**Adapting “Tame Your Gut” for patients with inflammatory bowel disease and co-morbid anxiety and/or depression Running head:** Online psychotherapy for IBD

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**Abstract**

This qualitative study collected stakeholders’ views on adapting an existing online psychotherapy programme, “Tame Your Gut”, to the needs of patients with inflammatory bowel disease (IBD) and comorbid anxiety and/or depression. Adult patients (n=13), and health professionals with at least two years of work experience with IBD patients (n=12) participated in semi-structured focus groups or interviews, analysed with a thematic analysis. Patients had a generally positive attitude towards “Tame Your Gut”, while health professionals saw it as useful for selected patients only. Both groups indicated their preference for clinician-assisted online psychotherapy. “Tame Your Gut” is acceptable to patients and health professionals but only when supported by clinicians.

**Keywords**: inflammatory bowel disease; psychotherapy; online; qualitative; stakeholders’ views

**Introduction**

Inflammatory bowel disease (IBD) is comprised of two main subtypes, Crohn’s disease and ulcerative colitis. IBD is a chronic debilitating gastrointestinal condition affecting >500,000 people in the UK (Jones et al., 2019). Symptoms of IBD include chronic (often bloody) diarrhea, urgency, pain, anaemia and fatigue.

IBD is frequently accompanied by anxiety and depression, with rates of the former exceeding 60% during disease flares (Mikocka-Walus et al., 2016a). Mental disorders co-morbid with IBD have been associated with more frequent disease flares (Mikocka-Walus et al., 2016b; Gracie et al., 2018), aggressive disease presentation (Kochar et al., 2018), hospital readmissions and increased risk of surgery (Ananthakrishnan et al., 2013).

Despite these associations between IBD and anxiety/depression, mental health is rarely addressed in IBD clinics and psychotherapy remains under-used in IBD. In a large survey (n=731) where 50% of respondents reported distress, only 15% were currently seeing a mental health practitioner, and more worryingly, nearly 70% of those with severe distress had no mental health practitioner (Mikocka-Walus et al., 2020b). High demand for psychotherapy in IBD has been observed in another large survey (n=578)(Klag et al., 2017). A smaller study (n=162) on experiences with psychotherapy noted its usefulness on quality of life, emotional wellbeing, and stress(Craven et al., 2019). However, a disparity between patients’ wishes to discuss their mental health needs and clinicians’ limited interest in the topic transpired. A shortage of therapists knowledgeable about IBD was also raised.

A recent meta-analysis has demonstrated usefulness of psychotherapy, particularly cognitive-behavioural therapy (CBT), in improving quality of life and symptoms of depression in IBD (Gracie et al., 2017). However, this meta-analysis highlighted a dearth of interventions focused on people "in need" of psychological support (e.g. those with comorbid anxiety/depression). This was because most available trials have focused on the unselected patients with IBD, targeting disease activity as the critical outcome. Further, the meta-analysis identified only two trials (both CBT-based) which examined online psychotherapy for IBD (McCombie et al., 2016; Mikocka-Walus et al., 2015). A more recent meta-analysis focused on online psychotherapy in gastroenterology did not identify any additional online psychotherapy trials in IBD (Hanlon et al., 2018)

Online guided CBT has been found to be as effective as face-to-face CBT for several mental disorders (Carlbring et al., 2018). Moreover, in the context of gastroenterology, both of these modes of CBT delivery appear to be superior to treatment as usual (TAU). However, the online intervention proves cheaper than telephone-delivered intervention in terms of quality-adjusted life-years (Everitt et al., 2019). In IBD specifically, biopsychosocial approaches to care have been found to reduce healthcare costs (Sack et al., 2012; Lores et al., 2020). Further, according to a small Australian survey (n=102), patients with IBD seem to prefer online to face-to-face psychotherapy (McCombie et al., 2014). However, the relevant trials show that online psychotherapy is associated with high attrition. This may result from the website format, therapy duration or lack of contact with a therapist (McCombie et al., 2016; Mikocka-Walus et al., 2015) but it is at present poorly understood. One of these studies used the “Tame Your Gut” psychological therapy program for Australians living with IBD (Mikocka-Walus et al., 2015). The second study used a modified (8-week) version of the original 10-week “Tame Your Gut” programme with a New Zealand cohort (McCombie et al., 2016). Apart from this Australian programme, no other online psychotherapy programmes for IBD have been tested to date. Although this online intervention was useful and well received by patients (McCombie et al., 2016; Mikocka-Walus et al., 2015), it was not developed for people with co-morbid anxiety and/or depression.

There is also a lack of qualitative studies conducted on end users’ views and experiences with online programmes in IBD. Qualitative research is essential in shaping future interventions, particularly complex and pragmatic ones, by facilitating the development of personalised / tailor-made approaches (O'Cathain et al., 2015; Jansen et al., 2010; Thirsk and Clark, 2017). In the present case, understanding the needs of patients with a complex mix of IBD and co-morbid anxiety/depression is particularly useful in order to adapt the existing intervention so that it meets the patient expectations.

Of relevance, a recent feasibility trial of a telephone-based CBT intervention for fatigue included a nested qualitative element (Artom et al., 2019). The study’s participants highlighted they improved knowledge and gained behavioural strategies to manage fatigue in IBD. They also praised the convenience of participating in the programme from home. However, their views on the possibility of an online intervention were mixed. Participants recognised the value of having a therapist to support the online intervention in order to guide the sessions, answer questions and ensure compliance with the intervention. Similarly, health professionals were satisfied with the telephone intervention as the anonymity allowed more self-disclosure than is usual in face-to-face psychotherapy. However, picking nonverbal cues was listed as a concern, and one therapist suggested that having some face-to-face sessions (e.g. the first one) would improve engagement in the therapy long-term. One therapist also saw a potential in delivering the intervention online as it could provide a personalised experience for the participants. However, this intervention was run by phone rather than online and the questions related to a hypothetical scenario. Consequently, there is a need for qualitative studies offering examples of online IBD programmes so that patients can visualise how such an intervention might operate. Therefore, in this study “Tame Your Gut” (Mikocka-Walus et al., 2015) served as an example of online psychotherapy, to facilitate exploration of participant views on online psychotherapy.

**Aim**

This study aimed to explore stakeholders’ views on adapting an existing online psychotherapy programme, “Tame Your Gut”, to the needs of patients with IBD and comorbid anxiety and/or depression. The following research questions guided the present study:

* What are stakeholders’ views about online psychotherapy for patients with IBD and comorbid anxiety and/or depression?
* What are the barriers and facilitators to adapting “Tame Your Gut” for this population?

## Methods

The full methods are presented in a previous paper focused on lived experience in IBD (Mikocka-Walus et al., 2020a).Briefly, the study used an exploratory descriptive approach (Sandelowski, 2000) to understand the needs of people with IBD and comorbid anxiety/depression regarding online psychotherapy.

We recruited adults living with IBD and anxiety/ depression and healthcare professionals who have worked with people with IBD for at least two years, via three tertiary gastroenterology services in one region of England. IBD nurses or gastroenterologists invited patients referred to a psychologist in the past or currently on the waiting list with symptoms of anxiety and/or depression. We employed a maximum variation sampling strategy to ensure diversity in terms of illness and demographic characteristics for patients, and role and experience for professionals (Patton, 1990). We also included people with various levels of computer literacy which was established using a self-report.

We conducted focus groups and interviews with patients (depending on patient preference and availability) and interviews with health professionals. Both had a semi-structured nature. A detailed topic guide was developed *a priori* in consultation with a patient representative, psychologists, gastroenterologists, and methodologists. The focus group of three IBD patients lasted approximately 90 minutes. The interviews with the remaining patients lasted between 25 and 45 minutes, and with the health professionals between 20 and 45 minutes. No incentives were provided.

Before the interview/focus group, participants were asked to familiarise themselves with the “Tame Your Gut” website (TAME YOUR GUT, 2019) as an example of how online psychotherapy programme might look like. Participants could refer to the programme during the interview. “Tame Your Gut” ([www.tameyourgut.com](http://www.tameyourgut.com)) is a 10-week, two-hour per week programme, which has been found to improve quality of life in two trials (McCombie et al., 2016; Mikocka-Walus et al., 2015). It comprises the following weekly sessions: 1) Education about IBD and CBT; 2) Stress and relaxation; 3) Automatic thoughts and cognitive distortions; 4) Cognitive restructuring; 5) Exposure and overcoming avoidance; 6) Coping strategies; 7) Assertiveness training; 8) Relationships and communication; 9) Attention and distraction; and 10) Relapse prevention for mental health problems.

Socio-demographic data and information on computer literacy were collected during interviews/focus groups. The data we collected were triangulated by obtaining information from different groups of stakeholders: patients and health professionals (doctors and allied health practitioners). Further, the researchers gathered information using a triangulation strategy by encouraging patients to tell their story, using open questioning techniques, facilitating patient responses, picking up verbal and nonverbal cues, clarifying ambiguous statements (Silverman et al., 2013; Miles and Gilbert, 2005; Patton, 2002), as well as writing the descriptive and reflective field notes (Creswell, 2015).

Thematic analysis following Braun and Clarke’s approach (Braun and Clarke, 2006) was utilised with the help of Nvivo software (QSR, 2018). For this element of the study, an inductive approach to coding was employed in order to build up an understanding from participants about the role of online psychotherapy and appropriateness of adapting “Tame Your Gut” to meet the needs of this patient group. The field notes were read and revised, audio records were replayed, and the preliminary reflection written. The data were coded to help summarise their interpretation (Clarke and Braun, 2013).

The analysis of the data was undertaken in two parts. At first, the health professionals’ and patients’ data were coded separately. The themes from both participant groups were closely aligned, hence we decided to combine them collectively under two overarching categories to distinguish between user- and programme-related factors that were key to understanding how the “Tame Your Gut” programme could meet the needs of people with IBD and co-morbid depression / anxiety, with the differences and similarities discussed.

The transcripts and analysis were checked and validated by two members of the team. A small number of transcripts were additionally double-coded by a researcher not involved in data collection. Any discrepancies were resolved by consulting the senior researcher (JT).

The ethical approval was obtained from the NHS Health Research Authority and the Department of Health Sciences Research Ethics Committee. All participants provided written informed consent before they participated in the study. This research was conducted according to the requirements of the Declaration of Helsinki. **Results**

Data saturation, where no new information was revealed, was reached with 13 people living with IBD and comorbid anxiety and/or depression and 12 health professionals.

Patients’ ages ranged from 20 to 70 years old with a median age of 45 years (Table 1). Of the 13 patients included, nine had Crohn's disease and four had ulcerative colitis. Patients had different disease durations, with some diagnosed one-two years ago 1 (8%) and others over 10 years ago 5 (38%), thus demonstrating the diversity in disease experience across the sample. There was a relatively even split of genders in the sample, with seven (54%) males, and all, except one, were Caucasian. Six participants were employed and four retired. Two participants reported no higher education.

In terms of computer literacy, two older participants (both in their 70s) considered themselves computer illiterate. Six patient participants were recruited from site 1, five from site 2 and two from site 3. In terms of patients’ previous experience with psychotherapy or online IBD resources, two patients had received online psychotherapy, but not IBD-specific. Two patients had previous experience of using Internet apps for depression, however, none used the apps or the Internet for IBD management.

Eight health professionals were female. Their age ranged from 32 to 54 years old. They were consultant gastroenterologists, nurses, dietitians, and psychologists. Eight health professionals were recruited from site 1, three from site 2 and one from site 3.

INSERT TABLE 1

Participants’ views on online psychotherapy such as “Tame Your Gut” for people living with IBD and comorbid anxiety and/or depression were grouped into two overarching categories:

1) Participant-related facilitators and barriers to the use of “Tame Your Gut”;

2) Program-related facilitators and barriers to the use of “Tame Your Gut” (see Figure 1).

INSERT FIGURE1

**User-related facilitators and barriers to the use of “Tame Your Gut”**

Except for one person, all patients expressed positive views about the Internet, mobile apps and participation in online psychotherapy (Table S1).

Patients appreciated the potential of the programme in helping accept their diagnosis of IBD, facilitating education of the disease, improving wellbeing and helping manage IBD flares through managing stress.

Patients expressed willingness to participate and complete the online programme irrespective of age and self-reported computer literacy. These two main factors were suggested by health professionals as potential barriers to participation in online psychotherapy. Less computer-literate patients expressed confidence in their motivation and personal commitment, if help from their family members and encouragement from health professionals was provided.

The differences in the views between patients and healthcare professionals were also observed regarding participation in the programme for less well-educated individuals. Health professionals thought that this group of people would opt-out of participation in the programme. However, patients suggested that people could watch the videos on the programme if they were less keen on reading information.

**Program-related facilitators and barriers to the use of “Tame Your Gut”**

Both groups agreed that the programme was flexible and could increase the accessibility of psychological help. The clinician-assisted version of the programme was preferred to the unassisted version, as it would encourage patients to comply with and complete the programme. In contrast, the health professionals concluded that the lack of human interaction, inability to tailor the intervention to the individual needs and the online format would prevent patients from participation. Most patients agreed that tailoring the intervention to individual needs is essential for the programme to work.

A concordance was observed between the patients and health professionals regarding the technical aspects and visual presentation of the online programme (see Table S2). Most of the patients and health professionals were satisfied with the format and user-friendliness of “Tame Your Gut”, though some suggested the need for a mobile-friendly version.

The health professionals suggested that the intervention should use plain language (a couple of patients preferred the scientific language), bullet points, to be visually cleaner with less text, have introductory videos to each session, and use the videos with patients and health professionals, as well as offer activities to download.

The health professionals expressed different preferences about the number and duration of sessions, varying between three and ten sessions, of 15 min to 1-hour in duration. This variation was also reflected by patients. However, there was more agreement about the specific content that patients wanted to be included in the online programme: other patients' experience, a patient forum, and a chat room. Patients also wanted to see the information about IBD itself, and various management strategies, including coping.

## Discussion

This paper documents the first qualitative study exploring patients' and health professionals' views on online psychotherapy for people with IBD and comorbid anxiety/depression. The study found that online psychotherapy is acceptable for this group and has provided practical suggestions on how to adapt an existing evidence-based, “Tame Your Gut”, programme to the needs of those people with IBD who suffer comorbid psychological symptoms.

“Tame Your Gut” was well-received by the participants who welcomed its format and user-friendliness. There were discrepancies in the responses from the health professionals and patients about the length and number of sessions. The proposed duration varied between 15 minutes and 1-hour and between 3 and 10 sessions. There is no univocal opinion on the number and duration of online psychotherapy sessions. Most studies in a recent systematic review (Hanlon et al., 2018) provided a 10-week therapy. However, a clear link between the length of the programme and the attrition rate was not observed. In fact, a 6-week intervention had a higher attrition rate than some 10-week programmes (Hunt, 2009; Ljotsson, 2011). Given similar efficacy and attrition rates of “Tame Your Gut” when delivered for 10 and 8 weeks (McCombie et al., 2016; Mikocka-Walus et al., 2015), the shorter duration seems more appropriate as it saves resources.

Most participants accepted the plain language and desired less but clearer text. This could be explained by the comorbid fatigue and the fact that patients with IBD and anxiety and/or depression are less able to process large amounts of information (Jamison et al., 1989; van Langenberg et al., 2017; Rock et al., 2014). Therefore, breaking the information into sections and presenting as bullet points would improve the satisfaction with the programme. In addition, participants felt that videos were more personalised than the text. This is supported by the finding of online health interventions for other mental health disorders, where patients found communication through videos to be more personal (Ben-Zeev et al., 2018). In addition, information delivered through videos appears to be more effective than the textual presentation of information, by improving patient engagement, concentration and interest (Lee, 2011; Alley et al., 2014; Soetens et al., 2014; Stanczyk et al., 2016).

Further, participants expressed concern about “Tame Your Gut” not being tailored and wished for future programmes to meet each patient’s needs. Hawkins et al. (2008) suggested that content matching, feedback and personalisation strategies help to attain the tailoring goals (Hawkins et al., 2008). Indeed, tailored online interventions appear to be more effective compared to non-tailored (Strecher et al., 2005; Lustria et al., 2013; De Cocker et al., 2016). Thus, future online psychotherapies should attempt to tailor content to participants’ individual needs.

Although some health professionals suggested that accessing the online programme would require a certain level of computer literacy and education, this was largely not supported by the results of the study. Patients of different ages, levels of education and computer literacy were interviewed and all of them understood the context of the existing programme and indicated that they would access the programme with the help of a clinician or family member. Further, despite the difference in access to psychological services, there were no differences observed with regards to the patients' acceptance of online psychotherapy at different hospital facilities. It is possible that some patients had an optimistic view of the online programme as a result of a very positive outcome of face-to-face psychotherapy. Therefore, they hoped for the same outcome, but without the long waiting list. On the other hand, a previous study exploring patients' willingness to participate in an online psychotherapy programme concluded that patients preferred the online mode of delivery compared to face-to-face (McCombie et al., 2014).

Both groups agreed that personal interaction was important for the success of online psychotherapy. This finding is supported by the wider literature. It also highlights the importance of a therapeutic alliance between a patient and therapist for good treatment adherence. For some patients, this alliance could be the facilitator of change (Barlow, 2014). The evidence from the literature suggests that online psychotherapy, CBT in particular, is effective when therapist-assisted, with the addition of telephone support, or combined with face-to-face interventions (Kessler et al., 2009; Brabyn et al., 2016; Erbe et al., 2017; Everitt et al., 2019; Grist et al., 2019). A systematic review (20 studies, 1418 participants) reported that guided internet-delivered CBT is possibly as effective as face-to-face CBT for some psychiatric and somatic disorders (Carlbring et al., 2018). Guided online interventions were more acceptable and offered by General Practitioners (GPs) in primary care compared to unguided interventions according to a large (n=1044) survey (Breedvelt et al., 2019). Nevertheless, some participants thought that the clinician-assisted or exclusively self-directed programmes should still be an option. Most participants in both groups recognised that encouragement from health professionals would increase compliance and completion of the online programme. Support from a clinician enhances the treatment effects of online interventions for some mental health disorders, including anxiety and depression (Kenwright et al., 2005; Saddichha et al., 2014). Thus, guided online psychotherapy, with some clinician contact, could be considered as a therapeutic option for patients with IBD and comorbid anxiety/depression.

The health professionals were unsure whether patients would agree to access online psychotherapy and complete the programme. However, most patients expressed interest in the programme participation and were confident about its completion. One reason for these varied viewpoints could be that all health professionals, except for one, had no previous experience of using mobile apps or the Internet for IBD or mental health management. However, this was not seen as a barrier for patients. Only two patients had experience of using mobile apps for the management of mental health. One found the intervention very useful, while the other stopped using it and had a negative experience. It is important to acknowledge that self-directed online psychotherapy might not be an appropriate tool for the management of anxiety and depression in some patients with IBD, for example, those with severe anxiety and depression who might require a more-focused approach. This might also reflect the usual practice of some health professionals who refer only those to psychotherapy who present with severe symptomatology. It is important for future research to provide guidance regarding the suitability of different patient groups for psychological interventions in the IBD context. A recent trial suggests that those “in need” of a psychological intervention might actually respond to it to a greater degree than others (Mikocka-Walus et al., 2015).

The health professionals and patients indicated that the online programme could improve the accessibility of psychological support. Therapy delivered online as part of the Improving Access to Psychological Therapies (IAPT) services is already recommended in a stepped care model for people with anxiety disorders and depression in the UK (NICE, 2019) and could widen access to the therapies in general (Kessler et al., 2009). On the other hand, a high dropout rate in online interventions is often experienced. A meta-analysis of data from 2,705 patients on self-guided online interventions for depression reported that such factors as lower education, male gender and co-morbid anxiety significantly increased attrition risk (Karyotaki et al., 2015). These factors reinforce the need for some contact with the clinician to be considered during the implementation of the intervention but also highlight the importance of health professionals being convinced that patients truly accept this approach. Health professionals could then act as the ambassadors for online psychotherapy in IBD.

### Implications

This study demonstrates that people with IBD and comorbid anxiety and/or depression are open to participation in self-directed online psychotherapy. If successful, an online intervention could be integrated into the IBD management. Provision of online psychological help could reduce long waiting lists to a psychologist and take the burden from the overstretched NHS resources and, potentially, reduce healthcare costs.

Patients and health professionals highlight the lack of psychological support and integrated care as a major concern for those with anxiety and/or depression (Mikocka-Walus et al., 2020a). The integration of an online intervention into usual care may fill this gap. Furthermore, online psychotherapy could improve the accessibility of mental health support, as all participants considered this as a significant advantage of the programme.

### Limitations

While prior to the study all participants had received the recruitment pack with the glossary, most participants did not read it. As a result, they had a vague understanding of psychotherapy, and this might have influenced their answers. As an example, one patient thought that it was "just talking", and wanted more "practical things", but after the explanation, they changed their perception. All participants were asked to familiarise themselves with the "Tame Your Gut" website prior to the interview/focus group. However, many participants did not do this. For these participants, the website was available during the interview.

In our recruitment, we relied on health professionals inviting patients referred to a psychologist in the past or currently on the waiting list with symptoms of anxiety and/or depression. This ensured they had clinically relevant levels of anxiety and depression however means that people who had not been vocal about their mental health to the treating team were not included in the study, reducing the sample’s richness.

## Conclusions

Patients had a generally positive attitude towards online psychotherapy such as “Tame Your Gut” while health professionals saw it as useful for selected patients only. Both groups indicated their preference for clinician-assisted online psychotherapy programmes. Such programmes could improve access to psychological help in IBD and patient outcomes.

**Declaration of Conflicting Interests**

The Authors declare that there is no conflict of interest. Outside this work: Dr Selinger reports grants and personal fees from Takeda, AbbVie, Janssen and personal fees from Dr Falk, Eily Lilly, Roche and Fresenius Kabi. Dr Mikocka-Walus reports personal fees from Ferring and Janssen.

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