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***A qualitative study exploring the experience of people with IBD and elevated symptoms of anxiety and low mood and the type of psychological help they would like. Psychology and Health. In press.***

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## **Abstract**

**Background.** People with Inflammatory bowel disease (IBD) are at increased risk of developing anxiety and low mood. We sought to explore the experience of people with IBD and moderate-severe symptoms of anxiety/low mood to identify psychological processes which could be targeted in psychological interventions, as well as the kind of psychological support preferred.

**Methods:** Twenty five participants with IBD and moderate- severe symptoms of anxiety/low mood were recruited for interview. Template analysis was utilised to analyse interview data. We explored the situations, cognitions and behaviour linked to symptoms of anxiety and low mood by people with IBD, as well as the kind of psychological help preferred.

**Results:** Two themes were identified within participants accounts of symptoms of anxiety; “under performance “and “preventing an accident”. Two further themes were identified for symptoms of low mood; “lack of understanding” and “stigma”. Expertise and understanding was the main theme identified for the type of psychological help desired.

**Conclusion:** The analysis highlights situations, cognitions and behaviour linked to anxiety and low mood by people with IBD and the type of psychological support desired. Our findings link to the knowledge and competencies set for psychological therapist working with long- term conditions.

Key words: Inflammatory bowel disease, anxiety, depression, cognitive behavioural responses, psychological support.

## ***Introduction***

Inflammatory bowel disease (IBD) including Crohn's disease and ulcerative colitis, is a long term disease with no known cause or exact cure. Intermittently the intestines become swollen and inflamed leading to periods of debilitating symptoms which include diarrhoea, fatigue and pain in the abdomen. The fluctuating episodic nature of IBD has been reported to disrupt employment, social and leisure activities, relationships and psychological well-being (Restall et al, 2016, Kemp et al, 2012). The empirical evidence suggests the life time prevalence rates of anxiety and depression for people with IBD is as high as 35.8% (Walker et al, 2008). The presence of disturbance to mood has also been identified as an independent risk factor for more frequent disease activity and is associated with a reduced quality of life (Mittermaier et al, 2004, Graff et al, 2006, Mikocka-Walus et al, 2016).

Although disease related factors such as remission status, frequency of relapse, pain severity, and extra intestinal manifestations have been linked to psychological adjustment in IBD, evidence suggests that psychological factors have a comparable influence (Jordan et al, 2016). A recent systematic review found that emotion focused coping strategies, extreme perceptions of the illness and of being stressed were significantly associated with worse mental health outcomes, and this was maintained when controlling for the influence of clinical factors (Jordan et al, 2016). However this body of quantitative research has been criticised for failing to capture the full experience of living with IBD. Qualitative studies have reported that people with IBD fear embarrassing symptoms occurring in public and describe feeling isolated, yet no quantitative studies have utilised measures to assess this (Kemp et al, 2012). These qualitative findings arguably provide a richer illustration of the burden of living with IBD from the patients perspective but currently offer no insight into how these experiences link to symptoms of anxiety and low mood.

Despite this gap in understanding a range of psychological approaches to enhance emotional states, for adults with IBD have been developed and tested. Initially psychodynamic and stress management approaches were trialled with limited efficacy (Timmer et al, 2011). More recently cognitive behaviour therapy has shown some promising results for improving the mental health of adults with IBD post intervention and at 6 month follow up (Knowles et al, 2013). However, apparent across all studies is a lack of information given about which psychological processes were targeted within interventions and how these factors were related to disturbances in mood (Timmer et al, 2011). A pre-requisite for establishing effective and targeted interventions is a more thorough understanding of the cognitive and behavioural responses linked to psychological adjustment in IBD. This has been

demonstrated in the development of CBT interventions specifically for multiple sclerosis (MS), where the intervention was in part based on insights gained through qualitative exploration of the adjustment process (Dennison et al, 2012). For adults with IBD this is of particular importance as they have been reported to express a higher need for psychological support than other chronic disease populations. Further, this need is associated with worries about the disease and symptoms of anxiety rather than with medical variables (Miehsler et al, 2008).

The goal of this mixed method study is therefore to explore and report the experience of adults with IBD and moderate to severe symptoms of anxiety and low mood. Our aim is to highlight commonalities of experience and illuminate psychological processes which it would be possible to target in psychological interventions. It is envisaged that our findings will not only contribute to the content of future psychological interventions but also provide knowledge that will support psychological therapists in achieving the competencies required to deliver it.

Specifically our primary research aims were to 1) investigate the specific situations, thoughts, perceptions, appraisals, beliefs and behaviour that people with IBD describe as linked to their symptoms of anxiety and low mood 2) explore the type of psychological help or support people with IBD and elevated symptoms of anxiety and low mood would like as part of routine medical care. A secondary aim was to consider our findings in relation to the knowledge associated with the competencies set for psychological therapists delivering interventions for long term conditions.

## ***Method***

### ***Study design***

A mixed method research design was adopted for this study. A qualitative approach with in-depth semi-structured face to face interviews was used to explore the experiences of adults with IBD who reported moderate to severe symptoms of anxiety and/or low mood on the GAD7 and PHQ9 measures respectively (Spitzer et al, 2006, Spritzer et al, 1999). Individual rather than group interviews were chosen as participants may have been reluctant to fully disclose personal and sensitive information in a group setting due to fears about judgement or confidentiality. Data were analysed using template analysis as detailed by King et al (2017), a technique which is well suited to answering practical research questions in real world settings. Further, it is compatible with the neo-positivist position assumed by this study in that we aimed to report the reality evident in the data in

relation to participant's experience of symptoms of anxiety and low mood and drew on CBT theory to inform constructs within our analysis (King et al, 2017). This mixed methods study was nested within a larger epidemiological study measuring illness perceptions, anxiety, depression, quality of life and functioning over a 3 month period.

### ***Recruitment***

Participants were recruited through an IBD clinical service in South East London, United Kingdom. Initially people over the age of 18 with a confirmed diagnosis of IBD were invited to take part in a cohort study measuring illness perceptions, anxiety, depression, quality of life and functioning over a 3 month period. A total of 150 people participated in this study, on its completion participants were asked to indicate their willingness to be interviewed. Following the initial analysis of demographic data, interested respondents were organised into subgroups based on their anxiety and depression scores. We then reviewed the pool of participants scoring in the moderately severe to severe range for symptoms of anxiety and/or low mood on the GAD7 and PHQ9 questionnaires (Spitzer et al, 2006, Spritzer et al, 1999) and purposely selected individuals of varied age, ethnicity and gender to represent the diverse impact of IBD. On this basis we selected 33 people for inclusion in the interview group. Of these 3 were not contactable, 2 arranged an interview but were subsequently not contactable and 3 changed their minds about participating. Thus the analysed sample consisted of 25 participants.

### ***Procedure***

Interviews were offered via telephone, Skype or face to face for flexibility and to lessen any potential burden to participants. All participants selected to meet with the lead author (CJ) in person within the clinical service with the interview being scheduled to coincide with their routine medical appointments. Immediately prior to the start of the interview each participant repeated the following measures to establish current levels of anxiety, low mood and disease activity and these are reported in table 1; the generalised anxiety disorder 7 measure (GAD7), a self-report questionnaire which measures key symptoms of generalised anxiety disorder. Scores in the 10- 14 range advocate a moderate level of symptoms, whilst 15 and above implies severe (Spitzer et al, 2006). Symptoms of low mood were measured by the patient health questionnaire, a multiple choice self-report inventory (PHQ9). Scores in 15-19 range signpost moderate symptoms of low mood, a score of 20 or more, severe (Spritzer et al, 1999). Current levels of symptomatic disease

activity were measured by the Harvey Bradshaw Index (HBI) (Harvey et al, 1980) for participants with Crohn's disease and the Simple Clinical Colitis Activity Index for participants with ulcerative Colitis (SCCAI) (Warmsley et al, 1998). The score derived from the HBI is based on 5 items that assess general well-being, abdominal pain, number of liquid stools per day, abdominal mass, and complications or extra intestinal manifestations. The score derived from the SCCAI is based on 6 items that assess daytime and night time bowel movements, urgency, and presence of blood in the stool, general well-being, and extra intestinal manifestations. Scores of <5 on the HBI and <3 on SCCAI are considered to suggest remission (Higgins et al, 2005).

Subsequently a one to one interview was conducted which typically lasted for 45 minutes. All interviews were conducted in English and followed a semi-structured schedule. Once the interviews were completed participants were given the opportunity to ask questions and were provided with information regarding accessing psychological services. All participants completed consent forms. Interviews were recorded and transcribed verbatim by the principal investigator and took place from August 2015-Feb 2016. This study was approved by the NRES committee London-Bloomsbury (REC reference 12/LO/1510).

### ***Data collection***

As this study focuses specifically on the experience of adults with IBD and elevated symptoms of anxiety and low mood an interview guide was constructed by the authors which focused on the following areas (1) situations or events which the person felt most anxious or depressed about, such as specific symptoms of the disease or situations which were difficult because of it (2) the meanings, appraisals and cognitions that were experienced about such events, as well as consequent emotional and behavioural responses (3) the type of emotional or psychological help or support the person would like to receive as part of routine medical care. Key interview questions included "Tell me what you feel anxious/ low about?" Can you tell me some of the things that go through your mind when you feel anxious or low in mood? What do you do when you feel anxious or low to cope with the situation? What help or support would you like with this as part of your IBD treatment & care? The interview schedule was piloted with two patients prior to the study commencing and no amendments were found to be necessary as a result.

### ***Data analysis***

All interviews were transcribed verbatim and analysed by the principal author (CJ) using template analysis (King et al, 2017), assisted by Nvivo version 10 ([http://www, qsrinternational.com](http://www.qsrinternational.com)). This deductive method was chosen because it is suited to studies with particular applied concerns which need to be incorporated into the analysis. Commonly the first procedural step involves identifying some potential “A priori” themes which are pertinent to the research question and expected in the data. Given the aims of this study, our initial template for analysis was organised around 1) symptoms of anxiety and associated situations, beliefs and behaviour 2) symptoms of low mood and associated situations, beliefs and behaviour 3) the type of psychological help wanted. Interview transcripts were analysed on a manifest level where visible and obvious components of the text relating to these broad domains were identified, coded and grouped into meaningful clusters. Consequently several subthemes were identified within each “A priori “theme. These detailed situations participants described as sources of symptoms of anxiety and/or low mood as well as specific cognitive and behavioural responses to these. As we aimed to hi-light commonalities in experience features in the data were considered a subtheme if they occurred across four or more transcripts. Data not fitting any themes or subthemes was placed in its own category and then reanalysed. No further themes were identified as a result. To ensure rigour, the final template was reviewed by two of the authors (CJ & RO). Themes and subthemes were verified through discussion and with reference to examples found in the qualitative data. Any disagreements were resolved through discussion with TC. CJ is an experienced psychological therapist with an interest in understanding and treating distress in IBD. Both RO and TC are experienced qualitative researchers and clinicians with an interest in understanding distress in long term conditions. The final template is presented in appendix A.

### ***Validity***

We followed the approach of Creswell and Miller (2000) to strengthen the credibility of our findings. Firstly to minimise the risk of researcher bias a consistent interview process was adhered to. Secondly, all themes are illustrated with rich descriptive quotes which were taken directly from raw data. Finally, a small group of participants reviewed our findings and considered their relevance and accuracy. No amendments were requested as a result of this.



## **Results**

### **Participants**

A total of twenty five individuals, 11 males and 14 females participated in this study. Eleven had a diagnosis of Crohn's disease and fourteen ulcerative colitis. Based on self- report scores derived from the Harvey- Bradshaw index of Crohn's disease activity (HBI) and Simple Clinical colitis activity index (SCCAI) the majority of the participants were currently in remission. The mean age of participants was 36.5 years (range 22-68 years), mean time since diagnosis was 5 years (range 1-20years). The participants reported a range of ethnicities. All participants scored in the moderate to severe range for depressive symptoms on PHQ9 (range from 11-20) and/ or symptoms of generalised anxiety disorder on GAD7 (Range 11-21) at the time of interview. Demographic, psychological and disease related factors are shown in table 1.

Table 1 about here.

### **Findings**

To align with the focus of this study our analysis concentrated on three main areas;

1. Symptoms of anxiety and the situations, appraisals, beliefs and behaviour linked to these emotional experiences by people with IBD.
2. Symptoms of low mood and the situations , appraisals , beliefs and behaviour linked to these emotional experiences by people with IBD.
3. The type of psychological support wanted.

These overarching themes, and their component subthemes will now be described and discussed with the use of illustrative quotes.

#### **1. Symptoms of anxiety**

The majority of participants associated their symptoms of anxiety with concerns about their ability to function at work due to episodic disease activity. Anxiety was also linked to attempts to influence or manage the onset of symptoms. Participants were particularly anxious about preventing an accident when out in public and this promoted a range of behavioural responses designed to minimise the probability of this occurring.

### ***Underperformance at work***

Participants reported being anxious that either absence or reduced functioning in the work setting due to symptomatic disease activity, would result in their reputation being compromised. As a consequence, participants described being concerned that they would be side-lined into a lesser role or at worse sacked or made redundant, although there was no objective feedback to suggest this. The financial impact should this happen was identified frequently as a major source of anxiety for participants. For example one participant said;

“It’s stressful when it comes to work and my finances. I am a self- employed actress and I really worry about the impact being ill is going to have on this. If I get sick and take time off, or last minute I can’t make it in then people will think I am unreliable and won’t offer me any further work. It goes on reputation a lot and if mine becomes sketchy I don’t know what will happen. If I don’t get paid you can imagine, how I will pay my mortgage and all that” (P1, age 47, UC)

Participants described an all or nothing behavioural response to these cognitions. This entailed working extended hours and taking on more whilst feeling well, to compensate in advance for future periods of reduced functioning due to illness. For example one participant said;

“When I think a flare might be coming on I do as much work as I can before , get as much done as possible because I know I might need to stop soon and take time off ” (P2, 40 CD).

This boom or bust behaviour was described by participants as having negative consequences in that it led to tiredness or fatigue which was cited as a further risk factor for underperformance at work. Participants frequently described a pattern of cycling between periods of excessive occupational activity followed by periods of retreat. For example one participant described;

“I exhaust myself to get as much done as I can if I am feeling ok, I then worry about how I am going to get on with all my work when I am so exhausted after doing so much. I feel like I am going to slip even further behind, I but I have to stop , rest, do nothing for a bit before I can get on with any more” (P13, 43 UC)

IBD symptoms has been reported to disrupt work activities in previous qualitative studies (Devlin et al, 2014). Our findings link this experience to specific concerns about the consequences of underperformance in the work place and to feelings of anxiety. This was reported to motivate an all or nothing behavioural response which was thought to be unhelpful for energy levels and perpetuated concerns about occupational underperformance. These psychological processes could

be addressed in a psychological intervention and a more helpful behavioural response could lead to a reduction in anxiety and more consistent energy levels.

### ***Preventing an accident***

The accessibility of toilets was described by participants as a significant source of anxiety which persisted even when a flare episode had subsided. Participants reported panicking when they were in a situation where toilet accessibility was obstructed or absent or when considering future situations where this might be the case. In both examples, this particular anxiety was described as being an overwhelming experience that it was difficult to disengage or become distracted from. For example one participant reported;

“I have a job where I am dealing with staff and students all day long, face to face. So I find myself in the middle of conversations thinking what if I need the toilet, how will I get out of this meeting? As soon as I think that I can’t focus any more I am just thinking about needing to get out, dreading anyone being in the toilet, I get really panicked about this” (P7, UC, age 34)

In order to manage these anxieties participants reported multiple behavioural strategies intended to manage or minimise anxiety about the occurrence of an accident in public. These included avoiding or restricting the use of public transport or where possible opting for transport that provided a sense of being more in control such as cycling. For example one participant said;

“I won't get on the tubes, I started to cycle to work as that way I can stop if I need to” (P9 aged 24 CD)

Having knowledge of the whereabouts of toilets and carrying spare clothes in case of “an accident” was another way that participants described managing their anxiety in this situation. In addition participants described getting up extra early in order to extend the time available to use the toilet in the mornings before leaving the house and reported restricting both what and when they ate. For example one participant described;

“I just don’t eat through the day and only eat in the evenings to avoid possible accidents. If there is nothing in there then there is nothing that can come out is my thinking”. (P11 age 48 UC)

On occasions participants described avoiding leaving the house. This was reported as a last resort strategy when feeling overwhelmed by the preparation considered necessary to minimise an accident outside of the house. Participants reported that this had negative consequences for their

mood as they were concerned that this would leave them susceptible to becoming socially isolated. For example one participant described;

“I just don’t go out some times, sometimes because I am not feeling well or am tired or just can’t face the anxiety of going out, getting prepared and not knowing what my bowels might do, I feel low then, stuck in the house, it worries me that I might end up a bit isolated” (P12 Age 62 CD)

Clearly participants go to considerable lengths to manage or minimise their anxiety about toilet access both in the moment and in anticipation of future situations. An unintended consequence of continuing to plan journeys around toilet locations or carry spare clothes beyond a flare episode seems to be that it maintains focus and attention on the feared event. Maintaining close proximity to toilets and having concerns about an accident occurring in public has been identified as part of the burden of living with IBD in several previous qualitative studies. Our findings link this behaviour and concern with symptoms of anxiety and indicates specific behavioural responses which it may be beneficial to target in a psychological intervention to reduce anxiety.

## **2. Symptoms of low mood**

Perceiving that others misunderstood IBD was reported by participants as a source of low mood which often led to social withdrawal. Where participants believed others were familiar with the illness this was often reported to lead to fears about judgement and stigma. In both examples illustrated below, perceiving others to hold negative and inaccurate judgements seems to be focal to the participants behavioural reaction.

### ***Lack of understanding from others***

The vast majority of participants linked feeling low in mood with perceiving a lack of understanding from their family members, friends and employers. Frequently interviewee’s reported that IBD was mistaken for irritable bowel syndrome which they felt underestimated the severity of their condition. As a result participants reported that they often felt that others were dismissive of their symptoms and lacked empathy towards them. In response to this participants reported withdrawing socially; for example one participant said;

“With friends I don’t think they understand that it’s not IBS, and that its chronic it will always come and go. Nobody understands so I just don’t bother talking about it or seeing people, it’s miserable, I feel low” (P7, UC, age 34)

This behavioural response was linked By withdrawing from friends the opportunity for social support is reduced and the perception “that no one understands” is likely to remain intact. The resulting isolation is reported to be unhelpful for mood as it perpetuates feeling low. IBD has been found to impact on relationships in previous qualitative studies. Our findings link this experience to low mood and highlights the perceptions and appraisals about others which motivate social withdrawal. To improve mood these appraisals could be tested for accuracy by increasing social activity as part of a psychological intervention. to low mood by participants.

### ***Stigma***

Some participants also linked feeling low in mood with concerns that they would be stigmatised and alienated by others due to the nature of the symptoms of IBD being focused around the bowels. Participants were particularly concerned that others would think they were unclean and as a consequence would avoid them or not want them involved in food preparation. For example one participant described;

“I am not the person you want preparing food. It’s the difference between the charity shop and a designer boutique. If you go to a charity shop you might touch things and then use hand gel, I am the charity shop, it’s depressing” (P12, UC age 29)

Behaviourally participants described a range of strategies intended to overcompensate for these concerns. Participants described appearing well groomed to others as a necessity and reported going to great lengths to demonstrate high levels of personal hygiene, for example one participant reported;

“I make a big effort to show them that I am washing my hands before I prepare food or touch anything” (P21, UC age 50)

For some participants concerns about stigma extended to their consideration of prospective romantic relationships as IBD was seen as a major obstacle to establishing a relationship. Concerns often focused on whether the disease rendered them unattractive to others for example;

“I can’t imagine anyone finding me attractive what with this. Who wants a girlfriend with gut problems, it’s depressing” (P23, CD age 30).

Participants described how this often meant they avoided disclosing their diagnosis for some time or underplayed the impact of their symptoms. This potentially contributes to the perception that

others misunderstand IBD. Testing out the accuracy of appraisals linked to feeling misunderstood and stigmatised may therefore be central to a psychological intervention targeting low mood in IBD.

### ***3. Psychological support: Expertise and understanding***

Overwhelmingly participants described that they would like some support from a professional with specialised knowledge of IBD, its symptoms and emotional impact. Interviewee's reported wanting to make sense of the illness, their emotions and coping strategies. For example one participant said;

“A professional to talk to who knows about the illness, gets it. To help me work out some of this stuff. Help me think through decisions I am making, work out what helps and what doesn't. Someone to share it with I guess and get some feedback” (P25, CD age 45).

Participant accounts highlight a motivation to adjust to the demands dictated by IBD and a desire for professional support to achieve this. Knowledge of IBD and its biopsychosocial impact was identified as crucial for the psychological therapist providing such support and we anticipate that our findings might be useful for developing this. Given that participants in our study cited feeling misunderstood as source of low mood, familiarity with IBD may be essential for psychological therapists to achieve competency in working with this group.

Some participants reported that talking to other people with IBD in a group setting was useful as it helped to normalise the experience of IBD and reduce the sense of being alone, for example one interviewee said;

“It helps to talk and to know that there are others that are experiencing the same. Talking to others has been useful, I joined a support group and that was useful” (P8, UC age 42).

This suggests that there may be advantages to delivering a psychological intervention in a group format. It could provide participants with a shared experience which may counteract the social isolation frequently described by participants in our study as a consequence of symptoms of anxiety and low mood.

## ***Discussion***

The results of our analysis link symptoms of anxiety for people with IBD to concerns about occupational underperformance and having an accident in a social situation. Within each of these domains distinct cognitive and behavioural responses have been described by participants and are

illustrated in figure 1. Participants main behavioural response to concerns about the consequences of reduced occupational functioning was to increase their workload in order to compensate in advance for future periods of sickness. This type of boom or bust behaviour whereby sustained periods of excessive activity are followed by episodes of withdrawal has been linked to fatigue in several long term conditions such as multiple sclerosis (Skerrett et al, 2006). Our results show that participants frequently linked this behaviour to fatigue which was perceived as a further risk factor for occupational underperformance. Adopting an all or nothing behavioural response in this context may therefore be unhelpful for people with IBD in that it may precipitate or maintain fatigue which could perpetuate concerns about underperforming and maintain anxiety levels. In addition this may influence the course of IBD as elevated levels of anxiety and stress have been linked to more frequent disease activity in several longitudinal studies (Camara et al, 2009, Mokoka-Walus et al 2016).

**Figure 1. Here**

A prevalent concern for the vast majority of participants was preventing the occurrence of an accident in public. This is consistent with the results of several previous studies exploring the lived experience of people with IBD (Dudley-Brown, 1996, Burger, 2005, Hall et al, 2005). Importantly the results from our study suggest that it is the perception or recognition that a toilet is inaccessible that triggers feelings of anxiety, rather than symptoms or sensations originating from the bowels. In response to this anxiety participants described a wide range of behaviours from changing modes of travel and carrying spare clothes to adjusting eating habits. Coping behaviours such as these which are intended to manage the anxiety and prevent the feared event occurring have been identified in a range of anxiety disorders and are referred to as safety seeking behaviours (Salkovskis, et al, 1998). Although arguably helpful in the short term, over prolonged period's safety seeking behaviours have been found to amplify anxiety by maintaining attention and focus on the feared event and preventing a realistic appraisal of it. In the context of IBD, a flare up in disease activity might initially necessitate a hyper vigilance towards symptoms and safety seeking behaviours such as knowing the location of toilets. Once symptoms begin to subside this selective attention to symptoms may be less useful and serve to focus the individual's attention on the feared event and provoke feelings of anxiety. As anxiety has been associated with increased bowel frequency in several studies (Gorard et al, 1996), this may cloud appraisals and maintain this fear.

Feeling misunderstood and stigmatised was linked to symptoms of low mood by participants in this study. Participants described thinking that others would find them less attractive as a potential partner and would not want them involved in food preparation given the nature of their IBD

symptoms. In response to these concerns participants described overcompensating by demonstrating excessive cleanliness, a behaviour likely to focus attention and perpetuate preoccupation with this concern. Perceptions of stigma have been linked to depression in one previous study (Taft et al, 2009). In response to thinking that others misunderstood their illness participants described cancelling social plans. This pattern of behavioural disengagement was apparent across other subthemes identified in our analysis as participants also reported withdrawing from social events to prevent accidents occurring in public. In all cases participants described feeling low in mood as a consequence. Behavioural withdrawal and avoidance has long been associated with low mood in the wider psychological empirical literature and is considered to be a perpetuating factor for depression (Ferster, 1973). Multiple quantitative studies of the psychological correlates of IBD have also linked this type of behaviour to poor psychological health (Seres et al, 2008, Dorian et al, 2009, Mussell et al, 2004, Petrak et al, 2001). Reducing activity levels in response to the many concerns and challenges posed by IBD is therefore likely to be unhelpful for mood. As depression has been found to lead to earlier and more frequent relapse in IBD, it is possible this behavioural response may also exert an indirect influence on disease activity and vice versa (Mikoka-Walus et al 2016).

Overall our analysis highlights the situations, cognitions and behaviours linked to symptoms of anxiety and low mood by people with IBD and we have hypothesised some potentially unhelpful interactions between these factors. Anxiety related responses appear catastrophic and lack acceptance whilst responses related to low mood were more characterised by hopelessness and withdrawal. Encouragingly cognitive and behavioural responses are potentially modifiable factors which it is possible to address in a psychological intervention and the vast majority of participants in our study stated a desire for psychological support. Significantly, our findings suggest a strong preference for this to be delivered by a compassionate practitioner who can draw on specialised knowledge of the key symptoms of IBD and their impact on functioning and mental health, with a focus on building coping strategies.

Transdiagnostic cognitive behavioural therapy (TD-CBT) would be well suited to promoting more adaptive responses in order to restore disruptions to mood. This approach is based on traditional cognitive behavioural principles with a particular emphasis on the way people respond to their emotions. Strategies include psychoeducation to introduce the main components of an emotional experience, namely thoughts, physical sensations and behaviour and the reciprocal relationships between these domains. This three component model is then employed across sessions to recognise



and track emotional experiences. This enables the individual to understand their responses to emotional triggers and situations and assess the short and long term consequences of their emotion driven behaviour. Where behaviour is identified as unhelpful the individual can work towards acting in alternative ways. For example, anxiety was linked to toilet accessibility when travelling on trains by participants in our study. A common behavioural response was to stay close to the toilet and monitor its occupation. On consideration, this might be recognised as unhelpful in that it maintains attention and focus on the feared event and amplifies feelings of anxiety. An alternative response might therefore be to sit slightly further away and focus attention on a more neutral activity thus lessening preoccupation and anxiety. Mindfulness and attention training exercises are employed to encourage such present focused awareness and support the development of alternative adaptive emotional responses. A recent meta-analysis which included 24 RCT's found that transdiagnostic CBT treatments outperformed control conditions for reducing anxiety and depression and improving quality of life (Newby et al, 2014).

Finally, our findings suggest that Psychological therapists working with this group would require advanced skills in conducting bio-psychosocial assessments in order to gain a clear picture of the differing psychological processes impacting on mood and levels of anxiety. Recently in the UK, a national curriculum was established to ensure efficacy in the delivery of psychological therapies for anxiety and depression in long term health condition. Our findings link to and support a range of competencies set out to achieve this demonstrated in table 2 (Roth & Pilling 2015).

[http://www.ucl.ac.uk/pals/research/cehp/research-groups/core/competence-frameworks/Psychological\\_Interventions\\_with\\_People\\_with\\_Persistent\\_Physical\\_Health\\_Problems](http://www.ucl.ac.uk/pals/research/cehp/research-groups/core/competence-frameworks/Psychological_Interventions_with_People_with_Persistent_Physical_Health_Problems)

***Table 2 about here.***

### ***Implications***

The findings of this study may therefore have clinical and training implications. To the authors knowledge this is the first time that anxiety and depression has been linked to differing yet specific aspects of IBD and with distinct cognitive and behavioural responses. Psychological therapists will be able to draw on these findings to increase their competency in working with this group of people.

Further these insights could assist clinicians working in IBD services with early detection of disturbances to mood for people with IBD and encourage referrals to psychological services for appropriate support and treatment. This may prevent poor mental health from negatively

influencing outcomes for people with IBD. Pharmacological treatment of emotional symptoms may also be beneficial (Jordan et al 2016).

### ***Future directions for research***

Our findings provide a framework which could be utilised in future studies. The themes participants identified as sources of anxiety and low mood along with the cognitive, behavioural and emotional responses to these should be measured in quantitative studies exploring the psychological factors linked to psychosocial adjustment for people with IBD. The findings of this study could also be utilised to inform the content of psychological interventions to improve mental health outcomes for people with IBD and to help psychological practitioners achieve competency in their delivery.

### ***Limitations***

This study does however have some potential limitations. Our participants had all taken part in an online survey measuring illness perceptions, anxiety, depression, quality of life and functioning and may therefore be more motivated to pursue psychological or emotional support. It is arguable that our deductions are therefore based on a specific cohort of adults with IBD which may not be generalizable to the wider population, although our findings are congruent with, and build on those of previous studies.

### ***Conclusion***

Our analysis of participant accounts illustrates that concerns pertaining to underperformance and preventing an accident link to symptoms of anxiety whilst low mood was associated with a lack of understanding and stigma. In each of these domains distinct cognitive and behavioural responses were described by participants. Participants in our study stated a desire for psychological support delivered by a professional with specialised knowledge of IBD to evaluate and build their coping strategies. Practitioners will be able to draw on the findings of this study in order to understand the specific psychological processes that contribute to the development and maintenance of symptoms of anxiety and depression for people with IBD.

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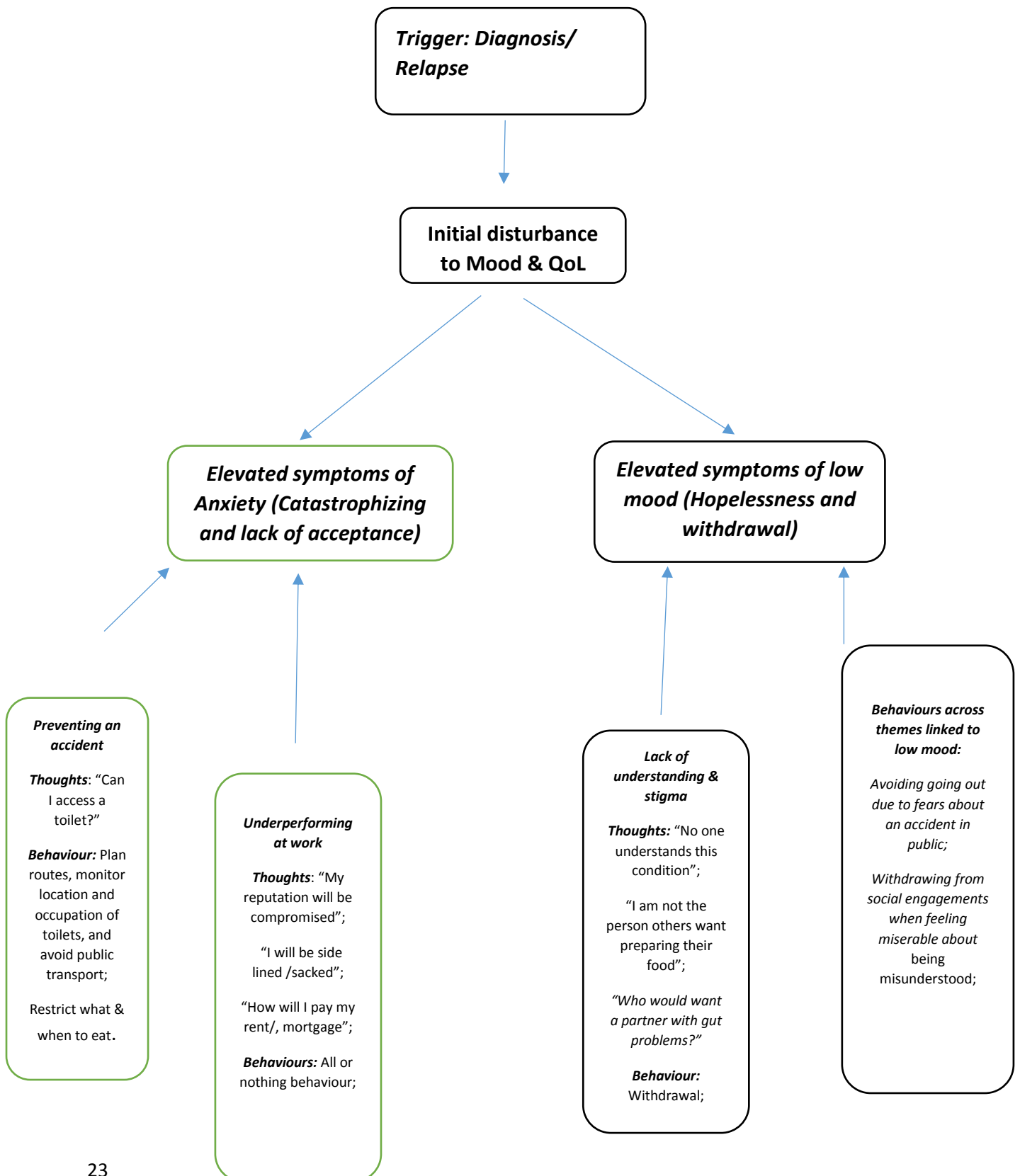
Table 1: Sampling Characteristics

|                                     |                     |          |
|-------------------------------------|---------------------|----------|
| <b>Female</b>                       | 14                  | 56%      |
|                                     | <b>Total (n=25)</b> | <b>%</b> |
| <b>Age</b>                          |                     |          |
| 20-29                               | 6                   | 24%      |
| 30-39                               | 10                  | 40%      |
| 40-49                               | 4                   | 16%      |
| 50-59                               | 2                   | 8%       |
| 60 and over                         | 3                   | 12%      |
| <b>Ethnicity</b>                    |                     |          |
| British white                       | 16                  | 64%      |
| British Caribbean                   | 3                   | 12%      |
| British African                     | 1                   | 4%       |
| Irish white                         | 2                   | 8%       |
| Turkish                             | 2                   | 8%       |
| Spanish                             | 1                   | 4%       |
| <b>Ulcerative colitis</b>           | 14                  | 56%      |
| <b>Crohn's disease</b>              | 11                  | 44%      |
| <b>Symptomatic disease activity</b> |                     |          |
| Inactive (<5 HBI) ( <3 SCCAI)       | 19                  | 76%      |
| <b>Disease duration</b>             |                     |          |
| < 1yr                               | 3                   | 12%      |
| 1-3 yrs.                            | 7                   | 28%      |
| 5 -6 yrs.                           | 6                   | 24%      |
| 7-10 yrs.                           | 5                   | 20%      |
| 15-20 yrs.                          | 4                   | 16%      |
| <b>Anxiety (GAD7)</b>               |                     |          |
| Moderate (10-14)                    | 10                  | 40%      |
| Severe (>15)                        | 15                  | 60%      |
| <b>Depression ( PHQ9)</b>           |                     |          |
| Moderate (15-19)                    | 21                  | 84%      |
| Severe (20- 27)                     | 4                   | 16%      |

**Table 2: Results linked to therapist competencies.**

| <b>Theme and findings relevant to competency</b>  | <b>Knowledge associated with competencies identified in the national curriculum for long term conditions</b>  |
|---|---|
|   | Ability to draw on knowledge of specific psychological process that contribute to the development and maintenance of distress, depression and anxiety, such as:   |
| <p><b>Theme: Symptoms of anxiety:</b><br/> <b>Sub theme:</b> preventing an accident.</p> <p>Selective attention to symptoms and toilet accessibility.</p>   | <p>- Attentional processes that increase the perceived severity and pervasiveness of sensations and symptoms</p>  |
| <p><b>Theme: Symptoms of anxiety:</b><br/> <b>Sub theme:</b> preventing an accident.</p> <p>Safety seeking behaviours: changing modes of transport carrying spare clothes, restricting what to eat and when. Mapping out the location of toilets.</p>   | <p>- Safety seeking behaviours which are understandable in the short-term, but which (in the long-term) tend to strengthen unhelpful beliefs, increase preoccupation and exacerbate concern</p>   |
| <p><b>Theme: Symptoms of anxiety:</b><br/> <b>Subtheme:</b> underperforming at work: I will be sacked.<br/> <b>Sub theme:</b> preventing an accident: what if the toilet is inaccessible?</p>   | <p>Catastrophizing and/or worry (“preparing for the worse”) which in turn primes negative ideas and increases preoccupation and may lead to procrastination</p>   |
| <p><b>Theme: Symptoms of anxiety</b><br/> <b>Sub theme:</b> underperformance at work: cancelling plans to rest.<br/> <b>Sub Theme:</b> preventing an accident: reduction in social activity.</p> <p><b>Theme: Symptoms of depression</b><br/> <b>Sub Theme:</b> lack of understanding: social withdrawal.</p> | <p>Unhelpfully restrictive behaviour, such as generalised withdrawal from physical activity or from role-related activity (such as relationships, work, and hobbies), leading to impaired mood, confirmation of unhelpful beliefs, reduced self-efficacy and disengagement from rewarding activities.</p> |
| <p><b>Theme: Symptoms of anxiety</b><br/> <b>Subtheme:</b> under performance at work: Boom or bust behaviour</p>  | <p>All or nothing (“boom or bust”) behaviours (undertaking activities beyond the level of which the person is physically or psychologically capable, resulting in symptom surges (e.g. fatigue, pain) and leading to more negative appraisal</p>  |
| <p><b>Theme: Expertise &amp; understanding:</b><br/> knowledgeable about IBD, understanding, supportive</p>   | <p>Ability to reflect upon the assumptions and expectations that people with LTHC may have about being referred for assessment and treatment and how this may impact on engagement</p>  |

**Figure 1: Thematic map of cognitive, behavioural responses linked to symptoms of anxiety and low mood in IBD.**





## **Appendix A.**

### **Final Template.**

#### **1. Symptoms of anxiety**

1. Underperformance: Work
  1. Cognitive and behavioural responses
2. Preventing an accident
  1. Cognitive and behavioural responses

#### **1. Symptoms of low mood**

1. Lack of understanding
  1. Cognitive and behavioural responses
2. Stigma
  1. Cognitive and behavioural responses

#### **3. Psychological support**

1. Emotional support