



Desperately seeking a cure: Treatment seeking and appraisal in irritable bowel syndrome

J. Matthew Harvey¹, Alice Sibelli², Trudie Chalder³, Hazel Everitt⁴,
 Rona Moss-Morris² and Felicity L. Bishop^{1*} 

¹Centre for Clinical and Community Applications of Health Psychology, Department of Psychology, Faculty of Social Human and Mathematical Sciences, University of Southampton, UK

²Health Psychology Section, Institute of Psychiatry, Psychology and Neuroscience, Kings College London, UK

³Academic Department of Psychological Medicine, Kings College London, UK

⁴Primary Care and Population Sciences, Faculty of Medicine, University of Southampton, UK

Objectives. Irritable bowel syndrome (IBS) is common and adversely affects patients' quality of life. Multiple potential treatment options exist for patients (and clinicians) to choose from, with limited evidence to inform treatment selection. The aim was to explore how patients with IBS go about seeking and appraising different treatment modalities, with a view to elucidating the psychological processes involved and identifying opportunities to improve clinical practice.

Design. Qualitative study nested within a randomized controlled trial of therapist-delivered and web-based cognitive behavioural therapy versus treatment-as-usual for IBS.

Methods. A total of 52 people participated in semi-structured interviews about their prior experiences of treatments for IBS. Transcripts were analysed using inductive thematic analysis.

Results. Key themes (desperation for a cure, disappointment at lack of cure, appraising the effects of diverse treatments, and hope for positive effects) clustered around an overarching theme of being trapped within a vicious cycle of hope and despair on treatment seeking. A desperation and willingness drove interviewees to try any treatment modality available that might potentially offer relief. Coming to accept there is no cure for IBS helped interviewees escape the vicious cycle. Treatments were appraised for their effects on symptoms and quality of life while also considering, but rarely prioritizing, other aspects including convenience of the regimen itself, whether it addressed the perceived root causes of IBS, perceived side-effects, and cost.

Conclusion. Treatment seeking in IBS can be challenging for patients. Supportive discussions with health care professionals about illness perceptions, treatment beliefs, and goals could improve patients' experiences.

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*Correspondence should be addressed to Felicity Bishop, Centre for Clinical and Community Applications of Health Psychology, Department of Psychology, Faculty of Social Human and Mathematical Sciences, University of Southampton, Southampton SO17 1BJ, UK (email: f.l.bishop@southampton.ac.uk).

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Statement of contribution**What is already known on this subject?**

- Irritable bowel syndrome (IBS) is a highly prevalent chronic relapsing functional gastrointestinal disorder.
- Studies show few treatment modalities provide complete symptom relief.
- IBS is associated with emotional and physical distress, and negatively impacts personal, social, and professional aspects of quality of life.

What does this study add?

- Patients appraise IBS treatments for impact on quality of life and treatment characteristics.
- Developing acceptance and coping strategies helps escape treatment-seeking vicious cycles of hope and despair.
- Clinicians could better support patients by discussing their illness perceptions, treatment goals, and values.

Irritable bowel syndrome (IBS) is a chronic functional gastrointestinal disorder or disorder of gut-brain interaction, currently conceptualized as involving multiple interacting biopsychosocial factors (Drossman, 2016). It affects around 10–14.9% of the UK population with similar worldwide prevalence (for a review see Lovell & Ford, 2012; Michalsen, Vandvik, & Farup, 2015), and it affects more women than men (Quigley, Bytzer, Jones, & Mearin, 2006). Symptoms include abdominal pain, discomfort, and altered bowel movements, and personal, social, professional, and health-related quality of life is typically reduced (El-Serag, Olden, & Bjorkman, 2002; Håkanson, Sahlberg-Blom, Nyhlin, & Ternstedt, 2009; Taft, Keefer, Artz, Bratten, & Jones, 2011; Taft, Ballou, & Keefer, 2013; Taft, Riehl, Dowjotas, & Keefer, 2014).

Few current treatments offer satisfactory symptom relief (Schoenfeld, 2005). NICE clinical guidelines (2008, updated 2017) recommend clinicians provide advice on the importance of self-help for the effective management of IBS, where self-help encompasses lifestyle adjustments, general diet advice, advice to be physically active, and symptom-focused medications. If general dietary advice is ineffective, then NICE recommend single food avoidance and exclusion diets under the supervision of a health care professional with expertise in dietary management. Beyond self-care, NICE recommend considering pharmacological management based on symptom type and severity, and the use of psychological therapies where symptoms have persisted for more than 12 months.

Trials, systematic reviews, and meta-analyses suggest that some treatment modalities are helpful in reducing IBS symptom severity. However, many trials lack methodological rigour, thus the findings should be treated with caution. For instance, a limited number of studies have tested the effectiveness of the low Fermentable Oligo-, Di-, Mono-saccharides and Polypols (FODMAP) diet. While these studies report a reduction in symptom severity, the effects are similar to other interventions, for example less-restrictive dietary advice (see Eswaran, Chey, Han-Markey, Ball, & Jackson, 2016; Marsh, Eslick, & Eslick, 2016). In relation to pharmacological interventions, a Cochrane review offered some support for antidepressants, but little support for bulking agents and antispasmodics (Ruepert *et al.*, 2011). In relation to psychological interventions, systematic reviews and meta-analyses have shown CBT to be efficacious in the short-term, with equivocal findings so far for longer-term outcomes (Li, Xiong, Zhang, Yu, & Chen, 2014; Zijdenbos, de Wit, van der Heijden, Rubin, & Quartero, 2009).

The NICE guidelines recommend clinicians not to encourage the use of acupuncture and reflexology, but between 20 and 50% of people with IBS use some form of complementary or alternative medicine (CAM) (Carmona-Sanchez & Tostado-Fernandez, 2004; Hung, Kang, Bollom, Wolf, & Lembo, 2015; Koloski, Talley, Huskic, & Boyce, 2003; Kong *et al.*, 2005). Using CAM can be motivated by a lack of response to conventional treatments and the disabling nature of IBS symptomology (Hussain & Quigley, 2006; Wu, 2010). While recent evidence suggests some CAMs may be helpful (see for example Bensoussan *et al.*, 2015; Cappello, Spezzaferro, Grossi, Manzoli, & Marzio, 2007; Manheimer *et al.*, 2012), Wu's (2010) review found the poor quality of trials in this area precluded judgements as to their effectiveness.

Håkanson *et al.* (2009) and Jakobson Ung, Ringstrom, Sjövall, and Simrén (2013) have explored how individuals seek ways of coping with, and adjusting to, life with IBS. In these qualitative studies, interviewees were described as having an altered self-image due to symptoms like bloating and flatulence (Håkanson *et al.*, 2009), wanting more autonomy in treatment decisions (Håkanson *et al.*, 2009), coming to accept they could not be cured (Jakobson Ung *et al.*, 2013), and seeking coping strategies to regain a sense of control in their lives (Håkanson *et al.*, 2009; Jakobson Ung *et al.*, 2013). They also described living a life revolving round 'periods of well-being interspersed with periods of deterioration and illness' (Jakobson Ung *et al.*, 2013, p. 1482). Relatedly, Paterson's (2001) meta-synthesis described how living with IBS involves diametrically opposite sequences, in which individuals mainly focused on managing symptoms during flare-ups but on strategies to protect themselves from further relapses in symptom-free times.

The idea that symptom experiences shape coping strategies has been formalized in the Common Sense Model (Diefenbach & Leventhal, 1996; Leventhal, Meyer, & Nerez, 1980; Leventhal, Nerenz, & Steele, 1984). According to this model, when people experience symptoms, they develop cognitive and affective representations that drive coping strategies including treatment seeking. The experience and effects of treatment are then appraised and inform modifications to illness representations, treatment utilization, or both (Diefenbach & Leventhal, 1996; Horne, 2003; Horne & Weinman, 2002; Leventhal *et al.*, 1980, 1984). The criteria by which patients appraise treatments may vary by treatment and/or condition (Dima *et al.*, 2013); for example, the therapist might be particularly important in shaping appraisals of complementary therapies (Bishop, Yardley, Cooper, Little, & Lewith, 2017; Yardley, Sharples, Beech, & Lewith, 2001) while beliefs about necessity and concerns are important for medications (Horne *et al.*, 2013).

The Common Sense Model has been applied in IBS, but the focus thus far has been on the role of illness perceptions rather than treatment appraisals. De Gucht (2015) found the impact of increased symptom severity on reduced health-related quality of life was partially mediated by the illness perception dimensions of identity, consequences, and emotional representation. Rutter and Rutter (2002) found higher rates of anxiety and depression were strongly associated with perceiving IBS as having severe consequences. Riedl *et al.* (2009) found that people who attributed their IBS to psychological factors had a better quality of life than those with somatic attributions. While qualitative studies have explored patients' experiences of IBS in general, no in-depth studies have explicitly focused on how patients experience and appraise treatments. It is important to explore how patients experience and appraise

treatments for IBS because of the treatment context faced by patients: A variety of potential modalities which offer limited symptom relief that are not all widely available on the NHS.

This study reports the findings from a qualitative study nested within a three-armed randomized controlled trial of therapist- and web-based CBT vs treatment-as-usual for IBS (the Assessing Cognitive Behavioural Therapy in Irritable Bowel trial, ACTIB; Everitt *et al.*, 2015). The aim was to explore how patients with refractory IBS seek and appraise different treatment modalities tried prior to entering the trial. Patients' experiences of CBT in the trial will be reported elsewhere.

Method

Design

This qualitative study was nested within a large trial (summarized below) and used a critical realist theoretical framework (Bhaskar, 1975; Gerrits & Verweij, 2015). Semi-structured interviews were conducted with a subsample of participants drawn from each arm of the trial on completing trial treatments (3 months post-baseline). Adopting an inductive and thematic approach permitted us to compare themes across individuals and groups of people (e.g., genders, IBS severity scores, primary and secondary care) as well as analysing key themes across the whole data set.

The parent trial

The main trial randomized patients to receive therapist-delivered CBT, web-based CBT, or treatment-as-usual (see Table 1 for summary, and (Everitt *et al.*, 2015) for full description of interventions). Eligible patients were diagnosed with refractory IBS fulfilling the Rome III criteria (Drossman, 2006) and were aged 18 years or over (for full details of trial methods see (Everitt *et al.*, 2015)).

Table 1. Summary of the interventions received by each trial arm

	Therapist-based CBT	Web-based CBT	Treatment-as-usual
Ongoing intervention	Treatment-as-usual from GP/consultant	Treatment-as-usual from GP/consultant	Treatment-as-usual from GP/consultant
Main Intervention	Therapy based on a paper-based manual	Previously piloted web-based CBT self-management programme (Regul8; Everitt <i>et al.</i> , 2013)	
Intensity	Six, 60-min telephone CBT sessions over 12 weeks	Eight online modules and three, 30-min therapist-delivered telephone sessions over 12 weeks	
Additional sessions	Two 1-hr booster calls at 4- and 8-months	Two 30-min booster calls at 4 and 8 months	Upon completion of the trial, participants offered the trial CBT intervention

Note. GPs and consultants were given a leaflet summarizing the NICE guidelines for IBS.

Participants

Maximum variation sampling was employed to interview people with a diverse range of characteristics: age, gender, ethnicity, geographical location, study arm, symptom severity scores, and from primary and secondary care.

Fifty-two interviews were conducted, 42 by AS and 10 by JMH. Interviewees were aged from 21 to 74 years ($M = 40.67$, $SD = 14.05$) and had IBS for an average of 16.26 years ($SD = 9.96$). Table 2 summarizes interviewees' characteristics.

Table 2. Interviewees' characteristics ($n = 52$)

	N	%
Gender		
Male	12	23.08
Female	40	76.92
Recruitment Site: London		
Primary care	10	19.23
Secondary care	25	48.07
Recruitment Site: Southampton		
Primary care	15	28.85
Secondary care	2	3.85
Trial Arm		
Therapist-based	17	32.69
Web-based	17	32.69
Treatment-as-usual	18	34.62
Trial Arm (Gender – Male)		
Therapist-based	4	7.69
Web-based	3	5.77
Treatment-as-usual	5	9.62
Trial Arm (Gender – Female)		
Therapist-based	13	25.0
Web-based	14	26.92
Treatment-as-usual	13	25.0
IBS SSS		
Remission	4	7.69
Mild	9	17.31
Moderate	18	34.62
Severe	21	40.38
Ethnicity		
White British	38	73.08
White Other	9	17.31
White Asian	1	1.92
Irish	1	1.92
Indian	1	1.92
African	1	1.92
Other	1	1.92

Note. IBS SSS = IBS symptom severity score.

Interviews

Semi-structured interviews used a topic guide comprising broad, open-ended questions clustered into three sections: experiences of the trial to date, treatment regimens for IBS, and daily experiences of emotions (findings from the latter have been published separately; see (Sibelli *et al.*, 2017)). This study focuses on interviewee responses to questions exploring past treatment regimens for IBS. Questions included ‘could you tell me about the most helpful/least helpful treatments you have tried for your IBS?’ and ‘What did you like/dislike about these treatments?’ These questions did not explore the interviewees’ experiences of CBT or treatment-as-usual received during the trial. Interviews lasted on average 56 min (range 23–116) and were conducted face-to-face ($n = 10$) or over the telephone ($n = 42$), as per participant request.

Procedure

Prior to commencing the study, favourable NHS ethical clearance was received (ref: Berkshire REC 13/SC/0206). At the start of the trial, informed consent for interview participation was obtained. Before commencing each interview, interviewers built rapport, reminded interviewees of their rights, and obtained verbal consent. Interviews were digitally recorded, then transcribed and coded using NVivo (version 10; QSR International Ltd., 2012). Interviewers made field notes (e.g., observations of non-verbal aspects) to inform later analysis and document their own reflections. All participant names have been anonymized using pseudonyms to protect confidentiality.

Data analysis

Thematic analysis was used to identify themes (Joffe & Yardley, 2004) and followed the procedure espoused by Braun and Clarke (2013). To achieve familiarization with the data, interviews were listened to and transcripts read repeatedly. Memos were written to capture the researcher’s subjective thoughts and feelings, and preserve ideas that may become significant later in the analysis (Polit & Beck, 2004; Speziale & Carpenter, 2007). To generate initial themes based on the data, JMH read each transcript and attached newly devised labels to phrases and small chunks of data that addressed the research question. After conducting open-coding in this way on five transcripts, all labels and associated data excerpts were collated and reviewed. This process identified a large number of codes which were used to code the remaining transcripts, adding more codes when new ideas were encountered in the data.

Codes were defined in a coding manual and clustered around common themes; clusters were identified by comparing different codes and associated data excerpts. Preliminary themes were defined, diagrammed (in thematic maps), and reviewed against transcripts to ensure coherence and consistency with the data set overall. Other researchers were involved at this stage (FB, AS) to discuss the themes and suggest alternative interpretations of the data, thus ensuring the analysis was neither idiosyncratic nor inappropriately selective. Themes were modified and discussed iteratively and finalized when the team agreed they captured the interviewees’ experiences of previous IBS treatments.

We ran queries in NVivo to explore similarities and differences between groups of interviewees (Bazeley & Jackson, 2014). For example, a ‘matrix query’ explored how interviewees in the different trial arms experienced pharmacological treatments. Overall, these queries suggested that experiencing and appraising treatments were similar across

interviewees with different characteristics and from the different trial arms. Therefore, these queries are reported no further.

Study rigour

To enhance the quality and rigour of this study, we followed Lincoln & Guba's guidelines (1985). Trustworthiness was enhanced through keeping a clear audit trail and having regular discussions of emerging themes and findings within the research team. Maximum variation sampling helps to increase confidence that we have captured major themes of importance to a diverse sample of people seeking help for recurring IBS symptoms. Writing memos and field notes facilitated reflexivity and enhanced transparency and confirmability. The overarching theme ('being trapped within a vicious cycle') was reminiscent of CBT concepts, prompting a reflexive exploration of whether CBT concepts had been imposed by the researchers. The lead analyst (JMH) was a mature male postgraduate health psychology student, with no formal CBT training. Other researchers were trained and experienced health psychologists with and without CBT and clinical experience and an academic GP with expertise in IBS. Before settling on the final themes, we deliberately reviewed the data to check for inappropriate imposition of CBT concepts.

Findings

Interviewees described an everyday life compromised by an illness that, while not life-threatening or terminal, often had debilitating consequences for professional, personal, family, and social domains alike.

IBS can be like – a complete disaster in your life. . . . people don't associate with it – with – a condition that is – like really debilitating and I think – its just like very destructive in your life. (Elijah)

Accounts of treatment seeking for IBS were characterized by a sense of being trapped within a 'vicious cycle' of alternating hope (for new treatments) and despair (on finding them ineffective). Some interviewees, such as Lucas, discussed how this vicious cycle impacted them emotionally.

I was anxious about being unwell and that caused me anxiety and made unwell, which caused me anxiety, so there was a bit of a vicious circle going on and any amounts of – of – of – telling me – or telling myself – that this is er something that will go away and it wasn't serious or whatever, um [didn't] break that cycle. (Lucas)

While a few interviewees escaped this cycle through increased acceptance of IBS and improved self-management, others described a constant battle to control symptoms and a seemingly unending quest for a cure. Typically, participants had tried multiple interventions before enrolling in the trial and appraised pharmaceutical, dietary, and alternative treatments in different ways. Figure 1 depicts the interplay between the themes and subthemes, described below with selected illustrative quotes. In the text below and Figure 1, main themes are depicted in bold, subthemes in italics.

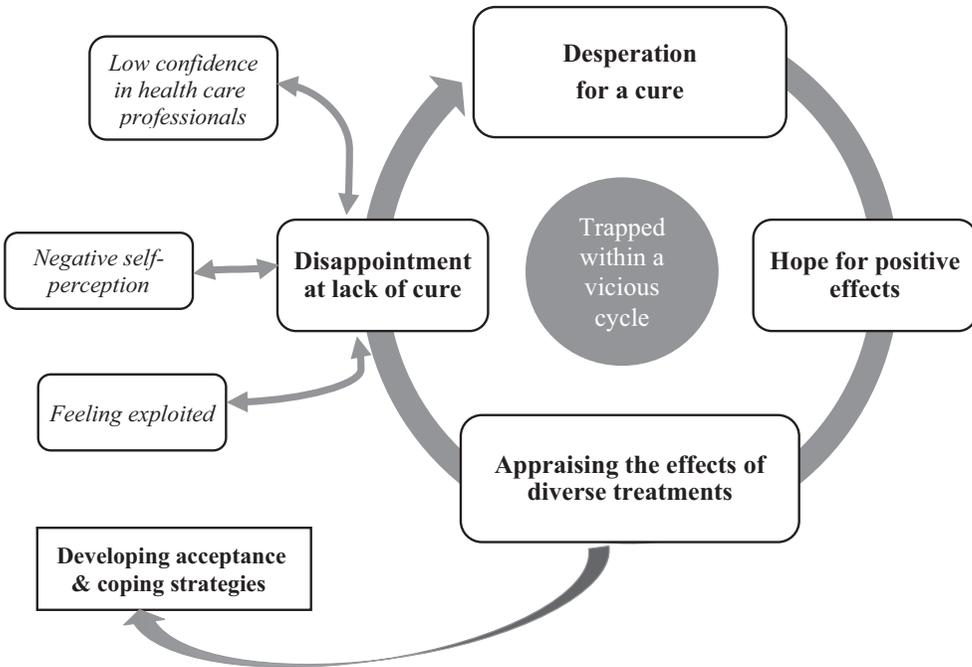


Figure 1. Thematic map depicting participants' experiences of seeking and appraising treatments in IBS. Note: Bold text represents main themes; italic text indicates subthemes.

Desperation for a cure and hope for positive effects

On seeking treatment for IBS, participants described desperation for a cure that manifested in a willingness to try anything, if there was even the slightest chance, it could offer some relief from symptoms. While they focused mainly on ‘quick fixes’ offered by medicines, non-pharmaceutical alternatives were considered. To identify potential treatments, participants drew on *recommendations and advice from diverse sources* including health care professionals, friends and family, fellow patients, and the Internet.

Well most of the treatments I’ve tried have either been through friends of friends of friends or have been recommended because someone in a chat room has recommended them and – so when you’re desperate, you will try – oh I’ll give that a go. (Sophia)

Interviewees then had to manage their hope for positive effects from a new treatment. Some *resisted the temptation to hope for a cure* (particularly when they had extensive histories of treatment seeking), despite hearing success stories from other patients. Others found that *success stories and recommendations encouraged them to hope for a cure*:

I had expectations that it would wave a magic wand overnight (Grace)

Appraising the effects of diverse treatments

Having engaged with a treatment, interviewees described appraising it for its *helpfulness in relieving symptoms* and offering physiological and psychological benefits. When

treatments were appraised as helpful, participants *regained a sense of control* in their quality of life and could begin breaking the vicious cycle. Finding a treatment modality that relieved symptoms such as bloating in the short-term allowed interviewees to enjoy a social life with friends and families and take less time off work. More commonly, participants were *disappointed with treatment effects* and continued seeking a more effective treatment.

Medications

Medications were the most frequently appraised interventions. Some participants described how medications offered *temporary symptom relief* (e.g., from bloating and stomach cramps) that meant they *regained some control* and were better able to socialize and perform daily activities without worrying that their symptoms would interrupt or embarrass them. Indeed, such *worries could be all-encompassing and disabling* in themselves so the relief from worry was valued as well as the relief from symptoms.

It's made my life easier in that respect, that I don't get caught out in situations where I would have been caught out before. So it's a relief that you can get on and not worry about it. (Jessica)

When *over-the-counter medications and prescribed medications were found to be unhelpful* in that symptom relief was not forthcoming, interviewees often persisted in trying different remedies and typically remained open to their potential benefits for others:

Okay, well – none of them really helped so I didn't – I didn't really like any of them. Yes – they just – they did not help my – my troublesome symptoms, the bloating and the trapped wind at night, so you know, I tried all of them for, whatever, a month or some of them I tried for longer and tried – on – you know – separate occasions. (Alice)

Over half of all participants expressed a general *dislike of taking medications* for their IBS, citing the following reasons: tablets difficult to swallow, inconvenience of having to take the medication at very specific times, concerns about falling foul of legal restrictions when travelling, childhood upbringing was generally antimedications, concerns over immediate and longer-term side-effects, feeling that medications treated (or masked) the symptoms without addressing underlying causes, and not understanding what they were putting into their bodies.

I don't like taking drugs because I always wonder what – what side-effects are there that perhaps aren't apparent now, but you then find out, say, 10 or 20 years down the line for example. (Liam)

A general dislike of medications and/or finding them ineffective led many participants (42%) to seek other ways of managing IBS (although they did not necessarily stop taking disliked medications if they provided some relief). Participants preferred alternatives to medication which treat IBS more *holistically* and avoid the use of chemicals, for example by managing their diet or working with a therapist.

I just didn't like the fact that I would have to take medication for – for something that could possibly be controlled in other ways, through perhaps – work with a therapist or hypnotherapy or something like that. (Olivia)

Dietary advice

Unlike medications, dietary changes were seen to have a social context which shaped participants' appraisals of such interventions. Participants described experiencing an *altered relationship with food* which could be empowering (when it became a way of controlling symptoms) but also demanding. Trying to identify triggers involved something of a *trial and error approach*, and when trigger foods were identified, this was experienced as a double-edged sword. On the one hand, it could enhance participants' sense of control in cases when their symptoms improved. On the other hand, it could be burdensome and created additional anxieties, in that it required considerable forward planning, necessitated detailed attention to ingredients when food shopping or eating out, and impacted on participants' work, social, and family lives.

My work involves a lot of travelling and not really any regular hours. So to get into any sort of routine with, say, food, is very tricky and doesn't leave much option for eating anything on the go, so everything has to be cooked in advance, prepared and brought with me. (Noah)

I dislike that I have to eat differently to my family; I dislike that it's not readily available to buy things while I'm out with others. (Emily)

Managing symptoms through diet decreased participants' *enjoyment of food*. Interviewees described finding food boring as they could only eat the same things, they disliked feeling unable to eat spontaneously, and they missed previously enjoyed foods and previously pleasurable aspects of food preparation.

Also I decided that food is obviously something that's really nice to enjoy so it's just really sad when you – when you can't eat like half the foods that you used to eat before. So I found that really – like demoralising. (Elijah)

Furthermore, some participants reported having managed the demands of complex dietary changes but without success.

Diet was just very imposing and no positive outcome. So you don't mind, you know, doing something that's restricting your life if you're going to get something out of it. I got zero out of it so that was frustrating. (Poppy)

CAM and other treatments

Twenty-four interviewees ($N = 46\%$) described having *sought other options* including CAM, colonic pack for manual bowel evacuation, and exercise. While some of these approaches were valued for attempting to address root causes of IBS, and not being pharmacological, ultimately, they were appraised according to whether they elicited meaningful benefits. As for dietary advice and medications, alternatives that were found ineffective were simply seen as another failed attempt that led to frustration and a renewed search for other remedies.

I've tried all sorts, I mean, you know, I've had tablets, I've been to the pain clinic and tried mindfulness meditation; I've paid for hypnotherapy, I've paid for acupuncture, paid for Chinese medicine, I've been to homoeopaths, I've paid for that. I've tried all sorts and nothing – nothing works. I've had CBT in the past and it didn't work then. I've tried all sorts. (James)

When alternatives such as regular exercise were appraised more positively as helping with one's symptoms, participants also reported experiencing *challenges to adherence* including lack of time and motivation, feeling lethargic, working long hours, and lacking enthusiasm for physical activities that were not inherently enjoyable.

I just found it too – too energetic because my energy levels can be pretty low sometimes and I just felt – it wore me out too much, that I didn't really get pleasure in it, I suppose that's the word, I didn't find it was pleasurable. (Amelia)

Disappointment at lack of cure

Irrespective of their *hopes, expectations*, or type of intervention, interviewees described being *disappointed when treatments provided neither a cure nor long-term symptom relief*. Interviewees' desperation to find a cure was fuelled by continuing to experience symptom flare-ups with little or no ability to manage them, thus maintaining the vicious cycle of treatment seeking. For example, Isla described being obsessed with keeping herself regular because of the pain she experienced and seeking different medications for pain relief.

I was using a lot of over-the-counter laxatives and some of them very strong, and I was just obsessed with taking them, just to try and keep myself regular because I was in so much pain. So I would try these ones – which did work but – they would work but they would not relieve the pain. So then I tried taking the other ones that were more [associated] with relieving the pain and then these actually never worked; I was always in pain. (Isla)

There were additional consequences of having tried ineffective treatments that both contributed to and were fuelled by disappointment in treatments. *Feelings of being exploited* emerged when participants found treatments to be expensive and then ineffective, and were perpetuated by the constant email bombardment from companies offering products that promised to provide relief from IBS symptoms.

it's costing all the time, you know, you're laying out a lot of money which you might not mind if something's really gone well. But to keep laying out money and, in the end, you're no different. (Phoebe)

A *lack of confidence in health care professionals* sometimes emerged when participants felt they were being treated as a 'case of IBS' rather than a unique individual person with IBS, when they felt they were not being treated respectfully, when they felt IBS was dismissed as not serious or 'all in the mind', and when they perceived that clinicians had taken a trial and error approach (to prescribing medications in particular). This could also decrease participants' hope for an effective treatment.

you suddenly realise – you are an individual and 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 look at you as – oh – you take that medication, blah, blah, blah, follow this routine and you might be cured. (Amelia)

I felt a bit hopeless, to be honest [inaudible word]. (I: Yes) I tried quite a few things and I thought - if the doctor can't get it right – what hope have I got. (Daisy)

Overall, confidence in a health care professional's ability to help cure or find symptom relief appeared to wane when participants' hopes for success were repeatedly met with disappointment and at times despair. It is however important to note that not all participants described losing confidence in health care professionals, and *more positive appraisals of clinicians* tended to emerge after effective treatments, helpful referrals, and respectful discussions that included providing a rationale for any prescriptions.

and the doctor prescribed that and she was a brilliant doctor and I think, as well, when the doctor has some confidence, you actually kind of believe in the drug a bit more. She had her reasons, she explained to me why she was prescribing it, so then I understood the point of it, not just chucking another prescription at me and telling me to go away. (Sophia)

On experiencing repeated failed interventions, participants began *thinking negatively about themselves* and the impact IBS had on their quality of life. IBS was seen as a source of personal embarrassment because of the perceived stigma around it, and because of uncontrollable bodily reactions. Treatments that offered some relief could also trigger negative thoughts, for example about the *need to rely on medication* to help relieve symptoms and the connotations of using antidepressant medications.

I mean, it's basically – what's it called a . . . tricyclic antidepressant. Now, I'm not depressed by any stretch of the imagination, I was just a bit – other than the fact that when your IBS [flares up], yes, you get down because – constant trips to the bathroom and obviously the way how it makes you feel physically. But other than that – if I didn't have my IBS, I'd be a perfectly happy person. (Liam)

Developing acceptance and coping strategies

Some participants had found coping strategies that enabled them to begin to break out of the vicious cycle of treatment seeking. This occurred when participants, such as Jessica, felt they had gained a degree of control over their lives, and/or came to *understand IBS as a long-term health condition* without a permanent 'cure'.

just coming to terms with the fact that it's a condition that's with people forever and er you just have to try and control it as best you can and there will always be er flare-ups and um days that are not so good and you just have to – you just have to accept that. (Jessica)

When participants accepted that they had a long-term condition for which there appeared to be no cure, they seemed better able to resist the temptation to continue seeking out new treatments in the hope of a magic cure. Instead of seeking an instant cure, participants took other steps to manage or cope with their symptoms. These included identifying and *avoiding food triggers*, *stopping or adjusting dosages of medications*, *maintaining a routine* to reduce feelings of stress, and *increasing exercise*.

I've it had a long time anyway, it's not curable; you will try anything but actually the bottom line is – it's only one or two small things that really do work – and it's better just to stick with them. I see new things come up all the time and I think about them, but, you know, I think –

well actually – I’m not going to rock the boat and take something new because somebody said, oh that’s really good – and they make things worse. (Genevieve)

For some interviewees, *becoming more aware of their bodies* and how their symptoms manifest was enough for them to find temporary escape from the vicious cycle that had engulfed their lives. For Poppy, learning more about herself through the ‘lightning process’ (designed to train people to understand mind–body interactions) was an empowering process that helped her to cope with her IBS.

I’m now able to see my triggers. I am now able – to control myself and my emotions a lot more, take the stress out of my life. I’ve now got a huge amount of awareness about myself and how I react to situations. . . . So – it’s – empowering me as a person, it’s saying use the tools and you can help yourself – which is really empowering. (Poppy)

Finally, the decision by interviewees to enrol into the trial fits in with their desire and desperation to find symptom relief on the one hand; and on the other, for those who have managed to regain some control in their lives, the ability to help develop further tools and a stronger capacity to self-manage, as both Isla and Amelia explain.

I agreed to do it because, as I said, I was looking for perhaps another tool; I find this is another tool to help me through what I was experiencing (Amelia)

probably over a year of seeing different doctors and consultants and not finding any solution to my – to my problem, so it was basically as like a last remedy thing . . . I was not very optimistic about it (Isla)

Discussion

In this study, we explored how individuals with refractory IBS seek and go about appraising different treatment modalities. The findings suggest that people primarily appraise treatment in terms of its perceived impact on reducing symptom severity but also in terms of how well it fits within and improves (or not) their personal, social, and professional lives. However, this must be understood within the broader context of treatment-seeking behaviours, wherein interviewees described being trapped within a vicious cycle of hope and despair for a range of different treatment modalities seen as potential cures.

A desperation and willingness drove interviewees to try any treatment modality available if it offered potential relief. After a period of time, interviewees appraised the treatment modality for its effects on symptoms and quality of life while also taking into account, but rarely prioritizing, other dimensions including convenience of the regimen itself, whether it sought to address the perceived root causes of IBS, perceived side-effects, and cost. The Common Sense Model posits a bi-directional relationship between beliefs about a treatment and appraisals, whether positive (improvement in symptoms) or negative (side-effects or symptoms persist; Diefenbach & Leventhal, 1996). Therefore, if the treatment modality proves beneficial, it is predicted that individuals are more likely to continue engaging with it, and in turn strengthen their beliefs about the treatment modality as useful in relieving symptoms. In our interviews, people who found the treatment modality offered some symptom relief, even if it was only in the short-term, were prepared to continue with it, and in some cases, this was described as ‘life-saving’. Often, but not always, this was true even when people found a treatment to be difficult to

adhere to or to have unpleasant or unwanted side-effects. For example, while diet was seen as a potentially helpful intervention, interviewees did not find it necessarily easy to adhere to. As Casiday, Hungin, Cornford, de Wit, and Blell (2009) note, managing strict dietary regimens was time-consuming and frustrating. For Horne (2006), this represents a 'common sense' approach to a necessity-concerns dilemma, whereby a highly valued outcome outweighs problematic aspects of treatment and perceived self-efficacy to maintain a treatment modality becomes important.

For those trapped within the vicious cycle, disappointment at not being able to find a way to reduce symptoms and improve quality of life contributed to negative self-perceptions, feelings of being exploited by marketers, and reduced confidence in health care professionals. Individuals wanted to have faith in health care professionals such as GPs and consultants who were often perceived as holding a lifeline to curing illnesses; when they were unable to provide the answers, interviewees felt helpless and frustrated. Disappointing experiences with health care professionals also contributed to negative self-perceptions, when people felt their symptoms were not being taken seriously or they were not treated as an individual. Of concern is that the development of negative self-perceptions may further diminish people's ability to cope with flare-ups, by reducing self-efficacy and expectations of response efficacy over time.

Similar reactions have been noted in chronic pain conditions. A meta-synthesis found that patients with chronic low back pain cycled through hope and despair, were left frustrated and disappointed when they felt disbelieved by health care professionals and others, and over time developed more negative perceptions of self and the future (Froud *et al.*, 2014). Some of these challenges faced by people with chronic pain may result from not easily fitting within a traditional biomedical model in which diagnosis leads to curative treatment (Toye *et al.*, 2013). Indeed, patients often expect a prescription aimed to alleviate symptoms or cure disease and health care professionals are aware of those expectations (Cole, 2014; Teixeira Rodrigues, Roques, Figueiras, & Herdeiro, 2013). Individuals with IBS in the current study felt a similar alienation from the biomedical model, in that a cure has not followed on from diagnosis and various treatment modalities.

Within our interviews, the primary route out of the cure-seeking vicious cycle was through an acceptance that there is no cure for IBS. For interviewees in the current study, developing acceptance and coping strategies seemed to increase self-efficacy to manage periods of flare-ups and provide a protective barrier against despair when a treatment ceased to reduce symptoms. Similarly, Jakobson Ung *et al.* (2013)'s interviewees – who had lived with IBS for a long time (on average 24 years) – were able to see themselves as 'healed but not cured' and were able to gain a sense of control in their daily lives. Acceptance and mastery have also been shown to be important in facilitating coping and reducing unhelpful cure-seeking in other long-term conditions (see Froud *et al.*, 2014; Garcia-Rueda, Carvajal Valcarcel, Saracibar-Razquin, & Arantzamendi Solabarrieta, 2016; Toye *et al.*, 2013). For example, low back pain patients who accepted their condition might not be curable and changed their outlook accordingly, were better able to cope with their back pain (Froud *et al.*, 2014).

This study has certain methodological strengths and weaknesses. Strengths include the use of maximum variation sampling to ensure a broad range of people were interviewed; the requirement for all interviewees to meet the Rome III criteria (Drossman, 2006) for IBS; and the use of established techniques to enhance analytic rigour. Our reflexive exploration of possible imposition of CBT concepts confirmed that the 'vicious cycle' concept had indeed emerged from participants' accounts. However, it is important

to bear in mind that interviewees all came from the ACTIB trial (Everitt *et al.*, 2015), and so all had a history of unsuccessful treatments from primary and/or secondary care. This means that our participants are very likely to have had more unsuccessful or disappointing experiences of IBS treatments in the past compared to a community-based sample of people with IBS. At the time of interview, our participants had been in the trial for 3 months: This might have shaped their reflections on treatment seeking. Further, while this paper did not explore interviewees' experiences of CBT, their participation in a CBT trial itself indicates an openness to CBT (and potentially other non-medication-based interventions) and ongoing treatment seeking.

The findings suggest some clinical implications. Clinicians could encourage patients to reconceptualize IBS as a condition which they can help to manage themselves with the right tools. This change in patients' perceptions of their IBS has not been a central focus of clinical guidelines. Our findings suggest strengthening the message that IBS is a relapsing remitting condition, which can persist but can benefit from active self-management could have potential benefit in breaking the 'vicious cycle' of desperately seeking treatment and repeated disappointment. Promisingly, Robinson *et al.* (2006) found educating IBS patients with a self-help guidebook significantly reduced perceived symptom severity and reduced primary care consultations by 60% compared to controls.

While symptom reduction appears to be highly valued by many, other outcomes such as regaining a sense of control and rediscovering pleasure in food may also be important to individuals. Initiating dialogue about treatment goals may help to foster better patient–practitioner interactions in IBS consultations. Such discussions may also enable tailoring of proposed management strategies to individuals with IBS, focussing on what is important to them, for example being able to live a valued life despite symptoms. Dialogue about treatment-related values could also help patients to feel supported in treatment seeking and encourage treatment choices that are based on a more informed appreciation of the various costs and benefits of specific medications such as antidepressants as well as non-pharmacological interventions.

In conclusion, this qualitative study has illustrated how individuals with IBS seek and appraise treatments in the context of their personal, social, and professional lives, while constantly striving for symptom relief. Treatments are experienced on an emotional rollercoaster of hope through to despair, which for some can be time-consuming and economically costly. Supportive discussions about illness perceptions and treatment beliefs during clinical encounters with health care professionals could improve patients' experiences.

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Conflict of interest

All authors declare no conflict of interest.

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