Lived experience in people with inflammatory bowel disease and co-morbid anxiety and depression in the UK and Australia

**Abstract**

This study explored the lived experience of people with inflammatory bowel disease (IBD) and anxiety/depression. It utilised a deductive biopsychosocial framework. Overall, 24 patients and 20 healthcare professionals from two countries participated. In the UK, the main themes included: 1) Bidirectional relationship between IBD and mental health, 2) The need for health care integration, 3) Lack of awareness about the disease. In Australia: 1) The “vicious cycle” of IBD and psychosocial health; 2) The need for biopsychosocial healthcare integration; and 3) The stigma of a hidden disease. Better communication around mental illness is essential in improving IBD healthcare.

**Keywords**: anxiety; depression; healthcare needs; inflammatory bowel disease; lived experience

# Introduction

Inflammatory Bowel Disease (IBD) is a chronic and relapsing condition affecting 300,000 people in the UK (CCUK, 2019) and 80,000 in Australia (CCA, 2019). The main IBD subtypes are Crohn’s Disease (CD) and Ulcerative Colitis (UC). IBD is increasingly considered a disease where brain-gut and gut-brain interaction plays an important role in patients’ symptoms and quality of life (Gracie et al., 2018). This bi-directionality is further evidenced by very high rates of anxiety and depression co-morbid with IBD as compared to the healthy population (Mikocka-Walus et al., 2016a), which are associated with more frequent IBD relapses (2016b), a more aggressive presentation of a bowel illness (Kochar et al., 2018), are linked to hospital readmissions and to increased risk of surgery (Ananthakrishnan et al., 2013). Even during remission, 28% and 20% of patients report symptoms of anxiety and depression, respectively, while these rates rise to 66% and 35% during IBD relapses, as compared to 13% and 10% in the general population (Mikocka-Walus et al., 2016a).

Due to the bi-directionality of the gut-brain communication, the biopsychosocial model has been frequently used to understand gastrointestinal illness, including IBD (Long and Drossman, 2010; Grover et al., 2009). According to this conceptualisation of IBD, gut health may be influenced by stress via the hypothalamic pituitary adrenal axis and gut bacteria (Grover et al., 2009). In particular, stress may impact on the immune functions and increase gut inflammation, but other psychological factors such as coexistent distress (anxiety/depression) and poor coping disinhibit visceral signals via the central nervous system pathways, intensifying pain and gastrointestinal symptoms.

While the biopsychosocial burden arising from IBD is well-quantified, the experience of living with IBD has also received attention from qualitative researchers, with a recent systematic review including 23 qualitative studies (Fourie et al., 2018). However, lived experience of those with IBD accompanied by anxiety and depression has not been widely studied. One recent qualitative study examined the experience of people with IBD, anxiety and low mood (Jordan et al., 2018), and documented the following four themes: 'under performance', 'preventing an accident', 'lack of understanding', and 'stigma'. However, this study focused only on patients with moderate/severe anxiety or low mood, and did not include the perspectives of health professionals working with people with IBD. It is important to address this gap in research, to increase understanding about the needs of those with lower levels of anxiety or depression that whilst impacting on the lived experience of IBD, may not be treated within current service provision (Carter et al., 2014; Patton, 1999). Further, there are no other qualitative studies exploring the experience of living with IBD and co-morbid anxiety and depression across more than one country, yet differences in culture and healthcare models may contribute to how patients perceive their lives and illness experience.

Indeed, models for healthcare delivery relevant to IBD care vary even between English-speaking countries such as the UK and Australia. While both have a well-developed public healthcare system, there is greater use of private healthcare in Australia, with 46% of Australians (APRA, 2018) versus just 11% of British people (Cooke O’Dowd et al., 2018) using private hospital cover in addition to public healthcare. On the other hand, in both countries only 12% of IBD services have access to a mental health practitioner (RCP, 2014; Mikocka-Walus A, 2018). Most patients therefore access mental healthcare via general not IBD specific pathways. In the UK, the Improving Access to Psychological Therapies (IAPT) program that offers psychological therapies for patients with anxiety or depression was implemented in 2008 (Clark, 2011). A recent report showed improved waiting times, referrals completion, and recovery using the IAPT (NHS Digital, 2018). However, despite these improvements, the majority of patients with common mental disorders do not receive adequate treatment and the inequalities in the access to treatment persist (McManus et al., 2016).

In Australia, Better Access initiative enables people with a mental disorder to receive up to 10 mental health services a year (DepartmentofHealth, 2018). Better Access initiative has improved access to mental healthcare, including those disadvantaged, with improved mental health outcomes, in a cost-effective fashion and with waiting times of only up to 14 days (DepartmentofHealth, 2014).

It is possible that these differences in mental health services might reveal distinct experiences of people with IBD with comorbid anxiety and depression, making the cross-country comparison of patients in the UK and Australia important to examine. Therefore, the present study aimed to explore the lived experience and healthcare needs of patients with IBD and mild to moderate comorbid anxiety and/or depression, and examine cross-cultural differences in the UK and Australia.

**Methods**

## Design

We pulled data from two concurrently run studies (one in the UK and one in Australia). We utilised a deductive biopsychosocial framework (Engel, 1977). This design shaped research processes, including creation of the interview guide and analysis, where we focused on biological, psychological and social aspects of the lived experience and their interrelations.

## Sample

We included adults living with IBD and anxiety / depression and the healthcare professionals who care for patients with this co-morbidity (at least for 2 years). Purposive maximum variation sampling was used (Patton, 1990). The diverse characteristics of the sample were chosen to maximise variation in lived experience and were applied across the following patient participant variables that from the literature and clinical input are likely to influence this: age, sex, IBD duration and severity, having anxiety or depression or both (Burisch and Munkholm, 2015; Burisch et al., 2014; Mikocka-Walus et al., 2016a; Mikocka-Walus et al., 2016b). For health professionals, we sought diversity in terms of type of profession (to explore multidisciplinary views essential in the biopsychosocial approach to healthcare (Engel, 1977) and sex (Hall et al., 2011)). Data were collected until data saturation was reached (i.e. until no new themes were detected) (Gentles et al., 2015: 1781). A priori, it was expected that approximately 10 patients and 10 health professionals would be recruited into the study in each country.

## Recruitment

Patient and healthcare professional participants were recruited via three gastroenterology services in one region of England (UK) and one large gastroenterology clinic in Australia offering both public and private healthcare services.

Potentially eligible patients with IBD were identified from medical databases/casenotes at participating hospitals by treating clinicians. In the UK, IBD nurses or gastroenterologists recommended patients known to have a history of anxiety/depression (e.g. referred to a psychologist in the past or currently on the waiting list). In Australia, the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983) was used to screen for mild to moderate anxiety and/or depressive symptoms (scores of 8-14). All eligible patients were sent a letter signed by the treating clinician inviting them to participate in the study. Eligible healthcare professionals were invited by the lead clinician or research co-ordinator in participating services.

## Data collection

We planned to collect patient data using focus groups and healthcare professional data using semi-structured interviews. Focus groups were selected for patients because they allow exploration of complex and sensitive behaviours and motivations, and utilise the shared identity of participants to draw out and discuss thoughts and beliefs about living with IBD and anxiety/depression that would not naturally occur in an individual interview setting (Holloway and Wheeler, 2010). However, to ensure we achieved a diverse sample, participants were offered an interview as an alternative. Focus groups would have been our preferred approach for healthcare professionals too. However, following consultation with the clinical services involved in the study, which highlighted significant practical and methodological challenges to conducting these (i.e., busy schedule, availability at different times, possible power issues between allied health professionals and doctors), we decided to use semi-structured interviews. Interviews were scheduled for up to 1 hour, and focus groups were planned for 2 hours. Both had a semi-structured nature, with a detailed topic guide and questions developed *a priori* in consultation with psychologists, gastroenterologists, and methodologists, e.g. What does good/bad physical, mental and social health look like to you? The interviews/focus groups were audio recorded and transcribed verbatim. Data saturation was reached with 13 patients and 12 health professionals in the UK and 11 patients and 8 health professionals in Australia.

## Reflexive statement

The interviewers were both women, one a medical doctor and the other a provisional psychologist who received training in qualitative methods as part of their higher degrees. The interviewers attempted to disregard their professional experience, affiliations in the research field, and assumptions about the topic to access the meaning that participants conveyed through their accounts (Ahern, 1999). These influences could have occured during data collection, coding and analysis, but this was reviewed continuously through linking field notes and memos to the lines in the transcribed text, and regular discussion with other members of the research team. A small number of transcripts were additionally double-coded by a researcher not involved in data collection (CE).

## Analysis

Before analysis started, participants were invited to review the transcript and provide comments, and the research team members cross-examined the process of the research to assure the trustworthiness of the study (Creswell, 2015). Thematic analysis was chosen, due to the flexibility of this approach towards data interpretation. Due to the differing researchers’ theoretical conceptualisations of the research question, for UK data, Braun and Clarke’s (Braun and Clarke, 2006) approach to thematic analysis was used, and for Australian data, Brooks et al. (Brooks et al., 2015) approach where there is a close relationship with the *a priori* theoretical framework. These analytic approaches overlap, with many similarities. The differences are summarised by Brooks et al. elsewhere (2015).

Briefly, the UK data analysis was carried out in the following steps (Braun and Clarke, 2006):

1. Familiarising yourself with your data
2. Generating initial codes
3. Searching for themes (including the first draft of mind maps)
4. Reviewing themes (including updates to mind maps)
5. Defining and naming themes (including updates to mind maps)
6. Producing the report ((including a final mind map)

The Australian data analysis was carried out in the following steps (Brooks et al., 2015):

1. Familiarisation with the qualitative material;
2. Preliminary identification and coding of key themes (related to the a priori theoretical framework);
3. Organise emerging themes into meaningful clusters;
4. Define an initial coding template;
5. Apply the initial template to further data and modify as necessary;
6. Finalise the template and apply it to the full data set.
7. Contextualising these themes in relation to a priori frameworks and interpreting them (reviewing themes; checking whether themes work in relation to the coded extracts and transcripts; final update of the mind maps).

NVivo® software was used for analysis in both countries.

## Ethical approval

The ethical approval was obtained from the NHS Health Research Authority and the Department of Health Sciences Research Ethics Committee; the University of York; Barwon Health and Deakin University. 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**

In total, 24 patients and 20 healthcare professionals took part in this study. Participants’ demographics and other characteristics are presented in Supplementary Table 1.

INSERT TABLE 1

## Themes

The patients' and health professionals' views on living with IBD and comorbid anxiety and/or depression in the UK were distributed across three main themes (Supplementary Figure 1):

1) Bidirectional relationship between IBD and mental health,

2) The need for health care integration, and

3) Lack of awareness about the disease.

In Australia, the themes included: 1) The vicious cycle of IBD and psychosocial health; 2) The need for biopsychosocial healthcare integration; 3) The stigma of a hidden disease (Supplementary Figure 2).

INSERT SUPPL FIGURE 1 AND 2

## UK themes

##### *Bidirectional relationship between IBD and mental health*

Patients and health professionals agreed that IBD affected a person’s quality of life (QOL):

*...when you have a flare […] it impacts your life because it is very restricting in both, work, family time, leisure time,* *it impacts every aspect in your life. (Patient 13, Male, 32 years old).*

*…If somebody has had an accident in front of, […] if you are a child or teenager that has a major impact on their mental health and can make people very depressed. (Health professional 9, Male, Gastroenterologist).*

The reaction to the diagnosis differed among patients: denial, resignation, hope for a cure, trauma or anger. One of the patients emphasised the importance of accepting the diagnosis:

*It's not going to go away, better it stays part of me, but I don't want it to define me. (Patient 1, Male, 50 years old).*

Some patients thought that the IBD symptoms made them housebound, which affected their mental health, but also, reduced their ability to manage their disease. One patient said:

*I don't leave the house for ages. [...] you’re so stressed to the point when [...] you don't want to leave in case you need to go, to the toilet. [...] it's horrible. (Patient 9, Female, 20 years old).*

However, the health professionals believed that the impact depended on the emotional resilience of the individual:

*Some patients with relatively moderate IBD symptoms […] feel anxious and depressed. (Health professional 4, Female, Gastroenterologist).*

Some of the health professionals also thought that the medication for IBD could influence mental wellbeing:

*The other issue is we give a lot of steroids which can have a marked effect on people's mental health, causing, um..., exacerbating a mild depression, mania and other problems as well, psychosis [...] (Health professional 10, Male, Gastroenterologist).*

Both health professionals clearly articulated the bidirectional link between IBD and anxiety and depression.

*I think, one provokes the other. […] it's possible that the physical condition makes it more likely that you will also be […] a little bit depressed. (Patient 6, female, 68 years old).*

*Because of the nature of the symptoms that it presents with and those symptoms then fuel further anxiety and low mood, which feed into the body and physical symptoms which create a vicious cycle between the physical symptoms and the emotional symptoms. […] regardless which one came first it's a bidirectional relationship between the two. (Health professional 7, Female, psychologist).*

Additionally, it was recognised that IBD symptoms could be over or underestimated in people with comorbid anxiety and/or depression, hence leading to inadequate treatment:

*When somebody has anxiety […], they would downplay their symptoms in order to avoid having an investigation from a gastroenterologist. Similarly, […] if the patient is depressed and anxious and you’re using a pain score, […] they score […] highly on, I feel ill, or I have pain. (Health professional 9, Male, Gastroenterologist).*

*The need for health care integration*

The services for supporting mental health in IBD were referred to as Cinderella services and characterised by lack of resources, long waiting lists, and limited psychological support:

*[...] mental wellbeing [...] they don't take it seriously. […] If I went to my GP and said I am now no longer able to cope, can I have counselling? There would be nine months waiting list, by which point, I would probably slit my wrists. (Patient 12, Female, 59 years old).*

*We have very limited psychological support at the hospital that we have to save for our ‘worst patients’ […] which means that we don't overly promote it because we haven't got the resources to fulfil patients' […] needs. (Health professional 1, Female, IBD nurse).*

Both health professionals and patients agreed that a multidisciplinary team need to care for people with IBD and comorbid anxiety and/or depression:

*I think to look after IBD patients; you need a complete team, you need your gastroenterologist, [...], the nurses, […] GPs, […] the psychological support, whether it be face-to-face, over the Internet […]. (Health professional 12, Female, IBD nurse).*

However, while health professionals felt that they provided holistic care for the patients, patients felt that, despite having supportive IBD nurses and gastroenterologists, they did not receive holistic care as part of their IBD management.

*Right from the very beginning, […] one of the IBD nurses will become involved in the**patient's care, and psychological aspects are a part of the holistic care that we give. (Health professional 1, Female, IBD nurse).*

*[...] a problem for an IBD patient is fragmentation of treatment. [...]. I had to go to 3 different hospitals. [...]. I have lots of different medications. [...]. I have been in the situation sometimes when they prescribe medication [...] then another consultant would tell me that it's not good and prescribe me something else. (Patient 12, Female, 59 years old).*

The same person said that not managing wellbeing in those with IBD was not cost-effective:

*[...] not managing the mental wellbeing [...] is a false economy […]. Because the reality is if we put prevention measures in place [...] and we put the support mechanisms in place, we would save ourselves so much money down the line in terms of NHS expense. (Patient 12, Female, 59 years old).*

Most patients were not receiving any form of psychological support and were relying on family members and friends for support:

*It's really been family and friends [...]. My husband; he gets a lot. (Patient 5, Female, 56 years old).*

*[...] not everyone needs talking therapy, but if everyone has a chance at least to talk about it. (Patient 1, Male, 50 years old).*

Health professionals highlighted that when patients did access psychotherapy, they had positive outcomes:

*[...] when you see the patients before and after, […] you definitely notice a vast improvement. (Health professional 2, Female, IBD nurse).*

However, even though all health professionals reported a bidirectional link between IBD and anxiety/depression, they admitted not vigorously screening for mental health issues:

*...we don't currently actively pursue patients looking for any signs of anxiety and depression. (Health professional 9, Male, Gastroenterologist).*

Patients understood that gastroenterology teams were not trained to deal with mental health issues and felt they should recognise the problem and refer to a specialist:

*[...] certainly, the gastroenterologist and specialist nurses are not equipped to support people with more severe psychological needs, and I don’t think they should be. I think what they need to [do] is [...] refer the person to the specialist’s help. (Patient 1, Male, 50 years old).*

#### *The lack of awareness about the disease*

Both health professionals and patients thought that those with IBD were not always aware of their anxiety and depression.

*At first, you don't know you're suffering from depression. [...]. I thought it was me failing to cope with the illness. (Patient 7, Female, 67 years old).*

*A lot of them don't realise that they have it... (Health professional 2, Female, IBD nurse).*

Patients also highlighted a lack of awareness about IBD in general among the public, but health professionals did not raise this issue.

*You look well on the outside, but you're absolutely feeling rotten on the inside [...]. I've lost lots of weight, and [...] I was so tired, but everybody thought I looked very well [...] you don't want to wear a budge [...] they don't see it as an illness, because you can't see it. (Patient 5, Female, 56 years old).*

*I think the quality of life is affected because people don't understand it. Because it's invisible. Therefore, people look at you and believe that you are fit and well and unfortunately you are not. (Patient 12, Female, 59 years old).*

***Australian themes***

*The vicious cycle of IBD and psychosocial health*

Patients and health professionals recognised that IBD impacted physical, psychological and social facets of patients’ lives in what was often described as a vicious cycle:

*Well it's weird because it kind of goes in a circle. Like you've got it so you're tired, and that makes you anxious. And then the more anxious you get, the more it fuels that. (Patient 1, Male, 30 years old)*

Patients and health professionals agreed that the unpredictability of symptoms was challenging to live with. To increase their sense of control, patients described various behavioural symptom management strategies, mainly avoidance of social interaction, reserving energy for employment, rigid planning around the location of toilets, but also strict diet adherence, and food avoidance:

*…it definitely impacts on my social life. I can't go out, or I will deliberately plan not to go out, or refuse to go places because I'm worried about having access to bathrooms and things like that. (Patient 4, Female, 25 years old).*

When strategies failed, this tended to perpetuate their sense of lacking control or perpetuated a defeatist position:

*I try to eat as best I can […]. But it sometimes doesn't seem to make a difference, it won't matter. Like if I'm going to have a flare up, I'm going to have a flare up […]. (Patient 11, Female, 38 years old).*

*So, you're sort of like trying to navigate your way around […]. And it doesn't seem to feel like things are ever going to change and you'll always be like this. (Patient 11, Female, 38 years old).*

Some patients reported behaviours like reduced medication and treatment adherence:

 *…with depression, it could be that withdrawal and potentially disengagement with some appointments and services, um because of feelings around it sort of being hopeless and no point. (Health Professional 5, Female, Health psychologist).*

Patients and health professionals agreed that the diagnosis of IBD fundamentally challenged patient self-identity and mental health:

*[IBD is] a real challenge to their identity and coping strategies and how they proceed forward. It's a real loss of a sense of future. (Health Professional 3, Male, Gastroenterologist).*

Patients diagnosed less than 2-years-ago reflected on how their self-identity was challenged following diagnosis, which health professionals recognised as the *natural sort of stress reaction to a chronic disease diagnosis (Health Professional 4, Female, Gastroenterologist).* Adjusting to the diagnosis, patients reflected on the process of *denial, processing,* and *coming to terms with* IBD. However, the chronicity, relapsing and remitting cycle, and the ‘hidden’ aspect of the disease made accepting IBD particularly difficult for some:

*You know, it's just hard. […] it's a struggle, struggle street. (Patient 5, Female, 25 years old)*

Patients diagnosed more than 2-years-ago spoke of becoming *comfortable with knowing what you can and can't do now (Patient 8, Male, 24 years old).*

Health professionals identified better health outcomes for patients with earlier acceptance:

*I would argue that my patients that have done the best are the ones that have accepted things early on. And you'll have patients that will say, look I can't change the cards that have been dealt to me, but I can choose how to play my hand. And they're very proactive and receptive to management, and tend to do well and tend to have less disability for the level of active inflammation they have, or diseased bowel. (Health Professional 3, Male, Gastroenterologist).*

Patients believed the *vicious cycle* was bidirectional in nature, with a majority reporting stress was a trigger for flares in IBD symptoms:

*It feeds in because when you're having these issues, you're not as productive as you want to be, and then you stress because you're not productive. And then the stress feeds into your disease and makes you have more symptoms, and makes you less productive and then it's a vicious cycle (Patient 3, Female, 35 years old).*

Most health professionals corroborated patient’s anecdotal reports of associations between stress and disease activity. However, health professionals’ beliefs differed on the mechanisms underpinning this relationship, with one identifying a *psycho-immunology component that we don’t fully understand (Health Professional 8, Male, Gastroenterologist),* and another attributing this to the *amplification of gut symptoms and noticing them more (Health Professional 5, Female, Health psychologist).*

*The need for biopsychosocial healthcare integration*

Patients described that they felt ill-informed about IBD:

*I think when you get diagnosed, they should explain it [IBD] to you, like what it is, what could happen, what things you might experience, and you know, what could happen in the future. […]. Instead of us going away and googling it and not understanding fully. (Patient 3, Female, 35 years old).*

Health professionals recognised the benefits of IBD-related education for patients, potentially easing anxiety, enhancing disease treatment, and increasing confidence to communicate IBD to others:

*It might even relieve people’s anxiety a bit to have had a discussion, like they may go into it [IBD treatment] a better way. (Health Professional 6, Female, IBD nurse).*

Following diagnosis, patients also overwhelmingly reported a lack of mental health screening or referral to psychological support from health professionals:

*I remember my gastroenterologist just gave me like a brochure […]. But that's not enough. Like if someone is diagnosed with cancer, they get a referral to a social worker or a counsellor, and they get information about accessing the cancer council and those sorts of programs for support, and there's so much out there. But you're really not given any sort of psychological support around diagnosis or my GP didn't even mention mental health care plans for anything. And that's a time that I could have really benefited from it. (Patient 4, Female, 25 years old).*

Some publicly treated patients speculated that receiving a different treating clinician every appointment may contribute towards health professionals overlooking mental health while those few who received private care perceived more holistic and consistent support from their gastroenterologist:

*I'm lucky, my gastroenterologist is actually pretty caring. Um, the first thing you do when you walk in is, she actually asks you how are you feeling? You know, so she actually does care, not just about your bowel! (Patient 5, Female, 25 years old).*

While all health professionals acknowledged the importance of integrating psychological care into patient treatment, gastroenterologists felt ill equipped to screen for psychopathology, reporting limited time for patient consultation, lack of mental health training, and fear and discomfort as barriers:

*I think [mental health] is an under managed area and we as gastroenterologists do it poorly because we don't have the specific training, and I think there's an element of fear that if we do uncover something, then what do we do about it. (Health Professional 3, Male, Gastroenterologist).*

Nonetheless, patients still regarded gastroenterologists as the first point of contact for mental health concerns:

*I feel like the Gastro is your first point of contact too. So when stuff is wrong, it all sort of impacts your mental wellbeing as well. So they’re they the first person you go though. (Patient 8, Male, 24 years old).*

Psychologists and IBD nurses positively viewed integrated psychological care, with perceptions from IBD treatment settings with and without a practicing psychologist:

With: *It's so amazing. Like we discussed, just recently, what to do with these patients. Because we had, we us nurses, were trying to manage, and part of my concern was are we telling them the right or the wrong thing? (Health Professional 6, Female, IBD nurse).*

Without: *Psychology would be great, but however there's just very minimal IBD clinics in Australia that do have a psychologist. So, I mean no one would doubt that that would be the ideal situation, but at the moment it's just not happening. (Health Professional 1, Female, IBD nurse).*

Patients spoke of ultimately desiring a holistic care approach from their gastroenterologist or combination of gastroenterologist, dietitian and psychologist support team. One patient reflected:

*Sometimes they treat you like you're just a colon or just a bowel. But there's other stuff going on here as well, like I'm still a person, I'm a whole body and I'm also a person. I need a whole approach, not just my gastroenterologist looking at my bowel. (Patient 4 Female, 25 years old)*

*The stigma of a hidden disease*

Participants often referenced the stigma within social networks surrounding having IBD. Health professionals recognised this burden as inherent to the ‘hidden’ nature of IBD:

*It's often a hidden disease, so that people won't readily get understanding, or friends and family that do sort of do know about it will say oh you just need to change your diet. Because there's no visible signs so much from these, so it's poorly understood. And so they often tend to suffer in silence because this significant disability that they have is not recognised. (Health Professional 3, Male, Gastroenterologist).*

Patients also spoke of IBD being a hidden disease, that *If I didn’t tell anyone, they probably wouldn’t know (Patient 1, Male, 30 years old).* Patients viewed stigma to stem from misunderstandings about IBD as *not like a serious illness, you’re just stressed* but were nonetheless labelled as *just being difficult, exaggerated, putting it on,* or *making it up.*

An IBD nurse reflected on the potential health consequences of stigma manifesting with non-adherence to medication use:

*Some people take the medications three times a day, they're out socialising with their friends, and they don't want to be seen taking the tablets (Health professional 1, Female, IBD nurse).*

Something which was not mentioned by patients, but spoken about by health professionals was the additional mental illness stigma when seeking support in the healthcare system:

*I think the health professional has a really important role to say look, it's not you being crazy, you know, it's really challenging to manage a chronic disease. (Health Professional 6, Female, IBD nurse).*

**Discussion**

This study is unique in offering perspectives from two countries on the lived experience of IBD comorbid with anxiety/depression while providing the views of patients and those of the health professionals, using a biopsychosocial lens (Engel, 1977).

The bidirectional links between IBD and mental health, translating into poorer health of those affected by IBD and mental illness, were commonly reported in both countries. These are now increasingly recognised by quantitative research (Gracie et al., 2018), which illustrates the impact of anxiety and depression on the frequency of IBD relapses (2016b), aggressive presentation of IBD (Kochar et al., 2018), hospital readmissions, and risk of surgery (Ananthakrishnan et al., 2013). This awareness of the brain-gut and gut-brain links has also translated into the emergence of a new field of psycho-gastroenterology (Knowles et al., 2019).

Looking specifically at significant biopsychosocial aspects of IBD, there was concordance between the two samples regarding the role of fatigue impacting quality of life in those living with both IBD and anxiety/depression. Fatigue is common in IBD, affecting approximately three-quarters of patients (Graff et al., 2013), including over 40% of those in remission (van Langenberg and Gibson, 2010). However, it is also poorly understood, with limited therapies targeting it in IBD developed to date (Borren et al., 2018; Czuber-Dochan et al., 2013b) . A recent qualitative study exploring fatigue in IBD showed it to be poorly understood by clinicians and not addressed in medical consultations despite its significant impact on overall wellbeing (Czuber-Dochan et al., 2013a). New multidisciplinary treatments corresponding with the biopsychosocial nature of fatigue are also needed, particularly in light of the promising results of a psychological intervention for IBD-related fatigue (Vogelaar et al., 2014).

The sense of isolation and being housebound due to toilet anxiety transpired in the reports of both samples. The alienation created by IBD has appeared as a theme in previous qualitative work (Khan et al., 2016), which suggested it could be alleviated by better patient-health professional communication and better support from the healthcare system. However, the present study highlights deficiencies in patient-doctor communication. Previous studies have linked patient-doctor communication with IBD outcomes suggesting that low satisfaction with patient-doctor communication contributed to non-adherence to treatment with IBD (Mountifield et al., 2014).

Accepting diagnosis was another important theme. A critical point of about two years post-diagnosis being the moment when coping with IBD becomes easier was noted. Indeed, accepting the diagnosis may offer benefits to patients – previous uncontrolled research demonstrated good efficacy of an IBD adaptation course on psychological wellbeing (Haapamaki et al., 2018). More studies exploring disease acceptance in IBD populations are needed. Acceptance and Commitment Therapy (ACT) is regarded as a promising psychotherapeutic approach to improve outcomes within chronic disease populations (Graham et al., 2016). Indeed, a recent randomised controlled trial of ACT for patients with IBD demonstrated significant reductions in stress and depressive symptoms but not anxiety (Wynne et al., 2019). Further psychotherapy research should target patients with IBD and comorbid anxiety and/or depressive symptoms to adequately address their needs and improve psychological wellbeing.

In terms of the broader context of the healthcare system, the UK sample more commonly articulated lack of healthcare resources, shortages of services, and longer waiting times to mental health practitioners. However, in Australia, where these services appear more available, health professionals miss opportunities to refer for psychological care. In the UK, the recent evaluations suggest that there is a need to revise the method of operating the IAPT service (Scott, 2018; Perez et al., 2018). A recent report showed improved waiting times, referrals completion, and recovery using the IAPT (NHS Digital, 2018). However, despite these improvements, the majority of patients with common mental disorders do not receive adequate treatment and the inequalities in the access to treatment persist (McManus et al., 2016). In addition, neither the IAPT nor the Australian Better Access initiative may be the most optimal pathway for mental health services in IBD. A recent study demonstrated that psychological care integrated into an IBD service improved mental health and quality of life, with greater engagement for those treated in-service versus those referred to external psychological services (Lores et al., 2019).

Of relevance, the UK health professionals reported their awareness of mental health issues in IBD, at the same time admitting the lack of regular screening for anxiety/depression. This might reflect that in a system with limited resources clinicians do not screen for psychological distress and restrict referrals to those patients coming forward with psychological distress or the most serious presentations. Similarly, the Australian health professionals reported problems discussing difficult topics such as mental health. In the UK sample, lack of psychological support from health services meant that family and friends were asked for such support. There is clearly a need for more frequent discussions of mental health between health professionals and people with IBD in both countries, with the screening becoming routine rather than occasional. However, for screening to be helpful there need to be sufficient resources on offer for those needing help.

Finally, holistic, multidisciplinary care was requested by patients and health professionals in both countries, which is consistent with larger quantitative research (Schoultz et al., 2016; Mikocka-Walus et al., 2018). Both countries recommend integrated approach to IBD care in their IBD Standards (Pavli et al., 2016; IBDUK, 2015), however, the practice has not yet fully followed the guidelines, particularly regarding access to mental health providers but also other allied health practitioners (Mikocka-Walus et al., 2018). It is important to promote multidisciplinary care as the current best practice in chronic illness in general (Grone and Garcia-Barbero, 2001) and IBD specifically where it is increasingly being shown as not only improving patient outcomes but also reducing healthcare costs (Sack et al., 2012).

**Limitations**

The limitations of the study include slight differences in methodologies applied, including a different approach to identifying people with anxiety/depression. While the data for both samples were analysed using a thematic analysis, we utilised two versions of thematic analysis. Nevertheless, similar themes appeared in both types of analysis.

**Conclusion**

The themes across two countries document a significant burden of mental illness comorbid with IBD, with the simultaneous lack of adequate healthcare resources to address patient needs. Better communication between a patient and their health professionals around mental illness is essential in helping patients receive adequate care. Holistic and multidisciplinary care is requested by both patients and health professionals to improve outcomes in IBD.

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**References**

Ahern KJ. (1999) Ten Tips for Reflexive Bracketing. *Qualitative Health Research* 9: 407-411.

Ananthakrishnan AN, Gainer VS, Perez RG, et al. (2013) Psychiatric co-morbidity is associated with increased risk of surgery in Crohn's disease. *Aliment Pharmacol Ther* 37: 445-454.

APRA. (2018) Private health insurance annual coverage survey December 2017. Sydney, NSW: Australian Prudential Regulation Authority.

Borren NZ, van der Woude CJ and Ananthakrishnan AN. (2018) Fatigue in IBD: epidemiology, pathophysiology and management. *Nature Reviews Gastroenterology & Hepatology*: 1.

Braun V and Clarke V. (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3: 77-101.

Brooks J, McCluskey S, Turley E, et al. (2015) The Utility of Template Analysis in Qualitative Psychology Research. *Qual Res Psychol* 12: 202-222.

Burisch J and Munkholm P. (2015) The epidemiology of inflammatory bowel disease. *Scand J Gastroenterol* 50: 942-951.

Burisch J, Pedersen N, Cukovic-Cavka S, et al. (2014) East-West gradient in the incidence of inflammatory bowel disease in Europe: the ECCO-EpiCom inception cohort. *Gut* 63: 588-597.

Carter N, Bryant-Lukosius D, DiCenso A, et al. (2014) The use of triangulation in qualitative research. *Oncol Nurs Forum* 41: 545-547.

CCA. (2019) *About Crohn's and colitis*. Available at: <https://www.crohnsandcolitis.com.au/about-crohns-colitis/>.

CCUK. (2019) *About Inflammatory Bowel Disease*. Available at: <https://www.crohnsandcolitis.org.uk/about-inflammatory-bowel-disease>.

Clark DM. (2011) Implementing NICE guidelines for the psychological treatment of depression and anxiety disorders: the IAPT experience. *International review of psychiatry (Abingdon, England)* 23: 318-327.

Cooke O’Dowd N, Kumpunen S and Holder H. (2018) Can people afford to pay for health care? New evidence on financial protection in the United Kingdom. Barcelona: World Health Organisations.

Creswell J. (2015) *Educational Research. Planning, Conducting, and Evaluating Quantitative and Qualitative Research.*

Czuber-Dochan W, Dibley LB, Terry H, et al. (2013a) The experience of fatigue in people with inflammatory bowel disease: an exploratory study. *J Adv Nurs* 69: 1987-1999.

Czuber-Dochan W, Ream E and Norton C. (2013b) Review article: Description and management of fatigue in inflammatory bowel disease. *Aliment Pharmacol Ther* 37: 505-516.

DepartmentofHealth. (2014) *Evaluation of the Better Access to Psychiatrists, Psychologists and GPs through the Medicare Benefits Schedule initiative*. Available at: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-ba-eval>.

DepartmentofHealth. (2018) *Better Access to Psychiatrists, Psychologists and General Practitioners through the MBS (Better Access) initiative*. Available at: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/mental-ba>.

Engel GL. (1977) The need for a new medical model: a challenge for biomedicine. *Science* 196: 129-136.

Fourie S, Jackson D and Aveyard H. (2018) Living with Inflammatory Bowel Disease: A review of qualitative research studies. *Int J Nurs Stud* 87: 149-156.

Gentles SJ, Charles C, Ploeg J, et al. (2015) Sampling in qualitative research: Insights from an overview of the methods literature. *The Qualitative Report* 20: 1772-1789.

Gracie DJ, Guthrie EA, Hamlin PJ, et al. (2018) Bi-directionality of Brain-Gut Interactions in Patients With Inflammatory Bowel Disease. *Gastroenterology* 154: 1635-1646.e1633.

Graff LA, Clara I, Walker JR, et al. (2013) Changes in fatigue over 2 years are associated with activity of inflammatory bowel disease and psychological factors. *Clinical gastroenterology and hepatology* 11: 1140-1146.

Graham CD, Gouick J, Krahe C, et al. (2016) A systematic review of the use of Acceptance and Commitment Therapy (ACT) in chronic disease and long-term conditions. *Clin Psychol Rev* 46: 46-58.

Grone O and Garcia-Barbero M. (2001) Integrated care: a position paper of the WHO European Office for Integrated Health Care Services. *Int J Integr Care* 1: e21.

Grover M, Herfarth H and Drossman DA. (2009) The functional-organic dichotomy: postinfectious irritable bowel syndrome and inflammatory bowel disease-irritable bowel syndrome. *Clin Gastroenterol Hepatol* 7: 48-53.

Haapamaki J, Heikkinen E, Sipponen T, et al. (2018) The impact of an adaptation course on health-related quality of life and functional capacity of patients with inflammatory bowel disease. *Scand J Gastroenterol* 53: 1074-1078.

Hall JA, Blanch-Hartigan D and Roter DL. (2011) Patients' satisfaction with male versus female physicians: a meta-analysis. *Med Care* 49: 611-617.

Holloway I and Wheeler S. (2010) *Qualitative Research in Nursing and Healthcare*: Blackwell Publishing Ltd.

IBDUK. (2015) IBD Standards Core Statements. London: IBDUK.

Jordan C, Ohlsen R, Hayee B, et al. (2018) 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. *Psychol Health* 33: 634-651.

Khan S, Dasrath F, Farghaly S, et al. (2016) Unmet Communication and Information Needs for Patients with IBD: Implications for Mobile Health Technology. *Br J Med Med Res* 12.

Knowles S, Keefer L and Mikocka-Walus A. (2019) *Psychogastroenterology for Adults: A Handbook for Mental Health Professionals,* London: Routledge.

Kochar B, Barnes EL, Long MD, et al. (2018) Depression Is Associated With More Aggressive Inflammatory Bowel Disease. *Am J Gastroenterol* 113: 80-85.

Long MD and Drossman DA. (2010) Inflammatory bowel disease, irritable bowel syndrome, or what?: A challenge to the functional-organic dichotomy. *Am J Gastroenterol* 105: 1796-1798.

Lores T, Goess C, Mikocka-Walus A, et al. (2019) Integrated psychological care is needed, welcomed and effective in ambulatory Inflammatory Bowel Disease management: Evaluation of a new initiative. *J Crohns Colitis*.

McManus S, Bebbington P, Jenkins R, et al. (2016) *Mental Health and Wellbeing in England: Adult Psychiatric Morbidity Survey 2014: a Survey Carried Out for NHS Digital by NatCen Social Research and the Department of Health Sciences, University of Leicester*: NHS Digital.

Mikocka-Walus A, Knowles SR, Keefer L, et al. (2016a) Controversies Revisited: A Systematic Review of the Comorbidity of Depression and Anxiety with Inflammatory Bowel Diseases. *Inflamm Bowel Dis* 22: 752-762.

Mikocka-Walus A, Massuger W, Knowles S, et al. (2018) My IBD Experience: Australian inflammatory bowel disease patient experience of health care. Camberwell, VIC: Crohn's & Colitis Australia.

Mikocka-Walus A MW, Knowles S, Moore G, Buckton S, Connell W, et al. . (2018) My IBD Experience: Australian inflammatory bowel disease patient experience of health care. Camberwell, VIC: Crohn's & Colitis Australia.

Mikocka-Walus A, Pittet V, Rossel JB, et al. (2016b) Symptoms of Depression and Anxiety Are Independently Associated With Clinical Recurrence of Inflammatory Bowel Disease. *Clin Gastroenterol Hepatol* 14: 829-835.e821.

Mountifield R, Andrews JM, Mikocka-Walus A, et al. (2014) Covert dose reduction is a distinct type of medication non-adherence observed across all care settings in inflammatory bowel disease. *J Crohns Colitis* 8: 1723-1729.

NHS Digital CaMHt. (2018) Psychological Therapies, Annual report on the use of IAPT services - England, 2017-18 [PAS]. NHS Digital.

Patton MQ. (1990) *Qualitative evaluation and research methods, 2nd ed,* Thousand Oaks, CA, US: Sage Publications, Inc.

Patton MQ. (1999) Enhancing the quality and credibility of qualitative analysis. *Health Serv Res* 34: 1189-1208.

Pavli P, Alex G, Andrews JM, et al. (2016) Australian IBD Standards: Standards of healthcare for people with inflammatory bowel disease in Australia Camberwell, VIC: Crohn's & Colitis Australia.

Perez J, Russo DA, Stochl J, et al. (2018) Common mental disorder including psychotic experiences: Trailblazing a new recovery pathway within the Improving Access to Psychological Therapies programme in England. *Early Intervention in Psychiatry* 12: 497-504.

RCP. (2014) National audit report of inflammatory bowel disease service provision: adult national report. London: Royal College of Physicians.

Sack C, Phan VA, Grafton R, et al. (2012) A chronic care model significantly decreases costs and healthcare utilisation in patients with inflammatory bowel disease. *J Crohns Colitis* 6: 302-310.

Schoultz M, Macaden L and Watson AJM. (2016) Co-designing inflammatory bowel disease (Ibd) services in Scotland: findings from a nationwide survey. *BMC Health Services Research* 16: 231-231.

Scott MJ. (2018) Improving Access to Psychological Therapies (IAPT) - The Need for Radical Reform. *Journal of Health Psychology* 23: 1136-1147.

van Langenberg DR and Gibson P. (2010) Systematic review: fatigue in inflammatory bowel disease. *Alimentary pharmacology & therapeutics* 32: 131-143.

Vogelaar L, van't Spijker A, Timman R, et al. (2014) Fatigue management in patients with IBD: a randomised controlled trial. *Gut* 63: 911-918.

Wynne B, McHugh L, Gao W, et al. (2019) Acceptance and Commitment Therapy Reduces Psychological Stress in Patients With Inflammatory Bowel Diseases. *Gastroenterology* 156: 935-945.e931.

Zigmond AS and Snaith RP. (1983) The hospital anxiety and depression scale. *Acta Psychiatr Scand* 67: 361-370.