Patients' experiences of telephone and web-based Cognitive Behavioural Therapy for Irritable Bowel Syndrome: A longitudinal qualitative study

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Abstract

Background: Cognitive behavioural therapy (CBT) is recommended in guidelines for people with refractory irritable bowel syndrome (IBS). However, availability is limited and poor adherence has been reported in face-to-face CBT.

Objective: Nested within a randomised controlled trial of telephone and web-delivered CBT for refractory IBS, the objectives of this qualitative study were to: identify barriers and facilitators of engagement over time with the interventions; identify social and psychological processes of change; provide insight into trial results.

Methods: Longitudinal qualitative study nested in a randomised controlled trial. Repeated semi-structured interviews at three (n=34) and twelve-months (n=25) post baseline. Participants received telephone CBT (n=17 at 3m, n=13 at 12m) or web-based CBT (n=17 at 3m, n=12 at 12m). Inductive thematic analysis.

Results: Participants viewed CBT as credible for IBS, perceived their therapists as knowledgeable and supportive, and liked the flexibility of online and telephone delivery; these factors facilitated engagement. Potential barriers to engagement (mostly overcome by our participants) included initial scepticism and concerns about the biopsychosocial nature of CBT; initial concerns about telephone-delivered talking therapy; challenges of maintaining motivation and self-discipline given already busy lives; and finding nothing new in the web-based CBT. Participants described helpful changes in their understanding of IBS, attitudes towards IBS, ability to recognise IBS patterns, and IBS-related behaviours. Consistent with the trial results, participants described lasting positive impacts on their symptoms, work, and social lives. Reasons and remedies for some attenuation of effects were identified.

Conclusions: Both telephone and web-based CBT for IBS were very positively received and had lasting positive impacts on participants' understanding of IBS, IBS-related behaviours, symptoms and quality of life. These forms of CBT may broaden access to CBT for IBS.

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Keywords

Irritable bowel syndrome; cognitive behaviour therapy; internet; primary care, self management

Introduction

IBS affects 10-20% of the general population [1]. Official UK guidelines for the management of IBS [1] recommend provision of diet and lifestyle advice, a trial of medications and referral for psychological intervention, such as Cognitive Behavioural Therapy (CBT), if patients have ongoing troublesome symptoms after 12 months (refractory IBS). CBT can improve IBS symptom severity and quality of life [2-5]. However, availability of face-to-face CBT for IBS is very limited, is of uncertain cost effectiveness [6] and has issues with poor adherence [7]. The ACTIB trial [8] aimed to determine the clinical and cost-effectiveness of therapist-delivered CBT over the telephone (TCBT) and web-based CBT (WCBT) for IBS. Both TCBT and WCBT groups showed significant improvements in IBS symptoms compared to treatment as usual at 12 months [9,10]. Telephone and Web-based CBT may overcome some of the barriers to traditional face-to-face CBT by offering

better cost-effectiveness for healthcare commissioners and providing greater flexibility in timing and location for patients. However, patients' experiences of these modalities of CBT for IBS have rarely been studied and could provide novel insights into the processes underpinning treatment uptake, adherence, and effectiveness.

We previously explored patients' experiences of using web-based CBT as part of a feasibility trial of the prototype of the web-based CBT programme used in ACTIB[11]. Participants in that study were positive about web-based CBT and described the website as 'well designed and easy to understand and use', though some felt that 'a user had to be self-motivated to work through the material'. Participants engaged with the website to varying degrees, with some having limited or no engagement because 'they did not find the website relevant to them' or 'the website was too impersonal'. Follow up was at just 12 weeks, so experiences of longer-term effects could not be assessed. To the best of our knowledge, this is the only study on patients' experiences of telephone and web-based and CBT for IBS. Studies in other populations suggest that web-based CBT is acceptable and helpful, and allows a level of anonymity when disclosing personal thoughts[12]. Similarly, trials of telephone based CBT in other populations have shown encouraging results in terms of symptom improvement, with no detrimental impact on patient satisfaction[13].

We conducted a large qualitative study nested within the ACTIB trial. Previously reported analyses using this dataset have focused on treatment seeking and appraisal processes [14], patients' perspectives on GP interactions [15], and emotional processing in IBS [16]. The aim of this study was to explore patients' experiences and views of telephone and web-based CBT for IBS immediately post treatment and at 12 month follow up. The objectives were to identify factors that facilitate or impede engagement with web-delivered and telephone-delivered CBT in this patient group both during and after the main intervention period; to identify social and psychological processes of change in the

short and longer term; and to provide insight into the quantitative results of this complex trial.

Methods

The ACTIB Trial and Interventions

The ACTIB trial recruited 558 participants from primary care (GP) and secondary care (gastroenterology clinics) in Southampton and London between March 2014 and March 2016. The participants were randomised to one of 3 groups: Therapist-delivered telephone CBT (TCBT), web-based CBT (WCBT) and treatment as usual (TAU). The TCBT group received 6 one-hour telephone CBT sessions over 9 weeks, a detailed patient manual, and two 'booster' 60-minute follow-up phone calls at 4 and 8 months. The WCBT group received access to the previously piloted IBS digital self-management programme 'Regul8'. Regul8 consisted of 8 online sessions to be completed on a weekly basis, three 30-minute telephone support sessions over 9 weeks, and two 'booster' 30-minute follow-up phone calls at 4 and 8 months. Both intervention groups also received ongoing treatment as usual, in primary and/or secondary care as appropriate. The two interventions contained similar content and the same therapists provided telephone support. The CBT content was based on an empirical cognitive behavioural model of IBS [17] and comprised education, behavioural and cognitive techniques, aimed at improving bowel habits, developing stable healthy eating patterns, addressing unhelpful thoughts, managing stress, reducing symptom focussing and preventing relapse[8]. The TAU group continued with their usual care (in primary and/or secondary care as appropriate) and were offered access to Regul8 on completion of the trial. For further details see the trial protocol [8]. The study was granted approval by the relevant National Research Ethics Service Committee on 11th June 2013 (13/SC/0206).

Nested Qualitative Study

Design

A longitudinal qualitative study was nested within the ACTIB trial, in an embedded mixed methods design with the qualitative component acting in a supportive capacity [18]. Repeated, also known as serial, semi-structured interviews were conducted with the same participants at 3 months and at 12 months. Serial interviews are rarely used in medical research but compared to one-off interviews are better suited to exploring patients' experiences over time and changes therein [19]. We therefore chose serial interviews because our objectives were oriented towards processes that occur in time (e.g. identifying processes of change in the trial) and because we were interested in how patients' experiences and reflections might change from the initial therapy phase to the subsequent follow-up phase.

Data Collection

Purposeful sampling was used to select a range of ACTIB participants to invite for interview. In order to best address our objectives and to capture the experiences of a diverse range of individuals, we sought to interview participants from all 3 ACTIB groups and to include variation within each group in gender, age, ethnic background, geographical location (Southampton or London), symptom severity score and recruitment path (primary/secondary care). 100 of the 558 participants were approached for interview, 58 of whom agreed to take part. The data for this analysis comprise the interviews conducted with people from the TCBT and WCBT groups at 3 months (n=34) and at 12 months (n=24); the characteristics of these participants are summarised in Table 1, demonstrating the breadth of our sample.

Table 1: Baseline Demographic and Clinical Characteristics of Interviewees by Trial Group

	Therapist CBT		**Web-based CBT**		**Total Sample**	
	3 month	12 month	3 month	12 month	3 month	12 month
n	17	12	17	12	34	24
Gender Female, n (%)	13, (76%)	10, (83%)	14, (82%)	9, (75%)	27, (79%)	19, (79%)
Ethnicity, n White British	11	7	12	9	23	16
White other	4	4	4	3	8	7
White Asian	1	1	-	-	1	1
African	1	-	-	-	1	-
Other ethnicity	-	-	1	-	1	-
Age Mean (SD)	39.94 (11.71)	38.4 (10.4)	42.41 (17.37)	45 (18.63)	41.18 (14.64)	41.7 (15.14)
IBS-SSS Baseline score Mean (SD)	283.47 (117.11)	278.58 (126.07)	259.65 (124.39)	219.58 (123.01)	271.56 (119.57)	249.08 (125.35)
Recruitment site, n Primary care	11	8	13	9	24	17
Secondary care	6	4	4	3	10	7
Duration of symptoms in years before study entry Mean (SD)	14.71 (7.10)	12.83 (6.94)	15.59 (8.89)	16.33 (9.24)	15.15 (7.93)	14.58 (8.19)
Length of IBS diagnosis when	7.94 (7.66)	6.5 (6.53)	11.82 (9.22)	13 (8.72)	9.88 (8.59)	9.75 (8.23)

entering the trial Mean (SD)						

Interviews were conducted either face-to-face (n=9) or by telephone (n=49), lasted between 22-113 minutes and were audio-recorded and transcribed verbatim using unique participant identification numbers to preserve anonymity and permit linkage between repeated interviews. A semi-structured topic guide was used flexibly, allowing the interviewer to explore any relevant issues raised by the participants. The topic guide included open-ended questions on expectations about the ACTIB trial and reasons for taking part, previous experiences of IBS therapies and management, experiences of being in the trial and the allocated therapy, and any changes that occurred since starting the trial.

Data analysis

Interviews were read repeatedly before being coded in NVivo (version 11) and analysed by working iteratively with the phases mapped out by Braun and Clark for inductive thematic analysis [20] supplemented with techniques from grounded theory[21,22] (see Table 2). During the final phase of analysis we also mapped the themes and coded data across trial groups and time-points, creating cross-tabulations similar to those produced in framework analysis[23]. An audit trail was maintained including code definitions and memos to document the analytic process.

Table 2: Summary of the Analytic Process.

Thematic analysis phase	Implementation	Supplementary techniques
Familiarization	Initial notes made as transcripts read repeatedly.	Listen to audio-recordings
Generate initial codes	Using the first 22 transcripts initial codes and a coding manual were developed.	Line-by-line open coding on a portion of the data;

	This coding manual was used to analyse subsequent transcripts and amendments were made iteratively when necessary.	constant comparison
Searching for themes	As the analysis evolved, codes related to similar manifest or latent concepts were grouped together. These groupings were considered as candidate themes and sub-themes.	Constant comparison; identify key concepts in the data; write memos
Reviewing themes	Candidate themes and sub-themes were reviewed to ensure they worked in relation to the coded extracts and the individual interviews, and that they captured relevant material from across the dataset.	Constant comparison; search for deviant cases; generate selected case summaries to capture participant stories and changes across 3 and 12 month interviews
Defining and naming themes and their inter-relations	Themes were refined and explicitly defined to clearly and succinctly capture patterns in the data relevant to the research objectives.	Constant comparison
Reporting	Selected compelling examples to illustrate themes and subthemes. Final analysis and contextualisation in relation to the literature and research objectives.	Cross-tabulations (using NVivo's matrix query) to compare theme content and relevance between the TCBT and WCBT groups and between 3 and 12 months.

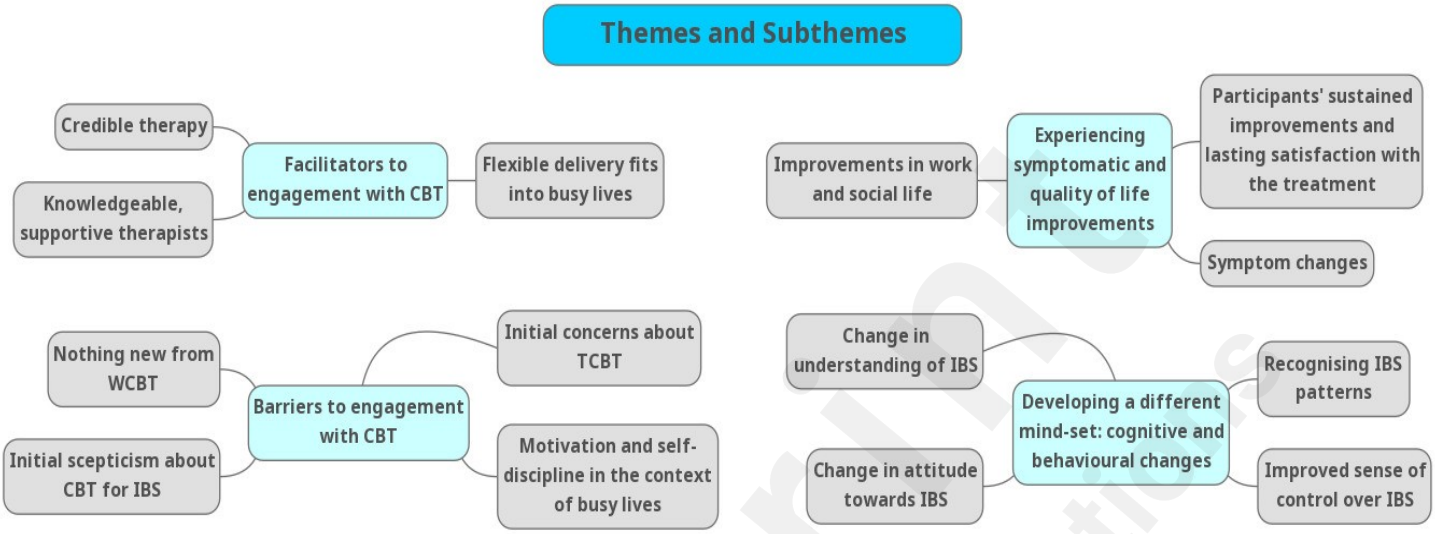
An attempt was made to bracket the influence of the researcher's prior knowledge and assumptions on the coding, while acknowledging that this is never fully achievable and that the emerging analysis is necessarily a product of the interactions between interviewer, interviewee, and analyst, situated within their particular sociocultural, intellectual, and historical contexts. This analysis was guided by the research objectives, supervised by an

investigator experienced in qualitative methods (FB), and led by junior non-clinical researchers trained in qualitative research but not CBT (SH, JMH, AvF) one of whom (SH) was very familiar with the Regul8 intervention. They identified initial themes and sub-themes, some of which resonated with the theoretical processes underpinning CBT. The initial and final themes and sub-themes were reviewed and interpreted (SH, AvF, JMH, AS) with input from trained CBT therapists (RMM, TC) health psychologists (RMM, TC, FB), and an academic GP (HE). RMM and TC led the development of the initial model underpinning the CBT intervention, and HE, SH, AS, and FB were involved in the development of Regul8. The credibility of this qualitative analysis was enhanced by the involvement of multiple researchers and the use of NVivo to facilitate (a) the iterative process of analysis moving between raw data, codes, and themes within a large data corpus and (b) systematic comparisons between and within individual participants.

Results

Four main themes were identified and were evident to some extent within both TCBT and WCBT groups: Experiencing symptomatic and quality of life improvements; Developing a different mind-set: cognitive and behavioural changes; Barriers to engagement with CBT; Facilitators to engagement with CBT. Each theme comprised multiple sub-themes, which are summarised in Figure 1. Below, we discuss the themes in relation to the objectives, highlighting individual sub-themes in bold typeface.

Figure 1: Summary of Themes and Subthemes Capturing Participants Experiences of Telephone and Web-Based CBT for IBS



Identifying Factors that Facilitate Engagement with Web-delivered and Telephone-delivered CBT for IBS

This objective was addressed by the subthemes collated under "Facilitators to engagement with CBT." High levels of satisfaction with CBT were suggested by participants' overwhelmingly positive comments about their experiences at both 3 months and 12 months and may have facilitated and/or reflected high levels of engagement. Participants' views of **CBT as credible for IBS** were shaped by perceptions that the ACTIB CBT: took a systematic well-ordered approach; presented material in a professional, engaging, and accessible manner; and provided clear explanations of IBS and a convincing rationale for CBT. Early improvements in symptoms also contributed to a view of CBT as credible for IBS. This was true for both CBT groups with no clear differences between the groups. A participant in the TCBT group explained:

"Literally after the second week of doing it, sort of reading through the books and

> *then - talking to [name of therapist] for the hour and going through everything, it was brilliant and the fact that it did really help, you know, week by week we were talking about different behaviours and – and I think, literally, I sort of saw improvement quite quickly really." P24547 (3m, TCBT)*

Similarly, a participant in the WCBT group reported:

> *"…overall I was very, very pleased, um, it was nicely laid out, um and I think that it's really contributed into helping me overcome some of the issues that I've dealt with – I've been dealing with – up until that point." P10074 (3m, WCBT)*

Participants in both groups valued being able to talk to **therapists who were perceived as knowledgeable and supportive**. They valued "*just having someone to talk to" (P39446, TCBT, 3m),* and found it particularly helpful to talk to someone who had IBS specific knowledge: *"it's just nice to have someone listen who is kind of – understands all the ins and outs." P45322, WCBT, 3m).* It would seem that the therapists were able to develop positive therapeutic relationships despite being constrained by the telephone to verbal communication only. Affective bonds were also evident, as participants described their therapists as *"really friendly" (P25044, TCBT, 3m), "very nice to speak to" (P20850, TCBT, 3m),* and *"friendly and approachable" (P16084, WCBT, 3m).*

One potential drawback of web-based interventions, at least for some patients, is the lack of human interaction and support [11,24]. The telephone sessions provided to support the WCBT mitigated this risk and participants described how this therapist contact helped to reinforce the messages from Regul8, provided the opportunity to discuss their particular case, and enabled them to ask questions and have them answered. In these ways, the 30-minute

telephone sessions helped to support engagement with the WCBT, in particular:

> *"I think with the actual online sessions, they've been really helpful, but then, being able to talk to them, to my therapist, has really helped me kind of put them into practice. I think, for me, the online sessions themselves weren't enough to deal with my case and my symptoms. I think being able to talk them over with the therapist has kind of – re-cemented things, reaffirmed things and just being able to talk about them as really helped." P28570 (WCBT, 3m).*

> *"talking to (therapist name) was really, really good. That was nice to have that kind of backup support and, you know, I had like – I think it was half an hour and it was a really good amount of time…" P45322 (WCBT, 3m).*

The **flexibility** afforded by both online delivery and telephone delivery was commented on positively by participants. Both modes of delivery were experienced as convenient for participants, who were able to organise their own schedules for completing the online modules and did not have to physically travel to attend appointments. For example, "*I liked the way it was presented and it's certainly helped me because I was able to do it my own time*" P16033 (WCBT, 12m); and "*I liked that it was over the phone sometimes as well, that I didn't always have to go somewhere and park and – that was good*" P25044 (TCBT, 12m).

Identifying Factors that Impede Engagement with Web-delivered and Telephone-delivered CBT for IBS

"Barriers to engagement with CBT" encompassed four main subthemes describing factors that impede engagement with WCBT and/or TCBT. Participants in both groups who discussed **initial scepticism** and **initial concerns** about the biopsychosocial nature of the

intervention also reported mostly overcoming these potential barriers to engagement. Some described feeling sceptical about how CBT could be either relevant or effective for IBS; and this scepticism was typically couched in a perceived Cartesian disjunction between CBT as focused on mental processes and IBS as a physical condition. Scepticism was overcome through beginning the intervention and learning about the cognitive behavioural model of IBS used in ACTIB and developed in an earlier trial [25]. The cognitive behavioural model was presented by starting with the physiological and biological changes that underpin the IBS symptoms and then exploring how these changes can be influenced by thoughts, feeling and behaviours and the autonomic nervous system responses linked to stress.

> *"To be honest, when I started I was very sceptical, I couldn't see how thought processes and things would actually affect your tummy, but when it's explained through the literature and when you speak to a therapist, you can really see the connection between how you think and how your tummy reacts and – I think it just takes somebody to tell you…" P25119 (TCBT, 3m)*

Some participants across both groups expressed **initial concerns** about whether the telephone was an appropriate mode of delivery for CBT as a form of talking therapy. For a few (2 TCBT interviewees, and 4 WCBT interviewees) these concerns persisted and appeared to derive from discomfort with the lack of non-verbal cues in telephone interactions.

> "*obviously over the phone it's slightly trickier than face-to-face. So we don't know what the other person's thinking or anything*" *P40192 (TCBT, 12m).*

Others overcame their concerns once they had started telephone sessions and focused more on the content of the CBT being delivered:

> *"I did think it is odd to do counselling over the phone, but now I think – actually – it*

doesn't matter, it doesn't really matter at all as long as the counselling is good." P40210 (TCBT, 3m)

Participants from both TCBT and WCBT groups referred to the need for **self-discipline and motivation** to complete the homework tasks contained within the CBT programme. Some found it difficult to motivate themselves to do this homework and may have been negatively impacted by the connotations of this terminology:

"I found it hard um… I'm not very good at doing homework and never have been and I don't suppose I will be, um… so where it's given my homework to do, I've not – I've not been, um let's say a Grade A student" P21339 (WCBT, 3m)

Participants described wanting to do the homework in order to experience the anticipated health improvements but also finding it difficult to do this within the context of busy lives and competing priorities. There was a sense in both WCBT and TCBT groups that investing more time in the programme would result in getting more out of it.

"I: What did you dislike about being in this group? P: I think probably the discipline of having to do the homework, but then I wanted to do the – it's kind of a bit of a paradox; I wanted to do the homework because I'm keen to participate and kind of make the best of it, but it's kind of remembering to do it and – having something else to do during the week." P25044 (TCBT, 3m)

"There could have been more I learned from it if I'd maybe done – spent more time on it or done it over a longer amount of time, then I might have got more out of it, but I did get a lot from it." P40567 (WCBT, 12m)

One final barrier that impeded engagement with WCBT for some participants was the sense

that this intervention **did not offer anything new (n = 4)**. This was mostly expressed by participants who felt that they had lived with their IBS for a long time and had already made themselves familiar with and tried to implement recommendations regarding lifestyle issues including diet, stress, and physical activity. Such participants felt that the WCBT did not therefore offer them any new insights or approaches to managing their IBS.

> *"I've followed all the little sections on the trial, looking at your diet, looking at your stress, looking at your activity and I've kind of gone through all of those on my own in the last few, you know, over the years. So-from –from my point of view, I didn't get an awful lot out of it because it was already telling what I already knew." P20066 (WCBT, 3m)*

Identifying Social and Psychological Processes of Change

Social and psychological processes of change were captured in the theme "Developing a different mind-set: cognitive and behavioural changes." Four sub-themes described different changes experienced by participants across both WCBT and TCBT groups: changes in their **understanding of IBS**, changed **attitudes towards IBS**, a newfound ability to **recognise IBS patterns**, and subsequent changes in behaviour associated with an **increased sense of control** over their IBS. At 3 months, participants felt they had an improved understanding of IBS as a reassuringly common condition which they could manage to some extent, based on their personal experience of improvements in IBS since commencing the trial.

> *"I'm really pleased [with that] and it doesn't mean the symptoms are completely gone, but it means that I understand them and I can control some of them. So I think that's something I'm going to keep for life; it's not something I'm going to forget about." P40015 (TCBT, 3m)*

> *"I feel relieved, relieved that – because going through the programme I realised that there are people out there who suffer exactly the same symptoms as I do, that it's actually fairly common" P10074 (WCBT, 3m)*

The CBT programme taught participants to recognise their personal cognitive and behavioural patterns related to their IBS and enabled participants to evaluate their responses to these patterns. When these ideas resonated with individuals they were able to reflect on them and think about things in a different way.

> *"I think like with the thoughts, just being aware of the sort of things that can kind of perpetuate the cycle of stress. I think catastrophizing or black-and-white thinking and things like that, I think I can see them in myself and I think just being aware of that, you can kind of try and take a back step and see it in another way and re-evaluate the situation." P26417 (TCBT, 3m)*

Possibly as a consequence of feeling that they understood their IBS better and could identify their personal patterns, participants also reported changing how they thought about IBS. For example, some described being able to feel more relaxed and less worried about their IBS. This change then appeared to be linked with positive changes in behaviour, for example enabling participants to liberate themselves from ingrained and socially limiting behaviours such as avoiding public or shared toilets.

> *"I started thinking to myself, you know, I don't need to stress and worry about it, there is a toilet here, it's there if I can use it, which has helped, because I used to go home early from parties and things like that with a tummy ache. But now I can just think, you know, I'm working myself up about it and then, more often than not, the feeling goes away and then I'm absolutely fine." P25119 (TCBT, 3m)*

Participants valued the cognitive and behavioural strategies that they developed through the CBT programme when they were found to effectively help manage their (response to) IBS. In this way, both WCBT and TCBT appeared to promote an increased sense of control over IBS and greater self-efficacy for coping.

> *"I would say I'm more in control than um previously because I have a whole series of tools to help me." P20822 (TCBT, 3m)*
>
> *"I feel so much more in control of my IBS and if something flares up I don't feel like it's the end of the world and I know that I've got strategies in place to be able to deal with them" P28570 (WCBT, 3m)*

The cognitive and behavioural changes promoted by the CBT programme were nicely summed up by a participant in the TCBT group who experienced total relief from IBS which was maintained at 12 months:

> "*I now have a different mind-set, if you like, and a few little aids along the way, which help me to – remember the interviews and I don't have any problems and haven't had any problems since the ACTIB course finished." P20822 (TCBT, 12m).*

Insights into the Quantitative Results of the ACTIB Trial

Cross-tabulating the themes by trial group and interview time-point helped to relate the qualitative data to the following key findings from the quantitative trial: the overall effectiveness of WCBT and TCBT, the maintenance of effects at 12 months, and adherence to the interventions.

In the trial, all primary and secondary outcomes showed significant improvement in both

CBT groups compared to TAU at 12 months[9] (the primary endpoint) and the overall pattern was for beneficial effects (in IBS symptom severity, mood, and impact on life roles) to be sustained, on average, from 3 to 6 to 12 months. There was also evidence of some sustained improvements and some attenuation of effects from 12 to 24 months[10]. The theme "Experiencing symptomatic and quality of life improvements" captures the range of patient perceived benefits of the CBT programme. The majority of participants in both therapy arms reported IBS symptom improvements over the period of the study; some participants also described how the symptomatic, cognitive and behavioural changes associated with CBT contributed to improvements in their work and social lives. These improvements were particularly emphasized when participants were interviewed at 3 months but were still very evident in the 12-month interviews, demonstrating the lasting positive impact on the lives of these IBS patients.

> *"I think it is much improved really; I've not had as much sort of constipation as what I used to have, so – so yes – for me, it has been really, really good." P24547 (TCBT, 3m).*
>
> *"if I do have a problem I know I can, you know, let my boss know and she's fine. I'll just say – I'm going to be in a bit late, whereas, you know, like I said before, I just – I would have just been like – I'm sick" Pt 45322 (WCBT, 3m)*
>
> *"I used to be very concerned about going round to people's houses or going out to dinner – or going for food somewhere, because I'd get very concerned that I might have a reaction and I'd need to run to the toilet straightaway and I think that stress and worry beforehand would always then trigger a bout of IBS, but now it's kind of – I started thinking to myself, you know, I don't need to stress and worry about it, there is a toilet here, it's there if I can use it, which has helped." Pt 25119 (TCBT, 3m)*

However, while some participants maintained improvements and felt they would carry these on into the future, others felt they had not managed to maintain earlier improvements.

> "*Unfortunately I'm unable to – control it as I did when I did the study and even though I still do a number of techniques and use the tools that I have learned last year, I've come to think that my mind has become immune to them and knows that these are just things I'm telling myself, but it's not registering; so the mind controls my body, still*." P10074 (WCBT, 12m)

To explore possible reasons why some participants felt they did not sustain beneficial changes after completion of active treatment we classified participants as responders (n=24) and non-responders (n=21) at 12 months and compared the themes and subthemes across these groups. A 'responder' was defined as a participant with a 50-point improvement on the IBS-SSS from baseline to 12 months[8]. This analysis suggested that people classified as responders had more positive experiences of active treatment than those classified as non-responders: at three months the responders talked more about developing a different mind-set and making cognitive and behavioural changes in response to CBT. Non-responders placed more emphasis on barriers to engagement. This suggests that patients' engagement with structured active therapy and their ability to embed cognitive and behavioural changes in their lives are, unsurprisingly, important for longer-term effects. Two case summaries presented in Box 1 help to illustrate this within the broader context of patients' experiences. Participants' reflections also suggest that any attenuation of beneficial effects could be partially mitigated by providing limited ongoing access to a therapist to help discourage relapse into unhelpful patterns.

> *"I would have found it very useful, as I'm sure most participants would, to perhaps*

long-term, for this kind of treatment, have maybe somebody that you could contact, a point of contact from time to time, when you were having a particularly difficult time or needed to be reminded of something or to re-motivate you, because like with all things, if we don't have somebody behind us, I think we tend to have good intentions and then just go back to our old habits" P20850 (TCBT, 12m).

Box 1: Case summaries of a responder and non-responder to TCBT

Two participants were selected for in-depth presentation to illustrate how one responder and one non-responder experienced CBT for IBS. These are not presented as representative cases but rather to showcase the interplay between themes as participants answered open-ended interview questions about their experiences over the course of a CBT trial. Both started the trial with 'severe' IBS symptom severity scores, both were randomised to the TCBT arm, and both completed all of their telephone sessions including their booster calls. Participant P24547 maintained improvements at 12 months and was classified as a responder while P40210 did not.

Participant P24547

P24547 had experienced IBS symptoms for 15 years and did not really expect to benefit personally from the trial, having previously tried many treatments and "*sort of thought it was something I just had to learn to live with, I didn't think that I'd get a huge amount out of [the trial]."* She had not previously tried CBT and did not express any reservations about it. When describing the nature of CBT and its impact on her IBS P24547 emphasized the cognitive aspects of the treatment. For example, when asked about any changes experienced since starting the trial she described how *"I used to get quite stressed and worked up about – people at work. So (therapist name) was always saying that a lot of*

people with IBS have got sort of a level of perfection in themselves and I've definitely changed in the fact that I – I'm trying to do as much as I can, the best – but I don't always – the best I can but I don't always strive for perfection – which – which I think is that sort of side me has really helped, working through those exercises." Related to this perceived need to make active changes to one's thinking patterns, a strong sense of empowerment to make such changes and thus manage any symptoms emerged from P24547's account of CBT. *"I think through this therapy it really sort of highlighted some of the things, even simple things like doing more exercises and – making myself go out and – and not stay in and just sort of think and worry about my pain and get annoyed because of why this is happening to me, sort of thing. It was sort of understanding that there are things that I can do to work with the idea. So – for me – it was sort of being able to recognise the symptoms and then know how to deal with them."* During the trial, P24547 found the interactions with the therapist helped to motivate her to practice implementing her new cognitive and behavioural styles and was concerned that she might struggle to sustain these changes after completing the trial, but at 12 months explained how *"actually I have continued to reflect on things and if I get cross about something, instead of getting myself wound up, which then tends to make my IBS even worse, I do – even literally last week – I got really cross about how something went and I then thought, no; I went to the toilet, I breathed, and I thought, right, how can I see this from their point of view, which is what the manual often went through. So even now I'm still finding it really useful."*

Participant P40210

P40210 had experienced IBS symptoms for 24 years and was struggling with her IBS symptoms, feeling desperate for help at the start of the trial and "*prepared to just try anything, I would have been happy to stand on my head if it had made it better."* She had

"*done CBT before for depression*" and was a little apprehensive about delving into her emotions to start with but appreciated the new insights that she gained from CBT for IBS "*now I know they [thoughts and feelings] are totally linked to my problems. So that's been a positive thing that's come out of it."* When asked about the effects of CBT she evidenced her new insight into her IBS triggers, but emphasized the improvements in her IBS symptoms and did not describe having adopted any cognitive or behavioural changes. *"I have – what symptoms I'm having now ... are a huge amount less, I mean a massive amount less. So it's mainly now wind, a bit of rumbling tummy and a little bit of – a little bit of acid reflux, a very small amount, but I can actually control that if I don't eat certain things. And also – I have had one incident – a sort of very small amount of soiling incident, which is very unusual, I haven't had that for about – three or four years. That was a day when I was particularly very stressed. And – small amounts of pain, you know, sort of spasm-type pain, sort of low down in my tummy, but really – a huge amount less than I had before."* P40210's account of CBT did not suggest that she thought it was necessary to actively work on making cognitive changes to help her IBS. Instead, she seemed to engage with CBT on a more limited basis, accepting a new understanding of IBS but not acting on that understanding, instead focusing on dietary measures. Without cementing the underpinning cognitive changes, P40210 did not manage to sustain her dietary changes at 12 months *"But now a year later, I think I've probably fallen back into probably old habits really and I think a lot of that is to do with the fact that – and I was discussing this with my daughters earlier – the fact that my IBS problems have been going for a considerable length of time. So it's as if the problems have outweighed the solutions, you know, the problems are more dominant than the solutions."*

Quantitative data suggested good levels of adherence to TCBT and WCBT. In TCBT 84% of participants completed at least 4 telephone sessions and in WCBT 88% completed at least

one telephone session while 69% completed at least 4 website sessions. Only 3 interviewees were classified as non-adherent, all of whom had received WCBT, and there was nothing in the qualitative data to distinguish these participants from those that were adherent.

Discussion

Main findings

Participants were overwhelmingly positive about both web-based and telephone CBT for IBS. They described improvements in IBS symptoms, positive changes in their understanding of and attitude towards IBS, a newfound ability to recognise IBS patterns, and change behaviours. This resulted in an increased feeling of control over their IBS and improved work and social life despite some initial scepticism regarding CBT for IBS. They highlighted the need for self-discipline to undertake CBT and maintain behavioural changes in the longer–term, but felt the flexibility of telephone or web-based CBT and high quality therapy input aided engagement.

Strengths and limitations

This study was a rigorously conducted qualitative study that benefitted from interviewing participants just after the CBT interventions to gather immediate perceptions at end of treatment (3 months) along with longer-term perceptions at 12 months. Participants were not interviewed again at 24 months, which reduced our ability to relate our qualitative findings to the 24-month quantitative follow-up[10]. The qualitative interviews enabled an exploration of individual differences in responding that are masked by the necessary focus in the trial data on group-level differences and changes over time. Participants were recruited from both primary and secondary care, which encompassed participants at different stages of their IBS journey, improving transferability to different settings. Participants interviewed had volunteered to take part, and results may have differed from a non-self-selecting sample.

Participants were mostly white, British and female, which is representative of the main ACTIB trial sample, but does not allow us to draw inferences about how people from other demographic groups might experience CBT for IBS.

Comparison to existing literature

To the authors' knowledge this is the largest qualitative study to date exploring the experiences of participants undertaking web-based and telephone CBT for IBS. This study expands on work by Tonkin-Crine et al.[11] by:

- Including participants at two time points; 12 weeks and 12 months post baseline, rather than just 12 weeks
- Using a larger sample
- Including participants who had received telephone-CBT, rather than just web-based CBT

The results from the present study showed similarities to the findings from the Tonkin-Crine et al (2013) study, for example, the overwhelming feelings of positivity about the web-based CBT, and the need for self-motivation to carry them through the programme. However, not all findings were replicated, notably the current findings did not describe the website as 'impersonal' or not personally 'relevant enough'. This difference in findings may be accounted for by the different levels of telephone support in each study; Web-based CBT participants in the current study received three 30-minute telephone sessions and two 30-minute booster sessions, all with a trained CBT therapist. Web-based CBT participants in the Tonkin-Crine et al (2013) study received much less telephone contact (one session of 30-45 minutes) which was conducted by a practice nurse. Participants in the present study valued the telephone support, and the expert knowledge of the therapists, and it may be that this extra contact time with expertly trained therapists addressed these previously reported barriers. Indeed, having individuals providing support who are perceived as trustworthy,

benevolent experts may be vital for such support to effectively engage patients in digital interventions[26].

Conclusions and implications for future practice/research

Future versions of this CBT programme may benefit from addressing the identified barrier around long-suffering IBS patients feeling the web-programme 'does not offer anything new'. It may be helpful for therapists to use Socratic questioning or guided discovery when discussing the patients' personal cognitive behavioural model in the initial telephone call to unpick familiar/unfamiliar areas, and if appropriate, provide reassurance that more novel content will be covered later in the programme.

Participants in the web-CBT group indicated that the small amount of telephone support they received was helpful to keep them on track, provided an outlet to ask questions and talk about their progress. Future research may investigate the minimal amount of therapist contact time needed in the delivery of an effective web-based programme for IBS: which may fall somewhere between the 30-45 minutes of nurse contact offered in the previous trial (Tonkin-Crine et al) and the 150 minutes of therapist contact offered in the ACTIB trial. In addition to this, the longevity of this support/contact time needs to be explored as some participants expressed the desire for longer-term support they could return to when they started to slip back into old habits. The potential source of this longer-term support also needs to be explored, for example, it is unclear whether this would need to be provided by a therapist, a website or a patient's GP.

Both telephone and web-based CBT for IBS were positively received by people with refractory IBS. The flexibility and perceived high quality of the interventions aided engagement. These forms of CBT have the potential to provide a lower-cost acceptable alternative to face-to-face CBT.

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Supplementary Files

Figures

Summary of themes and subthemes capturing participant experiences of telephone and web-based CBT for IBS.