have found that most interviewed GPs conceive IBS as a diagnosis of exclusion (as opposed to a positive diagnosis) and that they infrequently ask their patients about their understanding and experiences of IBS (30-32). The present findings expanded on prior research by: 1) providing insight into the elements that contribute to the negative perceptions individuals with refractory IBS hold of their interactions with their GPs, particularly in terms of GP's knowledge of IBS; 2) demonstrating understanding of how these perceptions are shaped during each stage of care; and 3) exploring how CBT focused on self-management for IBS can affect the attitudes towards GPs.

Overall, our participants seemed to have a pessimistic view of the relationship with their GPs (13, 33), which may be related to the refractory nature of their IBS. For instance, interviewees perceived IBS as a "last resort diagnosis." This highlights the importance of providing feedback and the need to create a clear explanation of IBS at the early stage of care. Indeed, research suggests that

the credibility of GPs increases when they create an explanatory framework for the condition that legitimises the symptoms (34). However, in the case of functional problems, doctors tend to either classify the symptoms as psychological in nature or ignore them (35, 36).

Similarly to individuals with chronic low back pain (37), our participants reported that lack of information sharing happened during both the diagnostic phase and the lengthy trial and error treatments process, which seemed to create unrealistic expectations of treatments and to reduce trust in doctors. A systematic review on the management of medically unexplained symptoms in primary care concluded that validating symptoms and explaining potential treatments can have a significant positive impact on the way patients understand and accept their condition, as well as their trust in GPs (38). However, the reality of time-pressured consultations may not allow GPs to cover all these aspects adequately.

Based on the accounts of our interviewees, CBT-based self-management programmes could be a valuable resource to support GPs at all stages of the patient journey. Offering access to CBT soon after diagnosis could actually help to create a biopsychosocial conceptualisation of IBS, promote acceptance of the condition and shape realistic appraisals concerning IBS treatments and the importance of self-management. Moreover, enhancing patient insight into how IBS is diagnosed and the fact that there is no “one size fits all” treatment can reduce frustration towards doctors and positively influence the common perception of GPs’ paucity of IBS knowledge. In support of offering early access to CBT, a RCT testing a CBT-based self-management programme in individuals recently diagnosed with IBS in primary care actually found that this approach promoted a significant relief from symptoms up to 6 months post-treatment when compared to TAU (39).

Participants in the current study reported the usefulness of CBT in providing reassurance and promoting a sense of shared responsibility with doctors regarding the management of IBS symptoms. Reassurance did not only come from talking to a therapist but also from reading the content of the CBT-based programme. Cognitive reassurance, which includes explanations and education, has in fact been associated with higher patient satisfaction, enablement and reduced concerns in primary care patients (40). Furthermore, our participants’ reports highlighted the potential role of self-management interventions in reducing health-seeking behaviour. In line with this promising finding, a RCT with 420 IBS patients recruited from primary care found that a self-help guidebook reduced primary care consultations by 60% at one year (41). This suggests that earlier access to self-management programmes can have promising clinical implications in primary care management of IBS, both for patients and doctors.

Implications for research and practice.

The current study highlights specific areas associated with each step of care perceived by patients as problematic. Framing realistic beliefs about IBS and its treatment could increase trust in doctors and potentially reduce GP consultations (42). Providing more information for patients on the process of diagnosing IBS; presenting IBS as a positive diagnosis (including an explanatory model for their symptoms); involving patients in potential treatment options (including a realistic appraisal of potential benefit) and acknowledging the impact of IBS symptoms on patients’ lives, appear to be key. A joint approach integrating GP advice and CBT self-management programmes for IBS may be a promising solution able to target these areas and mitigate some of the difficulties of providing this support during short GP consultations.

The efficacy of CBT interventions could be enhanced by including detailed information about how IBS is diagnosed and the lengthy trial and error process involved with searching for the right treatment(s). In turn, this may help to reframe the negative perceptions and attitudes towards GPs and potentially promote more collaborative doctor-IBS patient interactions. Further studies are needed to assess the role of CBT as an early intervention in IBS and its effects on the doctor-patient interactions.

Accepted Manuscript

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