

Doctorate in
Clinical Psychology

Lancaster
University



Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

June 2022

Doctoral Thesis:

The Role of Support for Individuals with Inflammatory Bowel Disease

Emma Mellor

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

Emma Mellor

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University Lancaster

LA1 4AT

Email: e.mellor@lancaster.ac.uk

Word Counts

	Main Text	Appendices (including tables, figures and references)	Total
Thesis abstract	297	-	297
Literature Review	7,999	10,418	18,417
Research Paper	7,994	6,869	14,863
Critical Appraisal	3,996	4,927	8,923
Ethics Section	4,855	6,957	12,577
	25,147	29,171	55,077

Thesis Abstract

This thesis is comprised of three sections which include a systematic literature review (SLR), an empirical research paper and a critical appraisal, focusing on the psychological wellbeing of individuals with inflammatory bowel diseases (IBD).

The SLR identified 22 qualitative research papers which discuss the importance of social support for individuals with IBD and its role in helping individuals cope with lifelong diagnoses. Three themes were found following thematic synthesis: (1) Supportive peers; (2) Shared experiences; and (3) Openness. A range of ways individuals with IBD utilise support from others to help them cope are identified, highlighting the importance of healthcare professionals including these systems in care and treatment of IBD.

The empirical paper explores the experience of difficulties with eating for individuals with IBD. Diet and nutrition become a central focus for these individuals yet little acknowledgement is given within research or by healthcare professionals to how this may impact on psychological difficulties. To develop an initial understanding, semi-structured interviews were completed with six individuals with IBD who report experiencing difficulties with eating. Interpretative phenomenological analysis was used to analyse data, which identified four themes: (1) The need to restrict and control diet; (2) Increased intrinsic and extrinsic awareness: the impact on body image; (3) Responsibility, guilt and engagement: The experience of clinical interventions; and (4) Feeling helpless: nowhere to turn. These findings provide insight into the processes through which difficulties with eating developed for these individuals, but also highlight more support with these difficulties is needed from healthcare services.

The final section provides a critical appraisal in which the candidate's interest in eating difficulties for individuals with IBD is discussed, alongside limitations of the papers. Focus is

given to the researcher's experience of IBD and the impact this had on issues such as reflexivity.

Declaration

The work presented in this thesis is the author's own and has not been submitted to support an application for another degree or other academic reward.

Name: Emma Mellor

Signature:

Date: 29th June 2022

Acknowledgements

Firstly, thank you to all the participants who took time out of their busy days to take part in the interviews, and provide such honest insights into their experiences of IBD.

To Craig and Georgina, for both applying a meticulous eye for detail, allowing me to develop and enhance my previously relatively non-existent research skills. I will be forever indebted to you both for providing me with these skills.

To my dad, Peter, thank you for inspiring me to want to work in the field of mental health through your own career as a mental health nurse. To my mum Amanda, thank you for always believing in me and picking up the pieces around the house and with childcare that I didn't always manage to juggle. To my brothers, Connor and Callum, thank you for providing a break from the seriousness of work with your laughter and silliness.

To my husband Sam, I couldn't have done this journey without you. Thank you for taking the brunt of the early get ups with Finlay whilst I was writing this thesis and weathering my occasional meltdowns and lack of self-belief.

And finally to Finlay, for coming along and providing me with the perfect reason to switch off from work, and enjoy your cuddles and fun loving spirit.

Contents

	Page Number
Word Count	-
Thesis Abstract	-
Declaration	-
Acknowledgements	-
Contents	-
Section One: Systematic Literature Review	1-1
Abstract	1-2
Introduction	1-3
Method	1-7
Results	1-11
Discussion	1-21
Conclusion	1-27
References	1-28
Tables and Figures	
Table 1. Database Search Terms	1-38
Table 2. Inclusion and Exclusion Criteria	1-39
Table 3. Outline of Papers Identified	1-40
Figure 1. PRISMA Flow Diagram	1-50

Appendix 1-A: Reasons for Article Exclusion: Full Text Accessed	1-51
Appendix 1-B: CASP Scoring	1-52
Appendix 1-C: Example of Analysis	1-55
Appendix 1-D: Process of analysis	1-56
Appendix 1-E: Overview of Themes	1-57
Appendix 1-E: Author Guidelines	1-58
Section Two: Empirical Paper	2-1
Abstract	2-2
Introduction	2-3
Method	2-7
Results	2-12
Discussion	2-21
Conclusion	2-27
References	2-28
Tables and Figures	
Table 1. Inclusion and exclusion criteria	2-33
Table 2. Participant Demographic Information	2-34
Table 3. Participant themes contributing to overall themes	2-35
Appendix 2-A: Interview Schedule	2-37
Appendix 2-B: Example of Transcript with Coding	2-39

Appendix 2-C: Example of Analysis	2-40
Appendix 2-D: Author Guidelines	2-43
Section Three: Critical Appraisal	3-1
Main Body	3-2
References	3-14
Appendix 3-A: Original Ethics Application	3-16
Appendix 3-B: Extract from Reflective Journal	3-29
Appendix 3-C: Extract from Reflective Journal	3-30
Section Four: Ethics Documentation	4-1
FHMREC Form	4-2
Appendix 4-A: Governance checklist	4-15
Appendix 4-B: Research Protocol	4-18
Appendix 4-C: Participant Information Sheet	4-35
Appendix 4-D: Consent Form	4-39
Appendix 4-E: Interview Schedule	4-41
Appendix 4-F: Email for field supervisor to distribute	4-43
Appendix 4-G: Email to Charity Organisations	4-44
Appendix 4-H: Social media/Website handle	4-45
Appendix 4-I: Expression of interest/ Opt-In Form	4-46
Appendix 4-J: Demographic Data Collection Sheet	4- 47

Section One: Systematic Literature Review

**The role of social support in coping for individuals living with Inflammatory Bowel
Disease: A systematic review and thematic synthesis of qualitative research.**

Emma Mellor

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

Emma Mellor

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster LA1 4AT

Email: e.mellor@lancaster.ac.uk

Prepared for: United European Gastroenterology Journal

Abstract

Objectives: Previous research has highlighted the importance of social support for individuals with long term health conditions, however little acknowledgment has been given to those with Inflammatory Bowel Disease (IBD) specifically. Therefore, this review aims to identify and synthesise the available qualitative literature on the experiences of social support for individuals with IBD and how this support has influenced their ability to cope with the illness.

Methods: A systematic literature search of four electronic databases, Medline, Web of Science, CINAHL and PsycInfo, identified 22 papers which included discussion on how individuals with IBD receive support from others. Thematic synthesis methods were used to synthesise these papers. **Results:** Three themes were produced: (1) Supportive peers (which emphasises how those around individuals with IBD help them to cope); (2) Shared experiences (within which other individuals who also have IBD help those with IBD to cope) and (3) Openness (whereby the degree to which individuals with IBD are open with others impacts on their ability to cope with IBD). **Conclusions:** The synthesis identifies a range of ways that individuals with IBD utilise support from others to help them cope with their health condition, signifying the importance of healthcare professionals including the individual's system in the care and treatment of IBD. In lieu of this support system, healthcare professionals should be mindful that these individuals will be missing vital ways to help them cope, and additional support may be needed.

Key words: adapt, adjust, Crohn's Disease, relationships, Ulcerative Colitis

Inflammatory bowel disease (IBD) is a chronic, life-long condition that refers to Crohn's disease (CD) and ulcerative colitis (UC). CD affects the gastrointestinal tract from the oral cavity to the rectum, whereas UC affects the rectum and colon (Quick et al., 2013). It begins during childhood and adolescence for 20% to 25% of individuals (Karwautz et al., 2008). The registered prevalence of CD varies from 0.6 to 322 per 100,000 in Europe, and from 4.9 to 505 per 100,000 in UC (Molodecky et al., 2012). The causality of IBD is complex but is thought to occur as a result of genetic susceptibility, dysregulation of the innate and adaptive immune systems, and environmental factors (Torres et al., 2017).

Within both CD and UC, the gastrointestinal tract becomes inflamed, which results in complications including diarrhoea and abdominal pain (Quick et al., 2013). The inflammation and scar tissue causes varying degrees of damage to the intestinal tract. This may cause difficulties for nutrients being absorbed from food, which can lead to malnutrition and delayed growth. Resultantly, some individuals with IBD have increased nutritional and caloric needs (Quick et al., 2013). Additionally, they may have low tolerance for certain foods and therefore dietary management may be necessary (Quick et al., 2013).

The use of prescribed medication, such as biologic agents and immunomodulators for patients in remission, or corticosteroids for acute treatment, is also necessary in most cases (Caio et al., 2021). Surgical options are also available, including colectomy for patients with UC; while this is deemed curative, it can result in a pouch or end ileostomy in approximately 30% of patients (Olendzki et al., 2014). Additionally, up to 70% of patients may develop pouchitis (Olendzki et al., 2014). Above 80% of CD patients require surgery, including surgical resection, which is not always curative (Olendzki et al., 2014). These treatment strategies aim for long-lasting remission, with the goal of reducing the need for acute treatment, such as steroids, and hindering disease progression (Torres et al., 2017). However, a briefing report by

the National Institute of Health Care and Excellence (NICE; 2014) suggest 50% of patients experience at least one relapse of symptoms annually.

A large body of research has demonstrated individuals with IBD also experience difficulties with mood and anxiety (Larion et al., 2015; Neuendorf, et al., 2016). Neuendorf et al. (2016) suggested the prevalence of these difficulties for individuals with IBD is 21% and 15% respectively. It has been suggested that the impact of being diagnosed with a lifelong illness, such as IBD, coupled with the necessity to adapt one's lifestyle to manage the illness, may contribute to the likelihood of an individual experiencing mental health difficulties (Larion et al., 2015).

Particularly within the field of health psychology, research has focused on how individuals cope with difficulties which arise from long-term health conditions (Folkman et al., 1986; Hagger & Orbell, 2003; Leventhal et al., 1992; Yi-Frazier et al., 2015). Turk et al. (1980) initially conceptualised individual coping as their effective response to situations which occur within a person's life, long-term health conditions being one of these. Consequently, many psychological theories on coping placed emphasis on the individual's ability to do this, for example their ability to make behavioural or cognitive changes to coping (Moskowitz et al., 2015), or personal attributes (Taylor & Armor, 1996). As a result, an individualistic approach to lifelong health conditions is often observed within service provider policies, where care and treatment is centred around self-management (Lorig, 2010), placing emphasis on the individual's role in coping with their illness through informed choice (Hibbard, 2003).

Atkin, Stapley and Easton (2010) however refute this and suggest "coping is socially negotiated, defined by the social space in which it takes place" (p.392). Being a member of a group can have a positive impact on coping, as it enables a sense of community which can reduce feelings of isolation, helplessness and worthlessness (Leshem, 2003). Consequently, it

is important to explore how an individual's experience of being part of a group and having social support networks impacts on their experience of coping.

Social support networks refer to any experience for two or more individuals where an exchange of resources occurs, which is perceived by all parties to enhance the receiver's wellbeing (Gottlieb, 1983). This can include behavioural or emotional support, whereby the support is offered as verbal or nonverbal, as well as practical support which may include material objects. Previous literature has found higher levels of social support are associated with an individual's increased ability to adapt to a chronic illness. For example, the benefits of social support for individuals with arthritis has been frequently cited as increasing feelings of validation and improving understanding, whilst an improvement in the experience of mental health difficulties, such as low mood and anxiety, has been observed (Kool et al., 2013; Kool & Geenen, 2012; Savelkoul et al., 2000). Despite this, research into IBD and social support remains limited.

Whilst a systematic review of qualitative studies which address social support for individuals with IBD directly is lacking, in a review concerning challenges of living with IBD, Byron et al. (2019) were able to provide initial insight into who these individuals drew support from, and what impact not receiving this support had on them. In a systematic literature review of quantitative studies which examined the psychological correlates of adjustment outcomes in adults with IBD, Jordan, et al. (2016) also drew conclusions on the impact of a lack of social support. Findings highlighted "perceiving oneself to be misunderstood or alienated from one's social support network when seeking support was significantly associated with reduced quality of life" (p.36). Recommendations suggested future research should focus on coping strategies.

It has been recognised social support is not provided in the same context for everyone. For some, social support is provided by the health care team (Altschuler et al., 2008; Cooper

et al., 2010; Håkanson, et al., 2010; Hall, et al., 2005). It is thought social support from healthcare professionals is welcomed as these professionals are perceived to hold knowledge about the individual's illness, which can make the individual feel safe and secure (Cooper et al., 2010; Hall et al., 2005; Husain & Triadafilopoulos, 2004; Krause, 2003). Yet others voice the opposite can occur when the health professional is perceived to be lacking the knowledge the individual feels they need, particularly at onset of treatment (Håkanson et al., 2010).

For others, support may be encapsulated by family and close friends, particularly during times of relapse (Husain & Triadafilopoulos, 2004; Lynch & Spence, 2008). Allison et al. (2013) report young adults with IBD described support from family and friends as both physical, such as being present during hospital stays, and emotional, including offering reassurance and being nurturing. Husain and Triadafilopoulos (2004) also suggest family support can help an individual to become accepting of their illness; Pihl-Lesnovska et al. (2013) suggest becoming accepting means the individual is able to acknowledge that the adversity of having a chronic illness is part of their life and find ways of managing this. During an autobiographical account of living with IBD, Kelly (1986) highlighted how the family's inability to accept the illness impacted on their own. Kelly recalled how despite experiencing active symptoms of the illness, such as blood and diarrhoea and acute abdominal pain, the family denied the illness, and refused to accept its existence, which they attributed to the illness having low visibility. Consequently, Kelly reported being unable to become accepting of the illness themselves until their difficulties were acknowledged and explained proficiently.

Self-help groups have also been identified as a crucial part of social support for some individuals with IBD (Krause, 2003; McCormick et al., 2012; Oliveira et al., 2007); these studies suggest support groups play a vital role for individuals in being able to share and answer questions, experiences and information. Similarly, Leshem (2003) argues support groups for people with IBD offer individuals the opportunity to share illness related strengths, which

previously they may not have had the opportunity to do. As suggested by Cosio (2020), the ability to do this within this setting is a result of support groups consisting of a group of people who have common difficulties and can support each other to cope with these.

Previous literature reviews in the area of IBD and support have been primarily concerned with research papers which use quantitative research methods or focus on an adolescent population. Limitations exist in focusing solely on quantitative research; Howitt and Cramer (2011) highlight the context and personal meanings of an individual's experience is not obtained through quantitative research studies. Qualitative reviews on the other hand enable new insights into phenomena through the synthesis of qualitative research findings. There is a growing body of qualitative research looking at IBD which has not been reviewed in this manner to date.

Aims and Objectives

Given the above arguments, this review aimed to identify and synthesise the experiences of social support for individuals with IBD and how this support has impacted on these individuals' ability to cope with the illness. This review focused on social support, that is behavioural, emotional or practical resources, received from those outside of individuals' care teams, including family, friends, peer support groups and co-workers.

Method

A thematic synthesis approach was utilised to synthesise qualitative studies, informed by Thomas and Harden's (2008) three stage approach: (1) coding text; (2) developing descriptive themes and (3) generating analytical themes. Thematic synthesis combines elements from meta-ethnography and grounded theory and facilitates the synthesis of methodologically heterogeneous studies (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008).

Search strategy

The search strategy was divided into four sections: (1) defining the focus of the synthesis; (2) locating relevant studies; (3) inclusion decisions and (4) quality assessment.

Defining the focus of the synthesis

The review focussed on studies which discussed how individuals with IBD receive social support from others, and what impact this has on coping. Discussions held with the university librarian as well as scoping searches allowed for the refinement of the review question and protocol. Key words were used to identify whether comparable registered systematic reviews were being conducted, using PROSPERO. This highlighted no existing reviews were being carried out which met criteria for this review.

During the initial scoping searches, search terms were checked within the American Psychological Association thesaurus for words frequently used by others for indexing, as recommended by Cherry et al. (2017). These were added to key words used for the current search. Debate exists within the literature about using full text searches with a set of terms that are uniform across a set of databases, or whether to use subject headings relevant to the database searched (DeMarrs & Perruso, 2022). Depending on the topic, subject heading searches can be more effective (DeMarrs & Perruso, 2022), whilst Jenuine and Floyd (2004) suggest free-text searching is more desirable. For the current topic, both methods have been drawn upon in previous reviews, with Jordan et al. (2016) using free-text searching and Byron et al. (2019) utilising subject headings. In the present review there was considerable diversity and heterogeneity in the subject terms across databases. As a result, it was decided to use a uniform free-text search across all databases. In retrospect, a better approach for the current literature review may have been to combine a subject heading search for each data base with the free text search carried out, in order to attain the most thorough review (DeMarrs & Perruso, 2022).

Locating relevant studies

The SPIDER tool (Cooke et al., 2012) was used to structure the systematic literature search in the following format: [Sample AND Phenomenon of Interest] AND [Design OR Evaluation OR Research type]. The decision was made to group design, evaluation and research in this way based on Cooke et al.'s (2012) recommendations, where they highlight the use of AND R results in a loss of relevant papers, and thus recommend the use of OR R. Full text articles on PsycINFO, CINAHL, MEDLINE and Web of Science were searched to give a good coverage of subject areas that relevant studies would be published in. The search strategy used is shown in Table 1. At this stage, an inclusion criteria of peer reviewed articles (as prima facie evidence of meeting a minimum quality threshold) and articles available in English due to lack of funds for translation services were selected.

[Insert Table 1]

Inclusion decisions

A comprehensive and systematic strategy was established to ensure the search would produce as many relevant studies as possible. As outlined by Atkins et al. (2008), identification of all studies within the topic area was not possible; Atkin et al. (2008) highlight poor indexing within qualitative research results in difficulties with electronic searches, whilst Cherry et al. (2017) state a further reason for this is the key words used in paper titles and abstracts of qualitative papers. The inclusion and exclusion criteria are highlighted in Table 2.

[Insert Table 2]

A summary of the primary reasons for exclusion following full-text review is provided in Appendix 1-A. It was decided support received from professionals would be excluded. It was felt all individuals seeking treatment for IBD would be routinely offered support from professionals, however the existence of positive social support networks from family and friends, as well as peer support groups, may not be equal for everyone. For example, support

groups are not offered within all geographical locations. Consequently, it was felt in choosing to focus on support from these areas, it would be possible to draw greater conclusions on the impact of not receiving social support. An argument also exists that support received from these individuals will impact on whether an individual chooses to access support from professionals (Håkanson et al., 2010), thus making it necessary to draw further distinctions between these areas of support.

Studies included

22 relevant papers were identified via methods set out above. Table 3 provides details of study location, sample, research question, methods of data collection and analysis.

[Insert Table 3]

Quality assessment of included studies

There is disagreement amongst qualitative researchers on the use of quality appraisal tools with those such as Noblit and Hare (1988) and Britten et al. (2002) choosing not to discuss these. However, in line with Atkins et al. (2008), the current reviewer chose to quality appraise papers to critically reflect on the contribution of each study to the research question. The Critical Appraisal Skills Programme (CASP) Qualitative Skills Checklist (Singh, 2013) was chosen for this review. This was enhanced using a three-point rating system for eight of the CASP items, developed by Duggleby et al. (2010). Studies which provided justification, explanation and clarity in the relevant area were deemed as being of high quality and were given three points, whilst two points were given to those papers within which some justification, explanation and clarity was found. If these features were lacking, a score of one was given. An additional researcher¹ also scored the papers independently, and interrater agreements were very high ($k = .864, p < .05$). Any disagreements were discussed with each individual providing justification for their score for a final score to be agreed upon. Papers

¹ Qualified Clinical Psychologist

were not excluded from this review based on CASP ratings, as strict journal word limits may have resulted in some quality-assessed information to have been removed from some published studies. Therefore, low CASP ratings do not necessarily indicate a study is low-quality. Results have been outlined in Appendix 1-B and ordered chronologically. A study number has been identified for each (S1 to S22), which is used to reference studies throughout the results.

Data analysis and extraction

The thematic synthesis methodology by Thomas and Harden (2008) was selected because it provides an explicit and transparent process to appraising qualitative data with varying reporting styles, including thin description and multiple quotations. As suggested by Thomas and Harden (2008), all data from the results, findings and discussion sections were treated as data for the synthesis, including participant quotations, to ensure the nature, meaning and context of concepts within each study was maintained.

The researcher copied findings into a data extraction form (appendix 1-C; Daker-White et al. 2015) and coded each line of verbatim text within the 22 studies. Remaining close to the original text, free codes were created inductively to form a bank of codes and further systematically organised into descriptive themes. The descriptive themes were re-interpreted inductively, developing analytical themes to answer the review question. Appendix 1-D demonstrates an example of this process.

Results

Searching of PsycINFO, Medline, CINAHL and Web of Science in July 2021 yielded 5812 results. After removing duplicates, 4047 results were screened by title and abstract. This left 78 results for full-text screening; 62 were excluded, leaving 16 full-texts. Database searches were supplemented by searching reference lists of included papers as recommended by Thomas and Harden (2008). The 'cite forward' function within Google Scholar was also used; an

additional 11 studies for full-text review were identified. Six of these were thought to be suitable for inclusion, resulting in a total of 22 studies. A diagrammatic representation of the inclusion decisions can be found in Figure 1.

[Insert Figure 1]

The synthesis of coding text and developing descriptive themes led to the development of three analytical themes, which answer the question “what social support do individuals with IBD receive, and how does this impact on coping?” These three analytical themes and their subthemes are: (1) Supportive peers (with subthemes of (a) Understanding, (b) Recognition-acceptance or denial, (c) Teamwork and (d) Presence); (2) Shared experiences (with subthemes of (a) Advice Taking and (b) Advice Giving), and (3) Openness (with subthemes of (a) Reducing Isolation, (b) Stigma and (c) Being a Burden).

Theme 1- Supportive peers

Synthesis of the 22 papers identified different support was received from peers (including family) without IBD to that received from those who shared participants’ experience of an IBD. This review highlighted agreement of this notion across 17 papers. The subthemes discussed here explore what types of support peers may provide and how this impacts on an individual with IBD’s ability to cope.

Understanding

The importance of understanding from family members was held by many (S2, S4, S9, S12, S13, S15, S16, S20, S21). For participants in Beck et al.’s (2013; S4) study, this understanding helped them cope with the debilitating impact of fatigue. Family members were able to recognise when the participant was fatigued, and adapt their lifestyle accordingly, by assisting with practical matters.

Conversely, in their high-quality paper, Dibley et al. (2019; S13) were able to draw out diverging evidence from participants, who highlighted how a lack of understanding from family members can have a negative impact on their ability to cope. This was discussed in relation to dietary intake; participants' highlighted mealtimes could be difficult if family members were not willing to facilitate necessary adaptations to diet.

Dibley et al. (2019; S13) suggested this inability to incorporate the chronic illness identity of their family into daily family functioning inhibits the process of normalisation for the individual and can lead to stigmatisation. They concluded invalidating responses from these individuals are experienced as more intense than that perpetrated by strangers and can have a greater emotional impact (Dibley et al., 2019; p. 1197; S13).

Nutting and Gafsky (2018; S12) described how a lack of understanding from family members, in particular partners, made physical symptoms of IBD difficult to cope with, which led to relational stress. One participant explained, "when I'm not feeling good, it makes it hard. He's a great dad and husband, but he does not know how to handle some of it. I don't know if he really understands how sick I can feel" (p. 181).

In contrast, when an individual's support system were understanding of the physical symptoms of IBD, this facilitated the individual to overcome feelings of embarrassment (Horgan et al. 2020; S16). One participant described how support from family and friends equipped him to cope with the demands of needing constant access to toilet facilities.

Fawson et al. (2021; S20) discussed the importance of understanding from employers. One participant described how their employer allowed them to work flexibly to help manage symptoms. They stated, "my boss was quite supportive with me working from home when I needed to. So, the days where I was going to the toilet 14 times a day, the bathroom was two

steps away from where I was sat” (p. 8). This flexibility provided by employers however was not replicated by professors for participants at college in Chaudry et al.’s (2020; S15) study.

Recognition- acceptance or denial

The subtheme of recognition of IBD occurred in six papers (S1, S3, S10, S13, S16, S18), and referred to the extent to which an individual’s support system recognised they had a chronic health condition and accepted or denied this. As Horgan et al. (2020; S16) explained, social acceptance is vital to participants’ quality of life and aids the process of normalisation (Allison et al., 2013; S3). One participant in Allison et al.’s (2013; S3) study explained how when they were surrounded by supportive friends they were treated equally. Pihl-Lesnovska et al. (2010; S1) defined this acceptance as confirmatory relations, and detailed that again it could be provided by different types of peers.

Both Polidano et al. (2020; S18) and Dibley et al. (2018; S10) found partners acceptance of a stoma following surgery greatly enhanced the individual’s ability to be accepting of it. One participant in Dibley et al.’s (2018; p. 243; S10) study stated: “My husband is absolutely amazing, just every single day tells me that I am beautiful and like he really doesn’t care what I look like and he’s completely accepted it”. Polidano et al. (2020; S18) expanded on these findings and suggested not being in a long-term relationship may have a negative impact on an individual’s ability to accept their stoma, due to concerns of starting new relationships and fears of what new partners might think.

Dibley et al. (2019; S13) particularly found participants emphasized the importance of acceptance from family members, and detailed many participants suggested grand gestures were not needed, but instead, subtle messages which demonstrated support, such as “the odd, Are you alright? you know, just reassurance really” (p. 1205). Dibley et al. (2019; S13) also discussed the impact of family members denying the illness as part of the individual. This may

have occurred as an attempt to “fix” the individual, to which participants experienced a sense of anger or betrayal. Dibley et al. (2019; S13) suggested this lack of recognition often led to a breakdown of relations or amplified pre-existing weaknesses.

Teamwork

A further subtheme evidenced by 11 studies (S2, S3, S4, S5, S11, S12, S13, S14, S15, S17, S19) is teamwork. Participants in Czuber-Dochan, et al.’s (2012; S2) study discussed the practical support family members provided, such as carrying out physical tasks they could no longer do:

My husband’s great...if I say I’m going to lie down, he goes, ‘Oh yes great.’ So we’ve got a deal, he does all the jobs in the house, because I can’t ... He’ll do all that and things like doing the shopping and lifting things down and that. But I, on the other hand, do all the planning. (Czuber-Dochan et al., 2012; p. 1992; S2).

Allison et al. (2013; S3) explored the idea of working together as a team further and revealed a distinction between gender in regard to what type of support was looked for. They found whilst males appreciated practical support, females looked to share difficult emotions and stress often experienced with IBD, and thus sought emotional support.

Nutting and Grafsky (2018; S12) highlighted the negative impact participants experienced if they did not share with those around them how their condition was impacting upon them emotionally; participants experienced relational strain but could “learn to cope with the strain by forming a team approach and move forward by making meaning of the disease in their lives” (Nutting & Grafsky, 2018; p. 182; S12).

Whilst many participants reflected on working together as a team as beneficial, participants in Ruan and Zhou’s (2019; S14) high quality study stressed this made them feel like a burden, as they could not return the care they received. One participant stated, “I not only

make little contribution to my family but I've also become a huge burden to my family now!" (p. 90).

Presence

The subtheme of presence emerged in three papers, S3, S10 and S14. It refers to supportive others offering unwavering support throughout the individual's journey. Participants in Allison et al.'s (2013; S3) study highlighted how being present helps them to cope at the beginning of their journey; they discussed how at this time they are "psychologically fragile" but "by being there during the hospital stay and in the early stages of recovery families provided a constant and reassuring presence and helped participants to cope" (p. 1571).

Ruan and Zhou (2019; S14) explored the notion of presence further and suggested unwavering support facilitates the individual's relationship with peers to improve. One participant suggested this is due to peers demonstrating how much they care: "Friends, they all care about you . . . It definitely didn't happen previously (before illness). So, my relationships with friends were enhanced" (p. 94). However, Allison et al. (2013; S3) suggested for some participants, demonstrations of care could have a negative impact on relationships. This seemed prudent to younger individuals who experienced parents as overprotective. Instead, participants in Allison et al.'s (2013; S3) study reported a supportive attitude from parents which encouraged them to live a normal life was more beneficial.

Theme 2- Shared experiences

This theme refers to those who share the experience of IBD. It includes subthemes, which highlight how those with shared experiences provided support to individual's with IBD and the impact this had on their ability to cope.

Advice taking

Participants frequently discussed reasons why they sought information from those with shared experiences (S3, S5, S6, S7, S8, S10, S11, S14, S16, S17, S20, S21, S22). For some, this was about gaining information that others, such as health professionals, could not provide. This could be practical support in relation to disease management (Schwenk, et al., 2014; S5; Rohatinsky et al., 2021; S22), treatment options (Larsson, et al., 2016; S7), or surgery advice (Baker et al., 2017; S8). For participants in Allison et al.'s (2013; S3) study, discussion around treatment helped them understand new situations, reduced anxiety, and provided reassurance before making treatment options. Baker et al. (2017; p. 186; S8) highlighted the detrimental impact for participants of not receiving this advice: "I could have done with speaking to other people that had it done [the operation].... There's a lot of stuff you don't pick up. Anecdotal stuff from experience that I don't think you can put in a leaflet."

Other participants expressed the importance of reaching out to, and receiving advice from, those with shared experiences for emotional support. One participant in Larsson et al.'s (2016; S7) high quality study stated sharing how she was feeling about the disease helped her cope with worries related to pain, fatigue and low mood.

The forum in which participants received advice through was also recalled as important. For some, attending support groups (Larson et al., 2016; S7) was cited as beneficial. Participants in Schwenk et al.'s (2014, S5) study suggested this facilitated relationships to develop on a premise of friendship, rather than shared disease. Yet participants in Fawson et al.'s (2021; S20) study reported the benefits of online support systems on social media platforms, for instance being able to access advice from lots of people and receiving this in a timely fashion: "The Crohn's forum on Facebook (is) quite good. There are tens of thousands of members ... and you can put a question up and get an answer almost straight away" (p. 9). Participants in Marques et al.'s (2021; S21) study reported receiving advice from these sites as opposed to healthcare professionals was preferable, as it was more relatable. This is the only

study where demographics regarding race were explored, which highlighted white participants were more likely to use these sites. Despite this strength, this study scored relatively low in terms of quality appraisal as it failed to draw out how this finding is valuable to the field of IBD.

Two participants in Baker et al.'s (2017; S8) study also refuted the use of social media platforms as beneficial. They recalled this could have a negative impact on their wellbeing as some individuals on these sites became competitive, in the sense of "I'm iller than you" (p. 186). It was also queried how accurate the clinical advice provided was.

Advice giving

Being there for others with IBD, by listening or providing moral support, was also highlighted as important to participants' own experience of coping with IBD (S6; S12; S20). One participant in Nutting and Grafsky's (2018; S12) study stated, "I've helped a lot of people with Crohn's and connected with them. I think maybe that's what I'm here for. To help people dealing with the same thing..." (p. 182). Nutting and Grafsky (2018; S12) reported this highlighted how advice giving to others with IBD has helped illuminate what individual meaning and values the experience of living with a chronic health condition had given to participants. Purc-Stephenson et al. (2015; S6) also demonstrated how advice giving assisted on a systemic level; it enabled individuals to develop stronger and more intimate relationships with others with IBD, achieved through providing emotional support, humour and information sharing.

Theme 3- Openness with others

The theme of openness with others refers to the extent to which individuals with IBD choose to disclose their illness. Twelve of the identified papers (S1, S2, S5, S7, S9, S10, S12, S13, S14, S17, S20, S22) discussed this, with participants bringing to light a range of reasons

why they chose, and chose not to, disclose their illness. As Dibley et al. (2018; S9) and Fawson et al. (2021; S20) highlight, being open with others could facilitate participants to be supported, and consequently cope with, the varied symptoms and challenges of living with IBD.

Reducing isolation

Participants expressed how being open with others helped reduce feelings of isolation often experienced in the early stages of receiving their diagnosis. For participants in Ruan and Zhou's (2019; S14) and Schwenk et al.'s (2015; S5) studies, finding and subsequently disclosing to others with IBD was paramount for this: "At first, I thought I was the only one. Suddenly, I found there were many people with the same diagnosis: "Wow, I have a lot of brothers and sisters! I am not alone" (Ruan & Zhou, 2019; p. 91; S4).

Participants in Schwenk et al.'s (2014; S5) study also highlighted how being aware others had IBD helped to normalise their experience and provided reassurance their situation could improve. However, some participants in Schwenk et al.'s (2014; S5) study refuted the idea of sharing with others with IBD to reduce feelings of isolation. They expressed that rather than boost low mood, the opposite could occur: "I think it would be rather depressing to sit [with a group of students with IBD] and talk about problems and stuff like that." (p. 1624).

Participants expressed the benefits of disclosing their illness to friends and family for reducing their sense of isolation; participants in Larsson et al.'s (2016; p. 652; S7) study stated, "It made me feel less alone with this problem." However, Dibley et al. (2019) highlighted the juxtaposition participants experienced when choosing to hide their illness; whilst participants expressed they wanted to hide their illness to protect their family, it perpetuated feelings of betrayal and abandonment, due to the family's lack of acknowledgement of their disease.

Stigma

The subtheme of stigma in relation to being open with others about their disease was discussed by participants in the papers of Ruan and Zhou (2019; S14). It was thought relevant to how individuals received support from others, as if they were unable to disclose they had a disease due to fear of being stigmatised, others would not be able to provide sufficient support. These papers recalled participants as referring to IBD as a “dirty disease” (Dibley, et al., 2018; p. 845; S9) and expressed that stigma, or perceived stigma, was experienced by participants due to the illness having symptoms related to the bowel which are often not talked about. Therefore, in their high-quality paper, Dibley et al. (2018; S9) suggested the relationship an individual with IBD has with others informed whether or not they choose to tell them:

“If you have a (bowel) accident, depending on who you’re with, it can be an issue. If you’re with family, they acknowledge there’s a problem. If you’re with close friends, they can live with it a little bit. But if you’re with extended family or people from work, who don’t really appreciate what the condition is, it’s, well, ‘Can’t even control himself.’” (p. 846).

The relationship participants had with others was highlighted as the biggest challenge when trying to build support networks (Dibley et al., 2018; S9). This notion was echoed by participants in Ruan and Zhou’s (2019; S14) study who professed disclosing their illness with colleagues was more difficult than family members due to the nature of their relationship. They chose not to disclose through fear of being stigmatised to the extent where they would not be treated as equal to colleagues: “I have worked so hard to pursue my career goal. Now, I am close to it. If I tell (I won’t reach this goal), but my colleagues will” (p. 92).

Being a burden

For some participants (S1, S2, S9, S11, S14, S17), the fear of being a burden prevented them from being open about their illness, again impacting on the ability of the family to provide

support. This seemed particularly pertinent when the participant had a caring responsibility. Karadag et al. (2020; S17) highlighted how parents experienced guilt when they could not carry out parental responsibilities, and consequently did not seek help when experiencing a flare up:

“I can’t look after my children properly – that impacts on my partner and his job... And my mum and stuff has to help...I also feel guilty because I know I know it impacts them, so I try and I try not to ask for help even though when sometimes I may need it...I don’t want to be a burden on anyone” (p. 9).

For parents in Garcia-Sanjuan et al.’s study (2016; S11), they reported attempting to compensate for these feelings of being a burden by doing as much as they can when in remission. A further difficulty arose for participants in Pihl-Lesnovska et al.’s (2010; S1) study; they described not wanting to burden family members with the fear of getting the illness themselves, due to its hereditary nature.

Discussion

This is the first review to utilise systematic methods to synthesise existing qualitative literature to develop a better understanding of experiences of social support for individuals with IBD and how this support has impacted on their ability to cope with the illness. From the 22 studies included, three themes were developed; supportive peers, shared experiences and openness.

Supportive peers encapsulated the different types of support individuals with IBD found beneficial to receive from others, in helping them cope with their IBD, namely understanding, recognition, teamwork and presence. The notion of supportive peers having a positive impact on these individuals is supported by Goffman (1963). In his seminal work on stigma, Goffman (1963) described how individuals with difference are, or perceive they are, thought of as less than others without difference, or a “mark” as Goffman (1963) termed. He

suggested there are individuals who are aware of another person's mark, who are referred to as knowledgeable others. Goffman (1963) defined these knowledgeable others as either "own", being those individuals that share the difference, or "wise" who are the individuals who are "intimately privy to the secret life of the stigmatized individual and sympathetic with it" (Goffman, 1963, p. 31). He went on to suggest the "wise" are unconditionally supportive towards those with difference and are therefore not in a position to make a "marked" individual feel stigmatised.

Whilst synthesis of the 22 papers identified for this review demonstrated agreement of this idea across 17 papers, disagreement of the supportive "wise" was acknowledged. Participants in Dibley et al.'s (2018) research highlighted the support they received from "the wise" was variable, influenced by the quality of the relationship, with family being the most tolerable, and work colleagues the least, who were often derogatory with their comments. This finding is similar to that identified in a quantitative review by Jordan et al. (2016) who highlighted individuals who experienced themselves as misunderstood or alienated from peers had a reduced quality of life. However, the qualitative nature of the current review allowed these findings to be explored further. Dibley et al. (2019) concluded invalidating responses such as these from the "wise" were experienced as more intense, and had a greater emotional impact, terming this experience "kinship stigma". Kinship stigma can result in the individual's inability to accept their chronic illness and find ways of managing it (Pihl-Lesnovska et al., 2013). Whilst this may be accurate, the experience of these comments may be more intense due to what Scambler (2004) termed enacted stigma, which are actual experiences of stigma, rather than felt stigma, which refers to feelings of shame and fear of being stigmatised. It is possible enacted stigma occurs more often from the wise, and thus has a greater impact, as opposed to unknown individuals. This could be due to individuals having a greater exposure to their wise, alongside the wise being more likely to attempt to provide sympathy in a well-

intentioned manner, which participants in Saunders' (2014) study stated resulted in their differences being emphasised and consequently feeling othered.

Thus, the findings of this review highlighted not only the importance of individuals with IBD having supportive others around them to cope, but also the detrimental impact not having support can have. Despite this, Dibley et al. (2018) recognised those supporting individuals with IBD may also need advice, help, and support, to incorporate the chronic illness persona into daily functioning, as although their inability to do this may be perceived by the individual with the chronic illness as stigmatising, it may in fact be due to a lack of understanding of the chronic condition, as well as feelings of blame, shame and loss for these individuals. Whitehead et al. (2018) recommended this could be improved through effective communication and the involvement of them by professionals.

The theme of *shared experiences* occurred within 15 of the identified papers, and highlighted individuals with IBD found it helpful to receive support from other individuals with IBD, in the form of receiving and giving advice. This was often facilitated by support groups, which allowed individuals to acquire new coping skills from each other (Leshem, 2003). This theme is consequently in line with more recent psychological theories of coping such as that by Atkin et al. (2010), who place importance on the experience of the social space. Whilst a similar finding was identified by Potter et al. (2017), their qualitative study focused on the social interaction with services. Despite this, their study also highlighted coping with lifelong health conditions is a dynamic process which develops through individuals' interactions with their social and cultural environments (Potter et al., 2017).

However, it is important to recognise individual differences exist amongst those with IBD, and thus conclusions cannot be drawn which assume attending support groups will result in a shared experience. Marques et al. (2021) explored race differences in relation to an

individual's experience of IBD in the United States, and found white participants were more likely to attend self-help groups or use online support forums than black participants. It is therefore possible the benefit of the shared experience depicted in this review is only representative of the experience of white participants, and differences may exist in sources of support dependant on an individual's race.

The theme of *openness* was found within 12 of the papers included in this review, with participants citing factors of reducing isolation, stigma and being a burden as reasons as to why they would choose or not choose to disclose their illness to others. For participants in Ruan and Zhou's (2019) study, which was carried out in Korea, a reluctance to share their illness experience with those around them was reported for fear of stigmatisation. Kim and Cohen (2010) state Chinese society is structured around the reciprocation of "guanxi", "renqing", and "face" (miàn zi), suggesting people's worth is largely defined by what others think of them. Additionally, bowel problems, especially those involving faeces, are regarded as taboo (Bischoff, 2011). Thus, the combination of both a loss of face and bowel problems violates key reciprocity norms in Chinese society and increases an individual's stigma experience (Yang & Kleinman, 2008). This concept may explain why participants in Ruan and Zhou's (2019) study were more concerned about self-identities and struggled with whether to disclose their patient identity.

Clinical implications

This review highlighted how the concept of "individualised coping", still adhered to within healthcare policies in the form of self-management strategies, is outdated and requires addressing. It has been identified the individual's social system plays a vital role in how an individual with IBD copes with both the emotional and physical impact of their condition. Thus, coping strategies should place a greater focus on this social system. Drawing on benefits

of *advice giving and advice taking* from those with *shared experiences*, the use of peer support groups, cited as not widely available across all services, could be increased; currently individuals are signposted to third sector organisations such as Crohn's and Colitis UK who hold regional peer group meetings. Furthermore, individuals' friends and family could be included throughout care and treatment. Consideration could be given to the individual's social support by the gastroenterology team during assessment, to ascertain if going forward, the individual has someone they would want to be invited to attend appointments with their IBD nurse specialist and treatment clinics. This will facilitate individuals with IBD to not only feel less responsible for their coping due to a greater *presence* of others, and more opportunity to engage in *teamwork*, but will also assist peers to develop a better *understanding* of the condition and be more informed in ways in which they can help.

This review has also highlighted how clinical psychologists can help individuals with IBD cope with the emotional impact of the condition; as Dibley et al. (2018) highlighted, the individual's system also experience difficult feelings akin to the individual with IBD, such as shame, worthlessness and hopelessness. Therefore, a systemic approach to IBD care would allow clinical psychologists to provide support to those experiencing these feelings as a system, by drawing on therapies which encourage *openness*. For clinical psychologists not working in health settings, a review of an individual's social support during assessment and formulation would help identify areas to target during intervention, for example where social support was limited, signposting to local peer support groups could be made.

Limitations

Several limitations of this review could be cited. Firstly, the current review chose to explore how social support assists adults with IBD cope with the lifelong health condition. This consequently excluded those under the age of 18 whose experience is likely to differ; it could

be hypothesised additional social support would be needed for children and adolescents. Therefore, conclusions cannot be drawn, or recommendations made for those working in paediatric IBD care. An issue pertaining to generalisability of findings could also be found within the sample of participants; although participants reported difficulties with being open about their condition, they felt comfortable participating. It is likely there will be some individuals for whom this would have felt too difficult and consequently their experiences will not be reflected.

A further limitation exists in that it was not possible to ascertain what support outside of social support individuals were receiving. This is likely to be a mediating factor for how much social support individuals draw upon. It is possible if individuals are receiving a vast amount of support from healthcare services, they may need less from peers. Thus, it would be of benefit for future research to explore all types of support an individual utilises to help them cope with IBD.

A methodological weakness of the review exists in that it was not possible to have several reviewers included to allow consensus to be reached when applying inclusion criteria, as suggested as good practice by Atkins et al. (2008) to increase reliability.

Future research

This review focused on how individuals with IBD experience social support and how this support impacted on their ability to cope with the illness; for this to be obtainable, it was necessary for participants to have an existing support system. It is therefore important to recognise a dearth of evidence exists for those without this. Future research should seek to explore experiences of individuals with IBD without this support to ascertain the impact not having it has on their physical health in relation to their IBD, but also their mental wellbeing.

There is a need for future research to focus on capturing differences within demographics observed within the IBD population as initial findings by those such as Marques et al. (2016) and Ruan and Zhou (2019) suggest demographic differences exist within this population and their consequent experience of social support and ability to cope with the illness. This is supported by research from Allmark (2004) which highlights white individuals are more likely to volunteer to participate in research studies, thus reinforcing the need for representation of individuals from different backgrounds.

Conclusion

Social support for individuals with IBD can be provided by those with an in depth understanding of the experience of having IBD due to personal experience, as well as by those who do not share the experience but care for the individual. The types of support these groups can offer differ but are equally valuable in helping the individual to cope with both the psychological and physical impact of the condition. It is also important to recognise difficulties can occur in terms of coping if individuals with IBD are not accepting of this support or choose not to share their experience with others to facilitate support. The qualitative nature of this review goes further than those previous in helping to explain how and why different types of support are important and effective.

References

- Allison, M., Lindsay, J., Gould, D., & Kelly, D. (2013). Surgery in young adults with Inflammatory Bowel Disease: A narrative account. *International Journal of Nursing Studies, 50*, 1566-1575.
- Allmark, P. (2004). Should research samples reflect the diversity of the population? *Journal of Medical Ethics, 30*, 185-189.
- Altschuler, A., Collins, B., Lewis, J. D., Velayos, F., Allison, J. E., Hutfless, S., & Herrinton, L. J. (2008). Gastroenterologists' attitudes and self-reported practices regarding inflammatory bowel disease. *Inflammatory Bowel Diseases, 14*, 992-999.
- Atkin, K., Stapley, S. and Easton, A. (2010). No one listens to me, no one believes me: self management and the experience of living with encephalitis. *Social Science & Medicine, 71*(2), 386– 93.
- Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., & Volmink, J. (2008). Conducting a meta-ethnography of qualitative literature: lessons learnt. *BMC medical research methodology, 8*(21), 1-10. <https://doi.org/10.1186/1471-2288-8-21>
- Baker, D.M., Lee, M.J., Jones, G.L., & Brown, S.R. (2018). The Informational Needs and Preferences of Patients Considering Surgery for Ulcerative Colitis: Results of a Qualitative Study. *Inflammatory Bowel Diseases, 24*(1), 179–190
- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Med Res Methodology, 9*(59). <https://doi.org/10.1186/1471-2288-9-59>
- Beck, A., Bager, P., Jensen, P.E. & Dahlerup, J.F. (2013). How Fatigue Is Experienced and Handled by Female Outpatients with Inflammatory Bowel Disease. *Gastroenterology Research and Practice, 2013*(2). <https://doi.org/10.1155/2013/153818>

- Bischoff S.C. (2011). 'Gut health': a new objective in medicine? *BMC Medicine*, 4(9), 24.
<https://doi.org/10.1186/1741-7015-9-24>
- Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: a worked example. *Journal of health services research & policy*, 7(4), 209-215.
- Caio, G., Lungaro, L., Caputo, F., Zoli, E., Giancola, F., Chiarioni, G., De Giorgio, R., & Zoli, G. (2021). *Nutritional Treatment in Crohn's Disease*. *Nutrients*, 13(5), 1628.
<https://doi.org/10.3390/nu13051628>
- Chaudhry, N. A., Pham, A., Flint, A., Molina, I., Zaidi, Z., Zimmermann, E. M. & Behar-Horenstein, L. S. (2020). College Students with Inflammatory Bowel Disease: A Qualitative Study of Challenges Associated with College Transition and Self-Care. *Health Equity*, 4(1), 190-197. <https://doi.org/10.1089/hecq.2019.0053>
- Cherry, M. G., Smith, H., Perkins, E., & Boland, A. (2017). Reviewing Qualitative Evidence. In A. Boland, G. Cherry, & R. Dickson (Eds.), *Doing a Systematic Review: A Student's Guide* (2nd Ed.). (pp. 193-222). Sage.
- Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, 22(10), 1435-1443. <https://doi.org/10.1177/1049732312452938>
- Cooper, J. M., Collier, J., James, V., & Hawkey, C. J. (2010). Beliefs about personal control and self-management in 30-40 year olds living with inflammatory bowel disease: A qualitative study. *International Journal of Nursing Studies*, 47, 1500-1509.
- Cosio, D. (2020). A group-based, acceptance & commitment therapy intervention for chronic pain. *Social Work With Groups*, 43(4), 334-346.

- Critical Appraisal Skills Programme (CASP). (2018). <https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf>
- Czuber-Dochan, W., Dibley, L. B., Terry, H., Ream, E., & Norton, C. (2012). The experience of fatigue in people with inflammatory bowel disease: An exploratory study. *Journal of Advanced Nursing*, *69*, 1987-1999.
- Daker-White, G., Hays, R., McSharry, J., Giles, S., Cheraghi-Sohi, S., Rhodes, P., & Sanders, C. (2015). Blame the patient, blame the doctor or blame the system? A meta-synthesis of qualitative studies of patient safety in primary care. *PLoS ONE*, *10*(8), e0128329
- Dibley, L., Norton, C. & Whitehead, E. (2018). The experience of stigma in inflammatory bowel disease: An interpretive (hermeneutic) phenomenological study. *Journal of Advanced Nursing*, *74*(4), 838-851. <https://doi.org/10.1111/jan.13492>
- Dibley, L., Czuber-Dochan, W., Wade, T., Duncan, J., Burch, J., Warusavitarne, J., Norton, C., Artom, M., O'sullivan, L., Verjee, A., Cann, D. & Stoma, P. P. I. T. (2018). Patient Decision-Making About Emergency and Planned Stoma Surgery for IBD: A Qualitative Exploration of Patient and Clinician Perspectives. *Inflammatory Bowel Diseases*, *24*(2), 235-246. <https://doi.org/10.1093/ibd/izx043>
- Dibley, L., Williams, E., & Young, P. (2019). When Family Don't Acknowledge: A Hermeneutic Study of the Experience of Kinship Stigma in Community-Dwelling People With Inflammatory Bowel Disease. *Qualitative Health Research*, *30*(8), 1196-1211. <https://doi.org/10.1177/1049732319831795>
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic

- illness. *Qualitative Health Research*, 20(2), 148-158. <https://doi.org/10.1177/1049732309358329>
- Fawson, S., Dibley, L., Smith, K., Batista, J., Artom, M., Windgassen, S., Syred, J., Moss-Morris, R. & Norton, C. (2021). Developing an Online Program for Self-Management of Fatigue, Pain, and Urgency in Inflammatory Bowel Disease: Patients' Needs and Wants. *Digestive diseases and sciences*, 19,1-14. <https://doi.org/10.1007/s10620-021-07109-9>
- Folkman, S., Lazarus, R.S., Gruen, R.J. and Delongis, A. (1986). Appraisal, coping, health-status, and psychological symptoms. *Journal of Personality and Social Psychology*, 50(3), 571– 9.
- Garcia-Sanjuan, S., Lillo-Crespo, M., Richart-Martinez, M., & Quiles, A.S. (2018). Understanding life experiences of people affected by Crohn's disease in Spain. A phenomenological approach. *Scandinavian Journal of Caring Sciences*, 32(1), 354-362.
- Goffman, E. (1963). *Stigma: Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Gottlieb, B. (1983). Social support as a focus for integrative research in psychology. *American Psychologist*, 38, 278–287.
- Hagger, M.S. and Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health*, 18(2), 141– 84.
- Håkanson, C., Sahlberg-Blom, E., & Ternstedt, B. (2010). Being in the patient position: Experiences of health care among people with irritable bowel syndrome. *Qualitative Health Research*, 20, 1116-1127.

- Hall, N. J., Rubin, G. P., Dougall, A., Hungin, A., & Neely, J. (2005). The fight for “health-related normality”: A qualitative study of the experiences of individuals living with established inflammatory bowel disease (IBD). *Journal of Health Psychology, 10*, 443-455.
- Hibbard, J.H. (2003). Engaging health care consumers to improve quality of care, *Medical Care, 41*(1), S161– S70.
- Horgan, L., Richards, H. & Joy, A. (2020). The Young Adult Male's Perception of Life with Inflammatory Bowel Disease and a Stoma: A Qualitative Examination. *Journal of Clinical Psychology in Medical Settings, 27*(3), 560-571.
<https://doi.org/10.1007/s10880-019-09695-3>
- Houtzager, B. A., Grootenhuis, M. A., & Last, B. F. (2001). *Support groups for siblings of pediatric oncology patients: impact on anxiety. Psycho-oncology, 10*, 315-324.
- Howitt, D., & Cramer, D. (2011). *Introduction to Research Methods in Psychology: Third Edition*. Pearson Education UK.
- Husain, A., & Triadafilopoulos, G. (2004). Communicating with patients with inflammatory bowel disease. *Inflammatory Bowel Diseases, 10*, 444-450.
- Jordan, C., Sin, J., Fear, N.T., & Chalder, T. (2016). A systematic review of the psychological correlates of adjustment outcomes in adults with inflammatory bowel disease. *Clinical Psychology Review, 47*, 28-40.
- Karadag, P., Morris, B. & Woolfall, K. (2020). The information and support needs of patients living with inflammatory bowel disease: A qualitative study. *Chronic illness, 0*(0), 1-14. <https://doi.org/10.1177/1742395320968617>

- Karwautz A, Wagner G, Berger G, Sinnreich U, Grylli V, Huber W. (2008). Eating pathology in adolescents with celiac disease. *Psychosomatics*, 49, 399–406.
- Kim Y-H, & Cohen D. (2010). Information, Perspective, and Judgments About the Self in Face and Dignity Cultures. *Personality and Social Psychology Bulletin*, 36(4), 537-550. <https://doi.org/10.1177/0146167210362398>
- Kelly, M. (1986). The subjective experience of chronic disease: some implications for the management of ulcerative colitis. *Journal of Chronic Diseases*, 39(8), 653-666.
- Kool, M.B., Van Middendorp, H., Lumley, M., Bijlsma, J.W., Geenen, R. (2013). Social support and invalidation by others contribute uniquely to the understanding of physical and mental health of patients with rheumatic diseases. *Journal of Health Psychology*, 18(1), 86–95.
- Kool, M.B., & Geenen, R. (2012). Loneliness in patients with rheumatic diseases: the significance of invalidation and lack of social support. *Journal of Psychology*, 146(1-2), 229–41.
- Krause, M. (2003). The transformation of social representations of chronic disease in a self-help group. *Journal of Health Psychology*, 8, 599-615.
- Larion, S., DeCecchis, P.D., Arnold, M.J., Vanslyke, A.J., and Tavakoli, R.H. (2015). Psychiatric Comorbidities in Inflammatory Bowel Disease. *Current Psychiatry Reviews*, 11(2), 124-129. <https://doi.org/10.2174/15734005110215050208333>
- Larsson, K., Loof, L., & Nordin, K. (2016). Stress, coping and support needs of patients with ulcerative colitis or Crohn's disease: a qualitative descriptive study. *Journal of Clinical Nursing*, 26(5-6), 648-657.
- Leshem, R.N. (2003). Inflammatory Bowel Disease Support Group: A Primer for Gastroenterology Nurses. *Gastroenterology Nursing*, 26(6), 246-250.
- Leventhal, H., Diefenbach, M. and Leventhal, E.A. (1992). Illness cognition: using common-sense to understand treatment adherence and affect cognition interactions. *Cognitive Therapy and Research*, 16(2), 143– 63.

- Lorig, K. (2010). Chronic disease self-management: from randomized trial to public policy. *European Journal of Public Health*, 20(1), S6– 7.
- Lynch, T., & Spence, D. (2008). A qualitative study of youth living with Crohns disease. *Gastroenterology Nursing*, 31, 224-230.
- Majid, U. (2018). Research fundamentals: Study design, population, and sample size. *Undergraduate research in natural and clinical science and technology journal*, 2, 1-7.
- Marques, I.C.D.S., Herbey, I.I., Theiss, L.M., Shao, C.C., Fouad, M.N., Scarinci, I.C., & Chu, D.I. (2021). Understanding the surgical experience for Black and White patients with inflammatory bowel disease (IBD): The importance of health literacy. *The American Journal of Surgery*. <https://doi.org/10.1016/j.amjsurg.2021.06.003>
- McCormick, J. B., Hammer, R. R., Farrell, R. M., Geller, G., James, K. M., Loftus, E. V., Jr., Mercer, M.B. Tilburt, J.C., & Sharp, R. R. (2012). Experiences of patients with chronic gastrointestinal conditions: In their own words. *Health and Quality of Life Outcomes*, 10(1), 1-11.
- Molodecky, N.A., Soon, I.S., Rabi, D.M., Ghali, W.A., Ferris, M., Chernoff, G., Benchimol, E.I., Panaccione, R., Ghosh, S., Barkema, H.W., & Kaplan, G.G. (2012). Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology*, 142(1), 46–54, <http://dx.doi.org/10.1053/j.gastro.2011.10.001>
- Moskowitz, J.T., Duncan, L.G., Moran, P.J., Acree, M., Epel, E.S. Kemeny, M.E., Hecht, F.M., & Folkman, S. (2015). Dispositional mindfulness in people with HIV: associations with psychological and physical health. *Personality and Individual Difference*, 86(1), 88–93.
- Neuendorf, R., Harding, A., Stello, N., Hanes, D., & Wahbeh, H. (2016). Depression and anxiety in patients with inflammatory bowel disease: a systematic review. *Journal of Psychosomatic Research*, 87, 70–80. <https://doi.org/10.1016/j.jpsychores.2016.06.001>

- National Institute for Health and Care Excellence. (2014). *Inflammatory bowel disease briefing paper* [2]. <https://www.nice.org.uk/guidance/qs81/documents/inflammatory-bowel-disease-briefing-paper2>
- Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesizing Qualitative Studies*. Sage Publications.
- Northen, H. (1989). Social work practice with groups in the health care. In J. H. Schopler & N.J. Galinsky (Eds). *Groups in health care settings*, 12(4), 7-26.
- Nutting, R. & Graftsky, E. L. (2018). Crohn's Disease and the Young Couple: An Interpretative Phenomenological Analysis. *Contemporary Family Therapy*, 40(2), 176-187. <https://doi.org/10.1007/s10591-017-9451-9>
- Olendzki, B. C., Silverstein, T. D., Pursutte, G. M., Ma, Y., Baldwin, K. R., & Cave, D. (2014). An anti-inflammatory diet as treatment for inflammatory bowel disease: a case series report. *Nutrition journal*, 13(5). <https://doi.org/10.1186/1475-2891-13-5>
- Oliveira, S., Zaltman, C., Elia, C., Vargens, R., Leal, A., Barros, R., & Fogaça, H. (2007). Quality-of-life measurement in patients with inflammatory bowel disease receiving social support. *Inflammatory Bowel Diseases*, 13, 470-474.
- Pihl-Lesnovska, K., Hjortswang, H., Ek, A.C., & Frisman, G.H. (2010). Patients' perspective of factors influencing quality of life while living with Crohn disease. *Gastroenterology Nursing*, 33(1), 37-46.
- Polidano, K., Chew-Graham, C.A., Bartlam, B., Farmer, A.D. and Saunders, B. (2020). Embracing a 'new normal': the construction of biographical renewal in young adults' narratives of living with a stoma. *Social Health Illn*, 42, 342-358. <https://doi.org/10.1111/1467-9566.13005>
- Prantera, C., & Andreoli, A. (1996). *Prevention of relapse and recurrence*. In C. Prantera & B.I. Korelitz. (Eds). *Crohn's disease* (pp. 291-310). Marcel Dekker.

- Potter, C. M., Kelly, L., Hunter, C., Fitzpatrick, R., & Peters, M. (2018). The context of coping: a qualitative exploration of underlying inequalities that influence health services support for people living with long-term conditions. *Sociology of health & illness*, 40(1), 130-145.
- Purc-Stephenson, R., Bolwby, D., & Qaqish, S.T. (2015). A gift wrapped in barbed wire' Positive and negative life changes after being diagnosed with inflammatory bowel disease. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 24(5), 1197-1205
- Quick, V. M., Byrd-Bredbenner, C., & Neumark-Sztainer, D. (2013). Chronic illness and disordered eating: A discussion of the literature. *Advances in Nutrition: An International Review Journal*, 4(3), 277–286. <https://doi.org/10.3945/an.112.003608>
- Rohatinsky, N., Boyd, I., Dickson, A., Fowler, S., Peña-Sánchez, J., Quintin, C., Risling, T., Russell, B., Wicks, K., & Wicks, M. (2021). Perspectives of health care use and access to care for individuals living with inflammatory bowel disease in rural Canada. *Rural and Remote Health*, 21(2), 6358.
- Saunders, B. (2014). Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Sociology of health & illness*, 36(7), 1020-1036.
- Savelkoul, M., Post, M.W.M., de Witte, L.P., & van den Borne, H.B. (2000). Social support, coping, and subjective well-being in patients with rheumatic diseases. *Patient Education Counselling*, 39, 205–18.
- Scambler, G. (2004) Re-framing stigma: felt and enacted stigma and challenges to the sociology of chronic and disabling conditions, *Social Theory & Health*, 2(1), 29–46.
- Schwenk, H. T., Lightdale, J.R., Arnold, J.A., Goldmann, D.A., & Weitzman, E.R. (2014). Coping with College and Inflammatory Bowel Disease: Implications for Clinical Guidance and Support. *Inflammatory Bowel Diseases*, 20(9), 1618-1627.
- Singh, J. (2013). Critical appraisal skills programme. *Journal of pharmacology and Pharmacotherapeutics*, 4(1), 76.

- Spiegel D., Bloom J. R., & Yalom, I. (1981). Group support for patients with metastatic cancer. *Archives of General Psychiatry*, 38(81), 527-533.
- Taylor, S.E. and Armor, D.A. (1996). Positive illusions and coping with adversity. *Journal of Personality*, 64(4) 873– 98.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45-45.
<https://doi.org/10.1186/1471-2288-8-45>
- Torres, J., Mehandru, S., Colombel, J.F., & Peyrin-Biroulet. L. (2017). Crohn's disease. *Lancet*, 389(10080), 1741-1755.
- Turk, D., Sobel, H.J., Follick, M.J., & Youkilis, H.D. (1980). A sequential criterion analysis for assessing coping with chronic illness. *Journal of Human Stress*, 6(2), 35-40.
- Villalva, C. M., Martínez, A. M., Mondelo, T. G., Losada, C. N., Fachado, A. A., & Garmendia, S. B. (2003). Influencia del apoyo social en pacientes con hipertensión arterial esencial [Influence of social support on patients with essential hypertension]. *Atención Primaria*, 31(8), 506-513.
- Yang, L.H., & Kleinman, A. (2008). 'Face' and the embodiment of stigma in China: The cases of schizophrenia and AIDS. *Social Science & Medicine*, 67(3), 398-408.
<https://doi.org/10.1016/j.socscimed.2008.03.011>
- Yi-Frazier, J.P., YaPangco, M., Semana, S., Buscaino, E., Thompson, V., Cochrane, K., Tabile, M., Alving, E., & Rosenberg, A.R. (2015). The association of personal resilience with stress, coping, and diabetes outcomes in adolescents with type 1 diabetes: variable- and person-focused approaches. *Journal of Health Psychology*, 20(9), 1196– 206.
- Zare, F., Ghafari, M., Ramezankhani, A., Kamran, B. L. & Kavooosi, A. (2020). Identifying dimensions of empowerment in patients with inflammatory bowel disease: a qualitative study. *Health Education Research*, 35(6), 637-647.
<https://doi.org/10.1093/her/cyaa023>

Tables and Figures

Table 1. Database Search Terms

SPIDER	Search String
Sample	inflammatory bowel disease OR ulcerative colitis OR crohn*
Phenomenon of Interest	relationship* OR couple OR famil* OR partner* OR spouse* OR wife* OR wives* OR husband* OR network* OR support* OR parent* OR friend* OR social*
	AND
	coping OR cope* OR adjust* OR change* OR reaction* OR resilienc*
Design	interview* OR observ* OR focus group*
Evaluation	view* OR experienc* OR opinion* OR attitude* OR perce* OR belie* OR feel* OR understand* OR know*
Research Type	qualitative OR mixed method* OR mixed-method* OR thematic* OR narrative* OR grounded theory* OR framework analysis OR content analysis OR phenomeno*

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1) Qualitative research, or mixed-methods if sufficient discussion of qualitative research	1) Insufficient consideration of role of relationships in coping
2) Participants have a diagnosis of IBD, namely Crohn's Disease or Ulcerative Colitis	2) Focus is on experience of family rather than individual
3) Participants are adults aged 18 years or over	3) Focus is on role of professionals in support
4) Sufficient discussion of role of support networks	4) Includes individuals with IBS
5) Report available in English	5) Not a research article (e.g. personal account)
6) Published in a peer-reviewed journal	6) Deductive analysis methods used

Table 3. Outline of papers identified

Author (Study Number) Setting	Year	Study design	Method of analysis	Participants	Topic and Aims	Results
Pihl-Lesnova et al. (2010) (S1) Gastroenterological clinic at a university hospital in southern Sweden		Semi-structured, tape recorded interview, using a question guide	Comparative analysis.	Theoretical strategic sampling was used among outpatients with Crohn disease. Eleven participants (six men and five women), ranging in age from 29 to 83 years were interviewed.	To identify and describe the meaning of QOL of patients with Crohn disease	Five categories emerged from the data: self-image, confirmatory relations, powerlessness, attitude toward life, and sense of well-being. All were related to the core category that was named “limitations.”
Czuber-Dochan et al. (2012) (S2) Focus Groups were run in five cities: Glasgow (FG1), London (FG2), Swansea (FG3), York (FG4), and Belfast (FG5)		Focus group interviews	Inductive thematic framework analysis.	A convenience sample of 46 participants (15 men, 31 women) was recruited from the Crohn’s and Colitis UK member database. CD= 28, UC= 18	To explore fatigue, the impact it has on daily life and the strategies used to ameliorate the symptom, as described by people with inflammatory bowel disease	Five themes were identified: the experience of fatigue, causes of fatigue, managing fatigue, consequences of fatigue, and seeking support.
Allison et al. (2013) (S3) Hospital within the UK		A narrative approach incorporating in depth Semi-structured interviews.	Storymapping and re-storying.	24 Patients (11 male and 13 female) aged 18–25 who attended the adolescent and young adult clinic at a single tertiary referral centre in the UK.	To explore the experience of young people with Inflammatory Bowel Disease who faced the prospect of, or had undergone, surgery for their condition.	Four themes were identified: Perceptions of surgery, support, self, strategies.

Author (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
Beck et al. (2013) (S4) Outpatient clinic of the Department of Gastroenterology at Aarhus University Hospital	Semi-structured interviews.	Malterud's principles of systematic text condensation.	Seventeen had Crohn's Disease and 7 Ulcerative Colitis. The study included 11 female outpatients, 7 with CD and 4 with UC. These patients were 40–59 years old and had IBD ≥ one year and a significantly increased fatigue score. Patients with severe active IBD, anaemia, comorbidity, or pregnancy were excluded.	To investigate how female outpatients with IBD experience and handle fatigue.	Three superior codes were identified under the heading experience of fatigue, which are named physical and mental fatigue, limitations, and emotional consequences.
Schwenk et al. (2014) (S5) Centre for Inflammatory Bowel Disease, which is staffed by the Division of Gastroenterology and Nutrition at Boston Children's Hospital.	Semi-structured telephone interviews. Questions in the interview guide were developed drawing on Protection Motivation Theory (PMT) and the Chronic Care Model (CCM).	Narrative data analysis.	Fifteen college students (7 males and 8 females) with IBD were recruited from the Boston Children's Hospital Centre for IBD.	To investigate how college-enrolled students with IBD conceptualize and manage their disease and how their experiences of going to college shape their health and health care behaviours.	Four primary themes related to the college experience for youth with IBD were identified: (1) The transition experience of college students with IBD is shaped by their health status, perceived readiness, and preparedness, (2) Elements of the college environment pose specific challenges to young adults with IBD that require adaptive strategies, (3) College students with IBD integrate their underlying illness with their individual and social identity, and (4) College students navigate health management by conceptualizing themselves, their families, and providers as serving particular roles.

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
Purc-Stephenson, et al. (2015) (S6) Virtual/online	Online survey.	The open-ended responses ranged from a few words to several paragraphs. Data were explored inductively using grounded theory.	378 participants with 251 having CD (66.4 %) and 127 having UC (33.6 %). 312 females, 66 males Recruited participants from the community via notices posted in local community centers and medical clinics in Windsor, Ontario, and on free classified ad Web sites and disease-specific support group Web sites.	To explore the positive and negative changes that have occurred since being diagnosed with IBD.	Thematic analysis of the data revealed five major positive changes, labelled Interpersonal Relations, New Life Paths, Personal Growth, Valuing Life, and Spiritual Growth. Four subthemes emerged from the data under Interpersonal Relations, labelled digging in, seeking out, sifting through, and reaching out. Thematic coding of responses revealed three major negative themes, labelled as Freedom Restrictions, Psychological Side Effects, and Social Isolation.
Larsson et al. (2016) (S7) Thirteen informants chose telephone interviews, and two preferred face-to-face interviews in a meeting room at the Hospital.	Tape recorded interviews using a qualitative design with a descriptive approach (Patton 2002).	Qualitative content analysis.	Informants were recruited from patients with UC or CD at a gastroenterology department at a university hospital. A purposeful sample was invited to the study to ensure variation in experiences with respect to the investigated phenomenon. The final sample included women and men with UC or CD of various ages and illness duration. Seven informants were diagnosed with UC (five women and two men)	To examine disease-related stress, coping strategies and the need for information and support in patients with inflammatory bowel disease (ulcerative colitis or Crohn's disease).	The results comprised the following themes connected to the three central areas: Stress: Disease-related stress and Relations to others; Coping: Behavioural strategies, Social strategies and Emotional strategies; and Need for help or support: Instrumental support and Emotional support.

Author (Study Number) Setting	(Year)	Study design	Method of analysis	Participants	Topic and Aims	Results
				and eight with CD (four women and four men)		
Baker et al. (2017) (S8) Gastroenterology department at a university hospital		Semi-structured interviews using a semi-structured interview schedule.	Inductive Thematic Analysis.	A purposive sample of 16 patients (7 males, 9 females) with UC who had interaction with either gastroenterology or inflammatory bowel disease nurses or surgical services at Sheffield Teaching Hospitals were identified.	To use established qualitative methods to describe patient informational needs and preferences when deciding between surgery and ongoing medical management for ulcerative colitis.	The 4 themes were: (1) experience of receiving surgical information; (2) decision-making, e.g., surgery vs medical management and IPAA vs stoma; (3) information preferences; this was based on retrospective informational desires from reflections of consultations and the lived experience of treatment choices and (4) online information, including use, what was accessed, and why it was used.
Dibley et al. (2018) (S9) Participants homes		Semi-structured interview schedule.	Diekelmann, Allen, and Tanner's interpretive method.	Forty community-dwelling adults (26 females, 14 males) with a self-reported diagnosis of inflammatory bowel disease were recruited purposively. Participants reported feeling stigmatized or not and experiencing faecal incontinence or not. 22 had CD, 13 had UC, 4 had Crohn's Colitis and 1 had Proctitis	The aims were to explore stigma experiences in people with IBD and to understand differences between stigmatized and non-stigmatized participants which might explain stigma resistance. The research question was: What is the experience of stigma in people with inflammatory bowel disease, with or without incontinence?	Analysis revealed three constitutive patterns, informed by eight relational themes: (1) Being in and out of control, (2) Relationships and social Support and (3) Mastery and mediation
Dibley et al. (2018) (S10)		Focus groups: Trigger questions, developed from relevant literature and from	Thematic analysis guided by a pragmatic	Using purposive sampling, participants were recruited from IBD nurse clinics and patient databases at 2	The research questions were: 1. What are patients' concerns about, and realities of, living with a stoma for IBD, and how does this influence	Four themes emerged: Preoperative concerns and expectations, Patient decision-making, Surgery and recovery, and Long-term outcomes.

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
Focus groups or telephone interviews	discussion with the PPI team, initiated discussion Telephone interviews using topic guides generated from focus group data, emerging themes were explored in detail.	analytical hierarchy.	hospitals, from an existing IBD database of research-interested community-dwelling people and via the CCUK online members' forum. Maximum variation sampling was used to select from all those volunteering to achieve demographic and geographic spread, resulting in 29 participants, 21 females and 28 males.	decision-making regarding stoma-forming surgery? 2. How do patients' and clinicians' perceptions of, and concerns about, stoma-forming surgery for IBD compare?	
Garcia-Sanjuan et al. (2018) (S11) Participants' homes	A phenomenological approach focusing on the life experiences perceived by those affected was conducted through in-depth interviews.	Data were analysed using Colaizzi's seven-step method to provide assistance in extracting, organising and analysing such narrative data set.	19 people with a definitive diagnosis of CD received more than 1 year ago and included males and females aged over 18 years living in the province of Alicante (Spain). Subjects were selected according to the 'snowball' method, achieving maximum variance sampling. Researchers used a small pool of initial informants to nominate, through their social networks, other participants who met the eligibility criteria and could potentially	The aim of this study was to describe the life experiences of people with CD towards understanding the changes they must face daily since they were diagnosed.	Five emergent themes were identified: self-protection against the unknown cause; self-training; learning to live with Crohn's disease; perceived losses associated to Crohn's disease; and relationship with others. The results portrayed a chronically ill patient who is unconscious about the chronicity and consequently must develop strategies to keep living a similar life like the one lived before.

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
Nutting & Grafsky (2018) (S12) In Person or Skype	Qualitative interview study.	This study utilized Interpretative Phenomenological Analysis for inquiry.	contribute to sample diversity. None of the subjects refused to participate in the interviews. 5 males and 5 females with Crohn's Disease employed by Purposive Sampling.	The first goal is to provide a copious understanding of how a partner's diagnosis of Crohn's disease is perceived to affect couple relationship functioning and satisfaction, as well as young adult life-cycle transitions. Second, is to provide researchers and healthcare providers with a better understanding of how the numerous physical symptoms of Crohn's disease cause psychological and social implications for the diagnosed individual and partner. Third, is to identify how a systemic, biopsychosocial understanding of Crohn's disease will encourage couple level clinical assessment and intervention.	Four final themes emerged during analyses. Couples' experiences of diagnosis described the diagnosis process as drawn out and often inconclusive. Biopsychosocial effects identified the perceived effects on participants' biological, psychological, and social well-being. Relationship functioning and satisfaction depicted how couples experience daily life, post-diagnosis. Interference in life-cycle transitions demonstrated how Crohn's disease poses challenges to the expected life trajectory.
Dibley et al. (2019) (S13) Face-to-face, telephone or Skype	Data were collected via individual, in-depth, unstructured, interviews (25-75 minutes) with the participant only, using	Data were analysed using an iterative hermeneutic method, based on Diekelmann, Allen, and Tanner's approach.	A total of 18 respondents (77% female) who met the inclusion criteria (over 18 years old, self-reported diagnosis of IBD, English-speaking, living anywhere within the United Kingdom)	To further explore the meaning of kinship stigma for people with IBD and reveal its significance.	Three relational themes (being invisible/becoming invisible; being the disease/having the disease; amplification, suffering and loss) and one constitutive pattern (lacking acknowledgement/ being acknowledged).

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
	a digital audio recorder.		took part. There were no exclusion criteria. No one withdrew from the study.		
Ruan & Zhou (2019) (S14) Varied based on patient preference.	A constructivist grounded theory approach was used to develop a theoretical understanding of illness experiences.	The data analysis included initial coding, focused coding, and theoretical coding using the constant comparative method and memo writing.	Purposive sampling and theoretical sampling were used to select 31 Chinese patients living with Crohn's disease.	The objective of this study was to explore the illness experiences of patients with Crohn's disease in China and construct an interpretive understanding of these experiences from the perspective of the patients.	"Regaining normality" was identified as the core category. The following four categories were conceptualized: comparing, struggling, reflecting, and realizing.
Chaudhry et al. (2020) (S15) College campus	Two Focus Group discussions of 90 min each were used to explore the research questions. An interview guide of questions was developed and sent to participants before the scheduled FG to encourage reflection about their experiences with IBD.	Data was analysed as by applying grounded-theory approach as described by Charmaz to identify any unique themes that arose from the collected data.	Purposive sampling was undertaken to recruit participants. Flyers were posted on campus and in clinics. Of the 50 students with IBD interested in research, 8 were able to attend the focus groups (FGs) at a mutually convenient time.	The aim of this research is to comprehensively understand the social challenges, coping mechanisms, and academic challenges that students with IBD face.	Six themes emerged: (1) transitioning to college, (2) interacting with physicians, (3) affecting social life, (4) managing the disease by yourself and through support, (5) coping strategies, and (6) facing disease challenges.
Horgan et al. (2020) (S16)	A qualitative approach was adopted comprising a single,	Verbatim transcripts of these interviews and	Purposive sampling was employed. Those with a histological diagnosis of	The purpose of this study was to achieve an understanding of the lived experience as depicted by young	5 superordinate themes emerged from the analysis: (1) Control, (2) Secrecy, (3) Patient

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
University premises	detailed semi-structured interview with each of the participants.	associated field notes were analysed using interpretative phenomenological analysis methodology.	IBD and a consequential stoma within the last 12 months were approached via a letter of invitation. Of those approached, 5 male patients aged 20–30 years agreed to participate.	adults with IBD and a stoma	education and support services, (4) Difficult emotions, (5) Acceptance and growth.
Karadag et al. (2020) (S17) Telephone or face to face	Qualitative interview study involving adults diagnosed with IBD recruited through social media.	Interviews were audio recorded, transcribed and data were analysed thematically.	15 participants (9 female, 6 male) were recruited online via social media such as Facebook, Twitter and Instagram.	To explore patients' experiences of living with inflammatory bowel disease (IBD) with a focus on their information and support needs.	Six themes were determined from analysis including: 1) Misdiagnosis and hesitation caused frustration and prolonged suffering, 2) information needs at the point of diagnosis. 3) Access to specialist staff facilitated trust and a change for the better, 4) positive and negative impacts of IBD upon individual wellbeing, 5) Family and partners as a source of emotional and practical support, 6) Sharing experiences and reducing stigma- the benefits of social media communities.
Polidano, et al. (2020) (S18) Location of the pts choosing	Interviews followed a broadly narrative approach encouraging participants to provide lengthy and detailed accounts about relevant issues relating to their subjective experiences.	Data analysis combined constructivist grounded theory and narrative analysis.	13 young adults (4 males, 9 females), aged 18–29 years, with a stoma resulting from inflammatory bowel disease.	To generate new theoretical insights in understanding the process of biographical (re)construction and the wider implications of stoma formation among this group.	For most participants, the stoma was represented as enabling a series of positive transformations; hence being perceived as a liberation rather than restriction. Based on these narratives, the concept of 'biographical renewal' was presented.

Author (Study Number) Setting	(Year)	Study design	Method of analysis	Participants	Topic and Aims	Results
Zare et al. (S19) IBD clinics	(2020)	Semi-structured interviews were conducted.	The data were analysed based on the Granheim and Landman's content analysis method.	26 participants (14 patients-6 male and 8 female; 8 HCP's) who were purposefully selected from 2 IBD clinics in Tehran and Shiraz cities to gain diversity in the clinical and demographic characteristics.	To explore the views of patients and health professionals on IBD patients' empowerment	Five main dimensions were found for the empowerment of IBD patients to control their disease and improve their quality of life.
Fawson et al. (S20) Location of the pts choosing	(2021)	Data were collected by using two methods: (a) secondary analysis of data collected via focus groups, (b) individual telephone or face-to-face interviews with new participants, to explore further the issues identified during the secondary analysis of focus group data.	Framework analysis for focus group data and thematic analysis for interview data.	Purposive sampling was used to recruit 40 people (22 females, 18 males) with IBD from UK clinics and from community-dwelling members of the Crohn's and Colitis UK charity.	To understand patients' symptom self-management strategies and preferred design for a future online symptom self-management intervention.	The data provided three core themes: ways of coping; intervention functionality; and intervention content.
Marques et al. (S21) IBD clinic	(2021)	Patients with IBD who had undergone surgery were recruited to same-race qualitative interviews. Semi-structured interviews explored barriers and facilitators to a	Inductive thematic analysis was used to code the data and develop themes and sub-themes, allowing the beliefs and views of the participants to	27 English-speaking patients were recruited who had an endoscopic confirmation of IBD and had undergone surgery between 2001 and 2018 in a tertiary-referral IBD centre in Alabama. Included patients	Racial/ethnic disparities in outcomes exist for patients with inflammatory bowel disease (IBD) undergoing surgery. The underlying mechanism(s) remain unclear and patient perspectives are needed. Researchers therefore aimed to characterize the surgical	Four themes emerged that most defined the surgical experience: the impact of the IBD diagnosis, the quality of provided information, disease management and the surgery itself. Within these themes, barriers to a positive surgical experience included inadequate personal knowledge of IBD, ineffective written

Author (Year) (Study Number) Setting	Study design	Method of analysis	Participants	Topic and Aims	Results
	positive or negative surgical experience.	emerge without any preconceptions.	were 18 years or older and all genders. Patients with unreported race/ethnicity were excluded from the study.	experience for Black and White IBD patients using qualitative methods.	and verbal communication, lack of a support system and complications after surgery.
Rohatinsky et al. (2021) (S22) Telephone interview	Interviews lasting 30–60 minutes followed a semi-structured interview guide and focused on gaining an understanding of participant perceptions of healthcare utilization and access to care in rural communities. Open-ended interview questions addressed the study objectives.	Interview data were analysed using thematic analysis.	Fourteen individuals with IBD living in rural areas and three HCPs working in rural areas participated. Various recruitment strategies were used to reach rural individuals with IBD, including distributing study information through Crohn’s and Colitis Canada national and provincial social media outlets and local events, hanging posters in rural pharmacies, sending posters and letters of invitation to rural HCPs to share with rural-residing patients, snowball sampling, and word of mouth.	The research questions explored in this study were: What are the care experiences of healthcare providers (HCPs) and persons living with IBD in rural areas? What are the enablers and barriers to optimal IBD care in rural environments? What strategies are necessary to enhance care delivery for these individuals with IBD?	Three themes were identified: communication, stressors and support systems, and coordination of care.

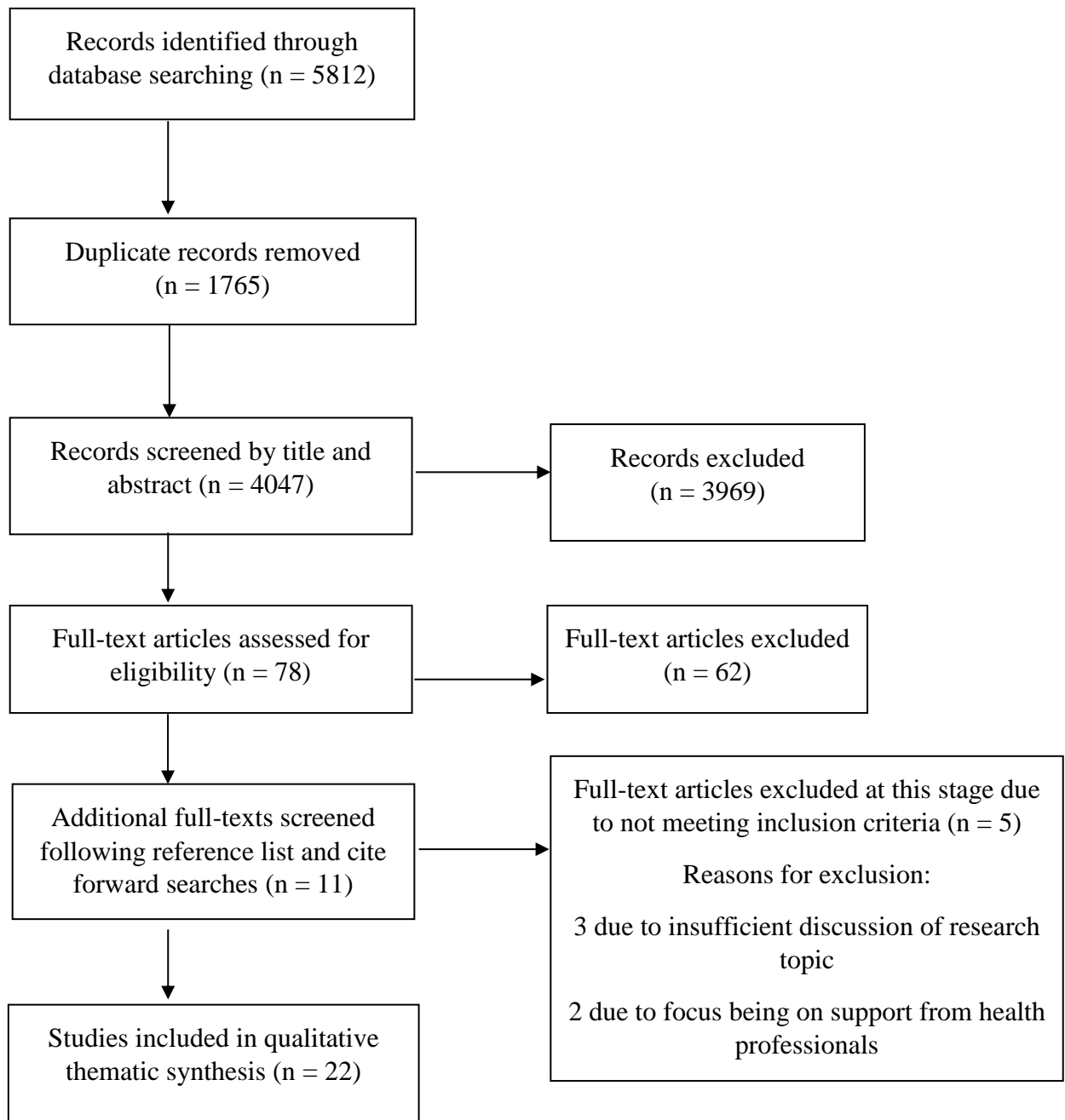


Figure 1. Flow diagram of article selection adapted from PRISMA (2009)

Appendix 1-A**Reasons for Article Exclusion: Full Text Accessed**

Reason for exclusion	Number
Insufficient consideration of role of relationships in coping	16
Support is provided from professionals	2
Inclusion of children	10
Quantitative/Insufficient qualitative analysis	15
Not available in English	1
Discusses additional health conditions/ doesn't include IBD	8
Focus is on experience of others e.g. family, rather than individual	2
Not a research article (e.g. personal account, diary entry)	6
Deductive approach taken to identify themes	2

Appendix 1-B
CASP Rating Scores

Author (Year)	Study number	Appropriate design	Appropriate recruitment strategy	Appropriate data collection	Researcher-participant relationship	Ethical considerations	Rigour of data analysis	Clear statement of findings	Valuable Research	Total (Duggleby et al., 2010)
Pihl-Lesnova, et al. (2010)	S1	3	3	3	1	2	2	3	2	19
Czuber-Dochan et al. (2012)	S2	3	2	2	1	3	2	3	3	19
Allison et al. (2013)	S3	3	3	2	1	3	2	2	3	19
Beck et al. (2013)	S4	1	3	3	1	3	2	2	2	17
Schwenk et al. (2014)	S5	1	2	3	3	2	3	2	2	18
Purc-Stephenson et al. (2015)	S6	2	3	2	1	2	3	3	1	17
Larsson et al. (2016)	S7	3	3	3	2	3	3	3	2	22
Baker et al. (2017)	S8	1	3	3	3	2	3	3	2	20

IMPACT OF SOCIAL SUPPORT

1-53

Dibley et al. (2018)	S9	3	3	3	2	3	2	3	3	22
Dibley, Czuber-Dochan et al. (2018)	S10	3	3	2	1	3	1	2	2	17
Garcia-Sanjuan et al. (2018)	S11	3	3	2	1	3	3	3	3	21
Nutting & Grafsky (2018)	S12	3	3	3	3	3	2	2	3	22
Dibley et al. (2019)	S13	3	3	3	3	3	3	3	3	24
Ruan & Zhou (2019)	S14	3	3	3	3	2	3	3	3	23
Chaudhry et al. (2020)	S15	3	2	3	1	1	3	3	3	19
Horgan et al. (2020)	S16	1	3	3	1	3	3	2	3	19
Karadag et al. (2020)	S17	1	2	3	1	3	3	2	3	18
Polidano et al. (2020)	S18	3	2	2	3	2	2	3	3	20
Zare et al. (2020)	S19	3	2	3	3	3	3	3	3	23
Fawson et al. (2021)	S20	3	2	3	1	2	2	2	2	17
Marques et al. (2021)	S21	1	2	3	1	3	3	2	1	16

Rohatinsky et al. (2021)	S22	2	3	2	2	2	2	2	2	17
--------------------------	-----	---	---	---	---	---	---	---	---	----

The CASP scores were rated according to the following criteria as specified by (Duggleby et al., 2010): A weak score (1 point) was assigned to studies that offered little to no justification or explanation for a particular issue (e.g., where, when, or how the data were collected was not mentioned). A moderate score (2 points) was given to studies that addressed the issue but did not fully elaborate on it (e.g., the justification for using constant comparisons was presented but the procedure itself was not explained). A strong score (3 points) was assigned to studies that extensively justified and explained the issue at hand (e.g., the authors explained semi-structured interviews were used, transcribed verbatim, and modified part way through the study, and offered example interview questions). Based on these criteria, studies were then given an overall rating of being of low quality if a total score of 1-8 was received, moderate quality if a total score of 9-16 was received or high quality if a score of 19-24 was received.

Appendix 1-C

Example of Analysis

Study	Free codes	Descriptive themes	Analytical themes
S2	Aware how much I need family and how bad things would be without them	Working together/ being a team	Supportive peers → Teamwork
S5	Parent support is very important for both practical and emotional support	Parental emotional and practical support	Supportive peers → Understanding and Teamwork
S7	Sharing how pts were feeling helped them to feel less alone	Share with others to reduce isolation	Openness → Reducing isolation
S9	Talking to others with IBD helped pts to make decisions	Importance of identifying those like me	Shared experiences → advice taking
S10	Pts felt like they were a burden to those around them and tried to make up for this when well	Burden to others	Openness → being a burden

Appendix 1-D

Process of analysis

1	Author	Free Codes	Descriptive Theme
2	Pihl-Lesnovska et al. (2010)	Confirmatory relationships as positive- Being confirmed by other people is very important. Some informants received confirmation from their relatives and friends, whereas others got it from their colleagues and supervisor. "I have a really calm and secure family; I think that's why I manage my disease quite well. My work is a source of stress" (Interview 8).	Knowledegable others --> own = acceptance
3		having confirmatory relations, at the same time it could elicit a sense of being a burden and dependency; in that context, confirmatory relations were a limitation. Informants expressed the importance of having healthcare professionals be accessible for conversations or other needs. Some said that they felt that they increased the burden if they discussed their worries about their disease with their next of kin. They did not want to worry them because of the fear of the disease being hereditary.	Being a burden
4	Czuber-Dochan, Dibley, Terry, Ream, & Norton (2012)	conscious about depending heavily on family support and aware how much more difficult their life would be if support was not forthcoming: My husband's great, we've been married for twenty years, ... he's good, if I say I'm going to lie down, he goes, "Oh yes great." So we've got a deal, he does all the jobs in the house, because I can't ... He'll do all that and things like doing the shopping and lifting things down and that. But I, on the other hand, do all the planning (FG3).	aware how much I need family and how bad things owudl be without them--> Working together/ as a team
5		Some reported that employers were not always supportive: I had my mobile phone in my pocket, I had it set every ten minutes to vibrate anyway, just in case I did fall asleep and the boss came back (FG4).	lack of support at work made me worry I'd get into trouble for taking the time I needed ot look after myslef--> Fear of getting into trouble at work
6		People reported different levels of support from family, friends and colleagues: I've got colleagues and they know. I'm a trainer and I train disability awareness. But they still don't understand, I don't want to say it: 'Today I feel terrible, but yesterday I felt terrible and last week I felt terrible and the week before that actually I felt terrible,' and you just can't keep saying it (FG3).	Different levels of understanding/ sense of responsibility to help others understand/
7		I'm quite lucky with the support I have. But I am kind of aware that you don't want to always complain (FG1).	sense of gratitude/ burden
8		Participants varied in whether or not they talked to work colleagues, friends, and family about their IBD and its resultant fatigue. Some said that it was their responsibility to raise people's awareness and understanding: I think my family are very supportive and so are my friends, they're understanding, because I've told them how I feel.... It's up to us to tell them how we are feeling (FG2). whilst others kept to themselves: I don't talk to anybody.... you don't tell them how you're feeling....no (FG1)	sense of loneliness and isolation/ sharing is helpful

A	B	C	D	E	F
Author	Analytical Theme				
Pihl-Lesnovska et al. (2010)	Supportive peers --> acceptance	Openness= Being a burden			
Czuber-Dochan, Dibley, Terry, Ream, & Norton (2012)	Supportive peers--> Working together/ as a team	Supportive peers =Fear of getting into trouble at work= lack of understanding	Supportive peers--> Different levels of understanding/ sense of responsibility to help others understand	Openness=sense of gratitude/ burden	Openness=sense of loneliness and isolation/ sharing is helpful

Appendix 1-E

Overview of Themes

Paper	Allocated number	Supportive peers	Shared experiences	Openness
Pihl- Lesnovska, et al. (2010)	S1	Yes	No	Yes
Czuber- Dochan et al. (2012)	S2	Yes	No	Yes
Allison et al. (2013)	S3	Yes	Yes	No
Beck et al. (2013)	S4	Yes	No	No
Schwenk et al. (2014)	S5	Yes	Yes	Yes
Purc- Stephenson et al. (2015)	S6	No	Yes	No
Larsson et al. (2016)	S7	No	Yes	Yes
Baker, et al. (2018)	S8	No	Yes	No
Dibley et al. (2018)	S9	Yes	No	Yes
Dibley et al. (2018)	S10	Yes	Yes	Yes

Garcia-Sanjuan, et al. (2018)	S11	Yes	Yes	Yes
Nutting & Graftsky (2018)	S12	Yes	Yes	Yes
Dibley et al. (2019)	S13	Yes	No	Yes
Ruan & Zhou (2019)	S14	Yes	Yes	Yes
Chaudry et al. (2010)	S15	Yes	No	No
Horgan et al. (2020)	S16	Yes	Yes	No
Karadag et al. (2020)	S17	Yes	Yes	Yes
Polidano et al. (2020)	S18	Yes	No	No
Zare et al. (2020)	S19	Yes	No	No
Fawson et al. (2021)	S20	Yes	Yes	Yes
Marques et al. (2021)	S21	Yes	Yes	No
Rohatinsky et al. (2021)	S22	No	Yes	Yes

Appendix 1-E

Author Guidelines

United European Gastroenterology Journal

Aims and Scope

Providing an international forum for research in gastroenterology, United European Gastroenterology Journal (UEG Journal) publishes original peer reviewed articles which describe basic research, translational and clinical studies of interest to gastroenterologists and researchers in related fields.

Articles from across all fields of gastroenterology are welcomed by the Editors, including luminal, liver and pancreatic diseases, endoscopy, gastrointestinal surgery, digestive oncology, as well as paediatric gastroenterology and nutrition. Published article types include original research, reviews, guidelines papers, and news items related to United European Gastroenterology.

Manuscript Submission

Open Access and Article Publication Charges

As of January 2021, UEG Journal is a fully open access journal. Please visit this page to review the Article Publication Charges (APC).

Submission and Peer Review Process

Manuscripts should be submitted online at <http://mc.manuscriptcentral.com/UEGJ>.

For help with submissions, please contact: uegjournal@wiley.com.

Article Preparation Support

Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design, so you can submit your manuscript with confidence.

Also, check out our resources for Preparing Your Article for general guidance about writing and preparing your manuscript.

Free format submission

UEG Journal offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at <https://orcid.org>. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
 - Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)
 - Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):
 - data availability statement
 - funding statement
 - conflict of interest disclosure
 - ethics approval statement
 - patient consent statement
 - permission to reproduce material from other sources
 - clinical trial registration

To submit, login at <http://mc.manuscriptcentral.com/UEGJ> and create a new submission. Follow the submission steps as required and submit the manuscript.

Article Types

Original Research Papers

Original research papers should be no more than 3,000 words (excluding abstract, keywords, references, figures and table legends only, and the title page elements – including acknowledgement, COI and funding statements) and contain the following sections: Title page, Abstract, Introduction, Materials and Methods, Results, Discussion, Acknowledgements, References, Tables, Figures, and Figure legends.

The journal publishes a Key Summary alongside original research papers. The two points below require concise responses, presented in bullet points within the manuscript file

between the Abstract and the Introduction. Please use a maximum of four bullet points to each response.

Summarize the established knowledge on this subject

What are the significant and/or new findings of this study?

Review Papers

Review papers focus on specific subjects of current interest where there have been recent and significant advances, ranging from basic neuroscience to clinical and more ‘applied’ areas. They are short, factual, focused updates, comprising: Title page, an unstructured Abstract of 100-150 words, 5 or so Keywords, 2,500 words of text (excluding references), a limited number of relevant and recent references (up to 35 or so), and an illustrative figure if appropriate.

Guidelines

UEG Journal publishes guidelines commissioned by UEG and groups under the UEG umbrella.

Overview of the requirements for manuscript submissions to United European Gastroenterology Journal:

Article Type	Abstract Word Limit	Main Text Word Limit	References	Figures/Tables
Original Research Papers	300	3,000	Up to 35	Up to 7
Review Papers	100-150	2,500	Up to 50	Up to 5

* Excludes references, tables and legends

Visual Abstracts

At the revision stage, visual abstracts will be developed by a journal illustrator for all Original Articles and Reviews. You will be asked to review and approve a visual abstract for your paper prior to export to production. Should you wish to submit a visual abstract with your paper, please use this template.

Statements, Permissions and Signatures

Preprint policy

UEG Journal will consider for review articles previously available as preprints. You are requested to update any pre-publication versions with a link to the final published article. You may also post the final published version of the article immediately after publication.

Registered Reports

See the Registered Reports Author Guidelines for full details.

Data Sharing and Data Availability

UEG Journal expects data sharing. Review Wiley's Data Sharing policy where you will be able to see and select the data availability statement that is right for your submission.

Data Citation

Please review Wiley's Data Citation policy.

Data Protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication. Please review Wiley's Data Protection Policy to learn more.

Funding

You should list all funding sources in the Acknowledgments section. You are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature.

Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

- Make a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data
- Drafted the article or revised it critically for important intellectual content
- Approved the version to be published

Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

In accordance with Wiley's Best Practice Guidelines on Research Integrity and Publishing Ethics and the Committee on Publication Ethics' guidance, UEG Journal will allow authors to correct authorship on a submitted, accepted, or published article if a valid reason exists to do so. All authors – including those to be added or removed – must agree to any proposed change. To request a change to the author list, please complete the Request for Changes to a Journal Article Author List Form and contact either the journal's editorial or production office, depending on the status of the article. Authorship changes will not be considered without a fully completed Author Change form.

Note that correcting the authorship is different from changing an author's name; the relevant policy for that can be found in Wiley's Best Practice Guidelines under "Author name changes after publication".

ORCID

This journal requires ORCID. Please refer to Wiley's resources on ORCID.

Manuscript Structure

Title Page

The title page should contain:

- A brief informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
- A short running title of less than 40 characters;
- The full names of the authors;
- The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

- Sources of funding, if any;
- Acknowledgments.

Main Text File

Abstract

The second page of the manuscript must contain only the abstract, which should be of no more than 300 words for original research papers, 150 for review papers, and 500 for guidelines papers. Your abstract must be clearly written and comprehensive to readers before they have to read the paper. An overview of the requirements for various article types can be found here.

The abstract should be structured according to the following subheadings: Background, Objective, Methods, Results and Conclusion. Abbreviations should be avoided, and reference citations are not permitted. See Wiley's guidance on writing for SEO here.

Any manuscripts submitted without a structured abstract will be returned to the author immediately without peer review, thus delaying the evaluation process of the manuscript.

Introduction

The introduction should assume that the reader is knowledgeable in the field and be as brief as possible.

Materials and Methods

Methods that have been published in detail elsewhere should not be described in detail. Avoid unnecessary detailed descriptions of widely used techniques. SI Units should be used throughout the text. Reports of experiments involving patients and healthy volunteers must describe the steps taken to obtain consent and to maintain confidentiality. Experiments involving animals must conform to accepted ethical standards.

Tables

Tables should be submitted in Word, typed on separate pages. Tables should be numbered consecutively with Arabic numerals and cited as such in the manuscript. The preferred placing of tables in the main text should be indicated. Tables should include a brief descriptive title and be self-explanatory. Footnotes to tables indicated by lower-case superscript letters are acceptable, but they should not include extensive experimental details.

Figures

Please review the basic figure requirements for manuscripts for peer review, as well as the more detailed post-acceptance figure requirements.

Figures should be supplied as separate files. All figures should be numbered using Arabic numerals and referred to in the text as Figure 1, etc. Please indicate the preferred placing of the figure in the main text. Symbols and keys should be given as a key on the figure, not in the legend. Magnification should be indicated by a scale bar on the photograph, not as a magnification factor in the legend.

Units, Symbols and Abbreviations

For detailed advice please refer to the guidelines in Baron, DN (1988). Units, symbols and abbreviations, 4th edn. (Obtainable from The Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE, UK). Note that the SI system of units is preferred. Because of the multidisciplinary nature of the readership and to avoid confusion, the number of abbreviations in the text should be kept to a minimum. Standard abbreviations acceptable without definition are limited to the following: CNS (central nervous system); CSF (cerebrospinal fluid); DNA (deoxyribonucleic acid); HLA (human leukocyte antigen; MRI (magnetic resonance imaging); CT (computerized tomography); UEGJ (United European Gastroenterology Journal); RNA (ribonucleic acid). Non-standard definitions must be defined in full at their first usage in the abstract and again at their first use in the text.

Supplemental material and Supporting Information

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc.) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplemental files. View Wiley's FAQs on supporting information.

Reference style

UEG Journal adheres to the Wiley Vancouver reference style. View the Wiley Vancouver guidelines to ensure your manuscript conforms to this reference style.

Peer Review

This journal operates under a single-blind peer review model. Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements.

In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is available [here](#).

As part of the submission process you will be asked to provide the names of two peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

You will also be asked to nominate peers who you do not wish to review your manuscript (opposed reviewers).

Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

UEG Journal is committed to delivering high quality, fast peer-review for your paper, and as such has partnered with Publons. Publons is a third-party service that seeks to track, verify and give credit for peer review. Reviewers for United European Gastroenterology Journal can opt in to Publons in order to claim their reviews or have them automatically verified and added to their reviewer profile. Reviewers claiming credit for their review will be associated with the relevant journal, but the article name, reviewer's decision and the content of their review is not published on the site.

Search Engine Optimization

Search Engine Optimization is important to the discoverability of your article. UEG Journal has provided examples of articles that are fully optimized for SEO and those that are not. You can review them here.

Ethical Guidelines

Guidelines on Publishing and Research Ethics in Journal Articles

The journal requires that you include in the manuscript details IRB approvals, ethical treatment of human and animal research participants, and gathering of informed consent, as appropriate. You will be expected to declare all conflicts of interest, or none, on submission. Please review Wiley's policies surrounding human studies, animal studies, clinical trial registration, biosecurity, and research reporting guidelines.

It is the policy of United European Gastroenterology Journal to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

This journal follows the core practices of the Committee on Publication Ethics (COPE) and handles cases of research and publication misconduct accordingly (<https://publicationethics.org/core-practices>).

This journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Where an article, for example, is found to have plagiarized other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean

of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

Research Ethics and Patient Consent

Manuscripts reporting data from research conducted on humans must include a statement of assurance in the methods section of the manuscript conforming to all four of the below points

- The study was approved by the ethical review board
- Name and date approval granted by the ethical board are included in the manuscript
- Written, informed consent was obtained from each patient included in the study
- The study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in a priori approval by the institution's human research committee

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

All research involving animals submitted for publication must be approved by an ethics committee with oversight of the facility in which the studies were conducted. The journal has adopted the Consensus Author Guidelines on Animal Ethics and Welfare for Veterinary Journals published by the International Association of Veterinary Editors.

Clinical trials

The International Committee of Medical Journal Editors (ICMJE, <http://www.icmje.org/>) defines a clinical trial as any research project that prospectively assigns human participants to intervention or comparison groups to study the cause-and-effect relationship between an

intervention and a health outcome. Interventions include but are not limited to drugs, surgical procedures, devices, behavioral treatments, process-of-care charges, and the like. All manuscripts reporting clinical trials must include a copy of the trial protocol including the complete statistical analysis plan (if the manuscript is accepted, the protocol will be published as an online supplement), a flow diagram (CONSORT flow diagram), and a completed trial checklist (the CONSORT checklist and template flow diagram can be found at <http://www.consort-statement.org/>). The trial registration number must be included at the end of the abstract and on the title page of the manuscript reporting a registered clinical trial.

Registration in a public trials registry is a condition for publication of clinical trials in UEG Journal in accordance with International Committee of Medical Journal Editors (ICJME, <http://www.icmje.org/>) recommendations.

Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

After Acceptance

First Look

After your paper is accepted, your files will be assessed by the editorial office to ensure they are ready for production. You may be contacted if any updates or final files are required. Otherwise, your paper will be sent to the production team.

Wiley Author Services

When an accepted article is received by Wiley's production team, the corresponding author will receive an email asking them to login or register with Wiley Author Services. You will be asked to sign a publication license at this point as well as pay for any applicable APCs.

Copyright & Licensing

UEG Journal is an Open Access journal: authors of accepted papers pay an Article Publication Charge and their papers are published under a Creative Commons license. This journal uses a CC-BY-NC-ND Creative Commons License. UEG offers CC BY and other licenses as mandated by certain funders; more information can be found here.

Information on the Article Publication Charges for publishing in UEG Journal is available [here](#).

If a paper is accepted for publication, the author identified as the formal corresponding author will receive an email prompting them to login to Author Services, where via the Wiley Author Licensing Service (WALS), they will be able to complete the license agreement on behalf of all authors on the paper.

Proofs

Authors will receive an e-mail notification with a link and instructions for accessing HTML page proofs online. Authors should also make sure that any renumbered tables, figures, or references match text citations and that figure legends correspond with text citations and actual figures. Proofs must be returned within 48 hours of receipt of the email.

Appealing the publication decision

Editors have very broad discretion in determining whether an article is an appropriate fit for their journal. Many manuscripts are declined with a very general statement of the rejection decision. These decisions are generally not eligible for formal appeal unless the author provides strong evidence or new data that can respond to and alleviate the concerns of the editor and reviewers. The author may appeal the decision by providing the Editor with a detailed written description, strong evidence, or new data they believe have emerged. UEG journal will respond to a formal appeal and investigate whether key aspects of the submitted work have been overlooked or new arguments have come to light in the initial review phase.

If an author believes the decision regarding their manuscript was affected by a publication ethics breach, the author may contact the publisher with a detailed written description of their concern, and information supporting the concern, at uegjournal@wiley.com

Section 2 Empirical Paper

Understanding the experiences of individuals with a diagnosis of inflammatory bowel disease and how this has impacted upon their relationship with food: A qualitative study

Emma Mellor

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

Emma Mellor

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

Email: e.mellor@lancaster.ac.uk

Prepared for: United European Gastroenterology Journal

Abstract

Objectives: Initial research has suggested some individuals with inflammatory bowel disease (IBD) may experience difficulties with eating, however little is known about how or why this may occur. This research aimed to address the question, “how do people with IBD and difficulties with eating make sense of the relationship between the two?” **Methods:** Semi-structured interviews were conducted with six individuals with IBD. Interviews were recorded, transcribed and analysed using interpretative phenomenological analysis to identify themes pertinent to participants’ experiences. **Results:** Four main themes were identified: (1) The need to restrict and control diet; (2) Increased intrinsic and extrinsic awareness: the impact on body image; (3) Responsibility, guilt and engagement: The experience of clinical interventions; (4) Feeling helpless: nowhere to turn. **Conclusions:** Participants’ experiences focussed around restricting their diet, clinical interventions and lack of support in regard to diet management which led to difficulties with eating. Findings indicated that discussions and advice around dietary intake is needed from healthcare professionals for these individuals to feel supported with these difficulties. Future research recommendations are made to develop an assessment tool to assist healthcare professionals to identify individuals with IBD at risk of developing difficulties with eating.

Key words: Crohn’s Disease, disordered eating, eating attitudes, Ulcerative Colitis

Crohn's disease (CD) and ulcerative colitis (UC) are two main forms of inflammatory bowel disease (IBD) thought to be caused by dysregulation of the innate and adaptive immune systems, environmental factors, and genetic susceptibility (Torres et al., 2017). Karwautz et al. (2008) report that for 20 to 25% of patients IBD begins during childhood and adolescence, however the prevalence for CD and UC differs; the registered prevalence of CD varies from 0.6 to 322 per 100,000 in Europe, whilst UC ranges from 4.9 to 505 per 100,000 (Molodecky et al., 2012).

CD affects the gastrointestinal tract from the oral cavity to the rectum, whereas UC affects the rectum and colon (Quick et al., 2013). For both forms of IBD, the gastrointestinal tract becomes inflamed, resulting in complications including diarrhoea and abdominal pain (Quick et al., 2013). The inflammation and scar tissue causes damage to the intestinal tract, which may cause difficulties for nutrients being absorbed from food, leading to malnutrition and delayed growth. Resultantly, some individuals with IBD have increased nutritional and caloric needs. Additionally, they may have low tolerance for certain foods and dietary management may be necessary (Quick et al., 2012).

The use of prescribed medication, such as biologic agents and immunomodulators for patients in remission, or corticosteroids for acute treatment, is also necessary for disease management (Caio et al., 2021). Surgical options are also available, including colectomy for patients with UC; while this is deemed curative, it results in a pouch or end ileostomy in approximately 30% of patients (Olendzki et al., 2014). Above 80% of CD patients require surgery, including surgical resection, which is not always curative (Olendzki et al., 2014). These treatment strategies aim for long-lasting remission, with the goal of avoiding complications and hindering disease progression (Torres et al., 2017). However, a briefing report by the National Institute of Health Care and Excellence (NICE; 2014) suggests 50% of patients experience at least one relapse of symptoms annually.

Previous research has examined the link between IBD and mood disorders, such as anxiety and depressive disorders (Larion et al., 2015; Neuendorf et al., 2016). Neuendorf et al. (2016) suggest the prevalence of anxiety and depressive disorders in IBD is 21% and 15%, with early age of onset being a risk factor for this psychological morbidity (Hoogkamer et al., 2018). In their quantitative research study, Lewinson et al. (2000) explored the correlation between eating disorders (EDs) and psychopathology and found EDs often co-occur in individuals with high levels of depression and anxiety severity. Yet Ilzarbe et al. (2017) highlight the relationship between EDs and IBD has not been extensively studied which is concerning as it has been found both illnesses negatively impact the other, which in severe cases can be fatal.

EDs refer to all illnesses which meet diagnosable criteria and are defined as “clinically meaningful behavioural or psychological patterns having to do with eating or weight that is associated with distress, disability, or with substantially increased risk of morbidity or mortality” (Grilo, 2006, p.3). It is important to highlight the divergence between disordered eating and EDs. Quick et al. (2013) describes disordered eating as those behaviours associated with EDs which would be described as abnormal, including restraint eating and controlling body weight and shape through unsuitable compensatory behaviours, that would not meet criteria for an ED as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V; 2013). Due to the current lack of recognition of EDs within the IBD population, comorbid diagnoses remain limited, thus disordered eating, or difficulties with eating, is deemed a more appropriate term.

In an initial investigation into diet related chronic health conditions (DRCHC), including IBD, Quick et al. (2012) conducted a case-controlled study which aimed to identify whether psychological experiences in healthy young adults with difficulties with eating are different to those with DRCHCs, namely type one diabetes, celiac disease, cystic fibrosis, IBD

and IBS². Results suggest participants with DRCHCs were six times more likely to carry out a dietary regimen and were twice as likely to have been diagnosed with an ED. Participants with DRCHCs were also more likely to control weight with exercise and medicine misuse. These factors are cited within ED literature as experiences of those with a diagnosis of an ED or difficulties with eating (Grilo, 2006). Therefore, Quick et al. (2012) identified preliminary factors which highlight what could contribute to the development of an ED in individuals with IBD, yet further research is needed to strengthen this argument.

In a further study, Quick et al. (2013), explored the association between difficulties with eating and DRCHCs, again including the population of IBD, coupled with IBS, by carrying out a literature review. Only six papers were identified as suitable within the IBD population. These papers explored the broader experiences of those with IBD, of which eating presents as a factor. Nicholas et al. (2007) carried out a qualitative study which explored challenges of children and adolescents with IBD, and found youths aged seven to 19 years struggled with food restrictions. The research also found female adolescents voiced concerns about weight gain or changes to facial features related to corticosteroid treatments. In a case study of two individuals who were diagnosed with bulimia nervosa after the onset of IBD, Meadows and Treasure (1989) suggested a similar association with corticosteroid treatments and stated associated weight gain may have played a role in the development of EDs.

Akin to Nicholas et al. (2007), de Rooy et al. (2001) found individuals with IBD expressed body image concerns and highlighted this could suggest an association with IBD and difficulties with eating. Van Balkom et al. (2012) suggested one factor which may affect poor body image could be the need for an ileo-anal pouch in severe cases of IBD. To add to this, following a qualitative content analysis of data from individuals with an ileo-anal pouch,

² Spiller et al. (2007) define irritable bowel syndrome as a “chronic, relapsing gastrointestinal problem, characterised by abdominal pain, bloating, and changes in bowel habit”.

Berndstonn et al. (2011) suggested factors such as food restrictions, feeling unable to live a “normal” life and being dependant on medical care could be associated with the development of difficulties with eating within this population. Whilst these papers do not address difficulties with eating in the IBD population directly, the use of qualitative methodology allowed factors to be identified due to gathering of rich, detailed information (Howitt & Cramer, 2011). This suggests a qualitative approach augments the quantitative approach used by Quick et al. (2012).

Quick et al. (2013) concluded there is not enough evidence to investigate prevalence and risk factors for developing an ED or difficulties with eating in individuals with IBD but difficulties with eating occur. They suggested “qualitative work such as conducting focus groups with health care providers of DRCHC patients and DRCHC patients themselves would increase understanding of how EDs develop in DRCHC populations and lead to a suitable theoretical framework for patient interventions” (Quick et al., 2013, p. 282).

More recent research conducted by Ilzarbe et al. (2017) included a case study of a female with a comorbid diagnosis of IBD and ED, as well as a systematized review of published cases of patients with the same condition. Their findings highlighted a possible association between IBD and ED and suggested several risk factors to associate EDs with IBD, such as “preoccupation with dietary management, fear of abdominal discomfort from eating food, weight and body shape concerns and poor body image” (p. 51). They went on to suggest clinical implications relevant to the field of clinical psychology, suggesting a multi-disciplinary team approach is necessary to provide adequate therapeutic interventions due to the complexity of cases. They also suggested a screening tool which evaluates eating attitudes early on in patients with IBD is needed, as the review found the association between IBD and ED may cause deterioration in both conditions. Ilzarbe et al. (2017) suggested research is needed to further consolidate the link between IBD and EDs and identify possible factors which could assist earlier identification of EDs. Thus, consensus exists amongst previous research that disordered

eating practices occur within the IBD population, however the understanding of individuals' experiences with their IBD and their consequent relationship with food and eating remains unclear.

Due to findings reported above that indicate further research is needed to identify how and why psychological difficulties with eating occur for individuals with IBD, the current study intends to use a qualitative design to address the following research question: "how do people with IBD and difficulties with eating make sense of the relationship between the two?" This aims to inform healthcare professionals working with these individuals, such as clinical psychologists, to provide adequate therapeutic interventions.

Method

Design

The present study has a particular focus on participants' experiences, how they make sense of these, and the resultant psychological implications. Interpretative phenomenological analysis (IPA; Smith & Osborn, 2003), which has a concern with phenomenology (lived experience), hermeneutics (how participants and researcher interpret experience), and idiography (arriving at an interpretative account that is considerate of individuals and the group) was therefore used to guide data collection and analysis. IPA calls for an in-depth idiographic analysis for small, homogenous samples (Smith & Osborn, 2003), therefore a sample size of six to ten participants was aimed for. Individual semi-structured interviews were conducted with participants to generate rich data regarding participants' experiences of IBD and their relationship with eating.

Recruitment

Purposive sampling was used to recruit individuals who had received a diagnosis of IBD and who self-reported experiencing psychological difficulties with eating; this also

included individuals who had received a formal diagnosis of an ED. There is consensus within the literature that the age of onset for EDs largely lies within adolescence and young adulthood (Halmi, 2005); Volpe et al. (2016) sought to clearly define this, and through a large scale study of 806 participants, found for all types of EDs, the average age of onset was 18 years old. Therefore, individuals from 18 years of age and onwards were recruited. IBD referred to CD and all forms of UC. Difficulties with eating referred to individuals who may experience disordered eating behaviours associated with EDs which would be described as abnormal, including restraint eating and controlling body weight and shape through unsuitable compensatory behaviours, that would not meet criteria for an ED as defined by the DSM-V (2013). Table 1 details inclusion and exclusion criteria.

[Insert Table 1]

Targeted recruitment efforts were employed; an email was sent to an identified contact person from Crohns & Colitis UK (a UK based IBD specific charity) to obtain permission to advertise the research on their website and social media platforms. A handle was requested to be advertised on social media platforms, which was also advertised on the researcher's professional twitter account. The researcher's field supervisor also sent an email to individuals who stated following a previous piece of research they would be happy to be contacted about participation in future research.

Participants expressed potential interest via contact information provided or used the expression of interest form. The researcher then provided them with information packs about the study, including the participant information sheet and consent form, via email.

43 individuals expressed interest to participate in the study, of which 42 met inclusion criteria. Eleven individuals were invited to participate, however four did not attend resulting in seven interviews being conducted. However, only six interviews were included; during interview it became apparent the fourth interview did not meet inclusion criteria as they did not

recall psychological difficulties relating to their difficulties with eating. Participants were aged between 19 to 37 years and included four males, and two females (Table 1). All participants confirmed they had received a formal diagnosis of IBD (age in years at time of diagnosis ranged from 12-26, mean = 19.3, SD = 0.2). Specific details of participants' socioeconomic status, educational attainment levels, race and ethnicity background were not recorded.

[Insert Table 2]

Conducting interviews and transcription

Participants were asked to attend a single interview with an average length of 54 minutes and 30 seconds. Individual interview lengths are provided in table 2. A semi-structured interview schedule covered key topics, whilst enabling some flexibility (appendix 2-A). Questions to be used within the interview were informed by literature pertaining to the research question, supervision from field and research supervisors and experts by experience (EBE). EBE were again individuals who stated they would be happy to be contacted about participation in future research. A copy of the interview schedule was sent by the researcher's field supervisor and EBE were asked to provide feedback; responses from four EBE were received which highlighted no changes to the interview schedule were necessary. Questions asked participants to focus on their experience from the point of receiving a diagnosis of IBD to the current date, to establish if participants experience and recount a relationship between their IBD and their experience of psychological difficulties with eating. For example, participants were asked, "what changes did you notice with your relationship with eating over time?" Interviews were conducted via skype or telephone and were recorded using a recording device. Once recorded, interviews were transcribed by the lead author and stored securely.

Analysis

Transcripts were analysed in date order using Murray and Wilde's (2020) approach to IPA. For each transcript in turn, initial coding took the form of line-by-line coding staying close

to the data and using phrases which reflected the experience of meaning making of the participant, but with codes only being recorded for data thought to be relevant, rather than every line (appendix 2-B). Physical copies in the form of post it notes were then created to cluster coding into grouped themes, representing specific experiences of the participant. Following this, an electronic table was created which held paragraph summaries for each cluster, which sought to capture the participant's experience of the specific phenomenon in a cohesive, narrative format, as well as corresponding quotes from the initial transcript (appendix 2-C). Titles were given to paragraph summaries which aimed to encapsulate the summary in an informative and explanatory manner. In accordance with IPA, the researcher 'bracketed' or 'put in abeyance' the interpretations reached for each transcript when analysing subsequent transcripts.

Once completed for each participant, theme titles from all participants were again placed onto physical post it notes for further clusters to be created which aimed to find shared participant experiences. Final summaries were developed with these clusters, which were re-titled to convey the lived experiences of participants for whom these themes were relevant. Table 3 demonstrates how each participant contributed to final themes.

[Insert Table 3]

Credibility and reflexivity

To enhance credibility within the study, the researcher referred back to original data at all stages of analysis, with particular emphasis on checking the process described within the final themes was reflected in the data (Chiovitti & Piran, 2003). Additionally, initial codes were kept close to the data to maintain language used in interviews and support the creation of final themes which demonstrate participants' contributions.

IPA involves two phases of interpretation known as the 'double hermeneutic', in which

the researcher plays an active role in making sense of participants' understanding of their own experiences (Smith & Osborn, 2003; Smith et al., 2009). Therefore, the researcher's interpretations of the data will have been influenced by their experience; the lead researcher received a diagnosis of an IBD at the age of 18 years and has noticed how this has impacted upon her relationship with eating. A reflective diary was kept throughout the research to support deeper reflection of the researcher's interpretations, personal biases, and thinking to consider its potential impact on the study. During the analysis, the researcher's own thinking and interpretations were 'bracketed' from the data to ensure the analysis focussed on the experience of participants, rather than preconceptions of the data (Smith et al., 2009). Reflections on this are discussed in the Critical Appraisal.

Ethical considerations

Ethical approval from Lancaster University FHMREC was sought; a detailed ethics form was sent via email to the FHMREC administrator, alongside supporting documents. This can be seen in Section 4.

Minimal risks were associated with taking part in this study. However, it was possible participants could find discussion of their experiences distressing. It was decided if participants were to become distressed, the researcher would offer to pause the interview and discuss any difficulties, or use resources provided on the participant information sheet. Participants could also use these if they wanted to seek additional support following participation.

Confidentiality and its limits were clearly explained prior to participation in the project. If serious concerns were raised, such as concerns about wellbeing and/or risk, it was important for the researcher to ascertain if it was necessary to inform appropriate services, such as services supporting the individual or relevant crisis teams. The need for this did not occur. Pseudonyms have been chosen by the researcher to provide anonymity to participants.

Results

The following four themes were identified during analysis: (1) the need to restrict and control diet; (2) increased intrinsic and extrinsic awareness: the impact on body image; (3) responsibility, guilt and engagement: the experience of clinical intervention; and (4) feeling helpless. For better readability, conversation fillers (e.g., “umm”, “you know”), stutters and repeated words have been omitted from quotes and replaced with an ellipsis.

The need to restrict and control

Restrictive eating was a dominant theme for all participants. As discussed later within the theme of “responsibility, guilt and engagement: the experience of clinical intervention”, medical interventions for IBD was cited as a trigger for this, but IBD as an experience in and of itself also appeared to be a predisposing factor. Participants reported they had become fearful of eating for fear of causing a flare up, and so restricted their diet to foods they felt would prevent this:

I wouldn't try things at all, I was literally just like sticking to like high carbs and protein like I thought vegetables have fibre in, fibre is going to upset me so I won't eat that and it sort of came...like that. (Phil)

The fear of having foods which participants deemed as bad for their symptoms also triggered psychosomatic feelings of anxiety, which they assimilated as symptoms of IBD. Thus, participants demonstrated rule-based eating, which are rules they had developed which stated which foods are acceptable to eat; for Hayley, this was based on foods being pure rather than processed, “it does bring sometimes the kind of obsession, or that's too strong for words, but focus on like good foods, bad foods, pure foods, not pure foods”. The use of the word obsession highlights the relentless and intrusive nature of the participants' thoughts, which led to negative feelings, including feeling shameful. Participants carried out behaviours which prevented them

from eating food categorised as bad to avoid or alleviate these difficult thoughts and feelings, for instance “they go to the food bank” (Hayley).

Participants reported it being difficult to move on from this categorisation and found themselves in a routine of eating the same foods daily. The reason behind this was twofold; firstly, when a routine was in place, participants did not criticise themselves for diverging from their routine and were also reassured they would not make bad choices, and thus felt less guilty. It also reduced feelings of anxiety, as described by Stephen, “I think being in control of my diet...makes me a lot less anxious.” Secondly, it was less mentally draining as they did not have to think about what foods they could eat that fit their restricted diet:

That's a big one for me...whenever I'm eating cos pretty much my dinner has been the same every night, it's something consisting of rice, something consisting of chicken and something consisting of a low-calorie pasta sauce. (Ben)

Thus, feeling in control of diet was important for participants to feel safe in the uncertain world of IBD, where many unknowns, such as when they will have their next flare up, exist. Outside of diet, the necessity to control presented itself within times of eating, alongside excessive knowledge of nutritional and calorie content:

Sometimes when I'm in a flareup I'll be thinking before I eat, after I've eaten, before the next meal...I'll be thinking what's for dinner, what can I get, do we need to get more food...how much of this can I eat, how much would this, can I not eat, should I not eat. (David)

When they were unable to follow these rules, for instance if they were eating at another individual's house, participants stated all or nothing thinking and behaviours occurred, where they would flip from adhering to rules, to engaging in what they described as unhealthy eating, or eating bad foods:

It just flips and then it just goes to like, oh well just if it's all like and then I'm just like eating unhealthy...stuff because it feels like good obviously when you eat something that's rubbish, it's fine for a treat but then it's not necessary to eat like sugary things or a McDonald's or things like that...regular you know, so it kind of like it goes between the two...it feels like you can't be free to eat, whatever, something for a treat, but then you can get carried away. (Hayley)

Thus, it seemed when participants experienced this flip, they again experienced shame for having eaten foods deemed bad, but also resentment towards having IBD and the consequent lack of enjoyment from eating.

Overall, participants experienced feeling out of control due to having IBD and the level of uncertainty and change this brought. To regain power, they sought to control things around them, which resulted in extreme restrictions of food, symbolic of psychological difficulties with eating.

Increased intrinsic and extrinsic awareness: the impact on body image.

This theme relates to participants' increased preoccupation with occurrences both inside and outside of their body as a result of IBD and how they subsequently felt about their body appearance. This theme again occurred for all participants.

Participants' previous experience with body image appeared to be a predisposing factor for the experience of psychological difficulties with eating following IBD diagnosis. Sarah and Ben reported during adolescence they had begun to feel self-conscious about body image. It was around this time they began to experience symptoms of IBD, which included significant weight loss. This appeared to provide the "perfect storm" (Sarah) for psychological difficulties with eating; IBD provided a reason to not eat, "I've gone through periods where I've perhaps not eaten very much because it's felt not only like it suited my needs for making my body feel

like I wanted to, but also look like I wanted it too” (Sarah). One reason Sarah gave for this was she was able to “rationalise that [not eating] as giving my intestines a break by just not putting as much through.”

Yet for others, weight loss highlighted a disparity between themselves with IBD, and themselves prior, and dissatisfaction with body image stemmed from appearing too thin. Phil voiced losing what he described as “good weight” in the form of muscle mass. This led to changes in his appearance, and deterioration in his mental wellbeing:

I used to like have muscles and things like that before and obviously lost all of that weight...I wasn't able to go to the gym at all for that time, I wasn't as active so I did then struggle mentally. (Phil)

This suggests gender differences may exist which reflect stereotypical desirable male and female body types. A similar response was voiced by Stephen who expressed he doesn't view weight loss experienced due to IBD as positive, “it is a downside of Crohn's, some people would argue well it's an upside if you can't put on weight, but I don't see it like that”.

Alongside heightened attention of body appearance, participants also focused on physical sensations which occurred internally due to IBD, such as bloating. If bloating was identified, participants interpreted this as being overweight, and experienced ruminating thoughts, often degrading in nature; Stephen stated being bloated made him feel bad about himself, to the extent that he would avoid attending social occasions:

I think it's just you know like some people look at themselves in the mirror and they might be great looking but they might feel, you know what I don't feel good enough, I think sometimes the bloating is a bit like that, that you know you might look fine but you don't feel great, you know from feeling bloated. I'm not going to fancy running on

a football pitch or naturally I'm not going to play my best and people are going to think I'm really bad so actually I might as well not turn up. (Stephen)

Consequently, participants reported restricting diet to manage bloating and avoid these difficult thoughts and feelings about themselves.

Yet a divergence of this experience existed for some. For Phil and David, there appeared to be a disparity between their awareness of intrinsic processes (what was happening inside their body), which appeared heightened, and their extrinsic self (their physical appearance, namely weight), which conversely seemed significantly reduced. This dissociation appeared to be protective as it facilitated them to not fully acknowledge weight loss as being a cause for concern, "I didn't see it as an issue at the time but others did and obviously I was then getting malnourished" (Phil).

This theme highlighted these participants experienced changes in their level of awareness of their bodies, both intrinsically and extrinsically, following their IBD diagnosis. This led to them becoming hypersensitive of change, which they interpreted negatively and led to critical thoughts and feelings about themselves. Subsequently, they attempted to use extreme measures to manage diet to feel more positive about their bodies.

Responsibility, guilt and engagement: the experience of clinical interventions.

This theme relates to the experience of different medical procedures which seem to have been triggering for five out of six of participants' experience of eating difficulties, namely Phil, Sarah, David, Ben and Hayley.

Phil reported when he was initially admitted to hospital and received his diagnosis of IBD, he was instructed to put on weight as quickly as possible by eating high calorie foods, "when I then started to recover they said that I needed to get the weight on quick like to get all the nutrients in me." Phil stated this led to an unhealthy relationship with food as he no longer

felt he was aware of when he was full and would often binge eat. This led to feelings of disgust for Phil, “If I saw anyone else doing that I'd be like you're a pig.”

To add to this, participants reported taking steroid medication had impacted upon their experience of psychological difficulties with eating. This was voiced by Sarah who reported the intervention caused swelling of the face, often referred to as “moon face”. She interpreted this as being overweight, which further stimulated her cycle of restricting diet. Steroid medication also made it difficult for participants to lose weight they had gained following IBD treatment, despite utilising appropriate weight loss methods, such as attending the gym. Consequently, feelings of frustration and frequent thoughts about weight loss and weight loss methods were experienced. There appeared to be an issue of risk present as participants reported they would utilise inappropriate methods of weight loss, such as stopping taking medication. A sense of desperation is felt, particularly from David who described this being the only option he had for losing weight, “sometimes I’m just like I just want a really bad flare up to go to hospital so I can lose some weight” (David).

A consequence of this risk was highlighted by Ben who explained how he experienced dizzy spells due to restricting his diet, which on one occasion caused him to faint:

I had one, not in the gym, but I had one time where I was just sitting at my computer and I fainted...like I got really dizzy and fainted but that's yeah I think that that was probably just Crohn's and eating related. (Ben)

Yet he stated he was not willing to change his eating habits as he does not see any other way of controlling his weight. Those around him commenting he was underweight did not seem to be a motivating factor, whilst telephone IBD consultations facilitated him to not cause concern with health professionals. This consequently highlighted a further issue of risk; telephone IBD

appointments prohibited the team from effectively assessing the impact of the patients' IBD on their weight.

Hayley cited the need to have to restrict a diet to only liquids prior to medical procedures was triggering for psychological difficulties with eating, as well as ongoing monitoring of inflammation levels. It appears she felt some level of responsibility when her inflammation levels were raised:

Then it's brought up a lot a lot of guilt I'd say, there's a connection I think with now like guilt and with eating related to health of your IBD or you might make it worse or cause it with the food you eat. (Hayley)

This therefore further encouraged individuals with IBD to restrict diet due to feelings of guilt in relation to causing inflammation levels to remain high, which they perceived was due to what they had eaten.

Despite this condemning evidence for the impact of clinical interventions on difficulties with eating, Phil presented diverging evidence. Although he experienced difficulties with body image initially after having a stoma formed, he quickly adapted to his new identity, thus reducing the likelihood of difficulties with eating due to distaste to his body appearance:

For the first time I'd say now that I'm more comfortable with my body appearance and got used to it but initially after having an operation and having the stoma like I didn't want like anyone to see me without a top on. (Phil)

Hayley also offered diverging evidence. Some medical interventions appeared to have had a more positive impact on her experience of psychological difficulties with eating; the necessity to take prescribed medication helped reduce the intensity of the eating difficulties, due to the desire to not contract infections whilst taking these:

When I started adalimumab [medication which aims to reduce inflammation], it kind of in a good way helped me, like from that point on I didn't want to like...don't feel the need to, well I didn't have anymore relapses of like throwing up after adalimumab, cause like it was obviously for my IBD but a positive side of it for me, because I was worried about infections, germs, all that kind of thing... (Hayley)

Engaging in dietary therapy appeared to have both a positive and negative impact on the experience of difficulties with eating however. Hayley described it as a “healing process” initially, as she was encouraged to have three meals a day which she had not been doing since the onset of her IBD, “it brought up a lot of difficulties at the start because I wasn't used to having a routine of like having meals.” However, a lack of support following discharge and transition to home resulted in restrictions of food becoming worse, as dietary therapy taught her to have black and white thinking regarding what foods she could and could not eat:

So because doing that [dietary therapy], it's brought up a lot a lot of guilt I'd say, there's a connection I think with now, like guilt and with eating related to health of your IBD, you might make it worse or cause it with the food you eat. (Hayley)

Overall, for these participants, certain clinical interventions contributed towards the experience of psychological difficulties with eating for reasons including changes in physical appearance. Despite this, some clinical interventions offered relief from these difficulties, and reintroduced patterns of healthy eating.

Feeling helpless: nowhere to turn

This theme relates to the feeling of helplessness participants experienced in relation to having to manage diet without support they felt was needed from their IBD team. This theme was cited by five out of six participants, Sarah, Stephen, Hayley, Ben and David.

It would appear support received from IBD teams in relation to the management of IBD was “very biologically focused” (Sarah). All participants stated they would benefit from guidance from their IBD team regarding the necessity to manage diet and the possible psychological impact of this:

I know it's not really related to the mental side of it but not, not directly but indirectly, it must because you know, I'm sure I'm not the only person who worries about what they eat with Crohn's and it's...scary how there's like extremes so you know, there's not even a consensus about what sort of food is good for you and what is bad for you and so no wonder people don't know what to eat and have issues with...a struggle with their diet and IBD. (Stephen)

Ben echoed this experience and stated his current team did not listen to concerns pertaining to IBD and eating, and instead provided unhelpful short-term solutions:

If I could contact them about getting around ways of you know eating healthily...and in a healthy way that can you know manage my Crohn's...I would be open to it...but then I don't...really know because like the...couple of appointments I have had they've been like...just eat what you usually eat and then have a repair in mind or an Imodium. (Ben)

This proved invalidating of the participant's experiences, demonstrated by the way he dismissed his own concerns as not being worthy of contacting the team, “it's not that I don't know who to contact it's just I don't know if it's a valid reason to contact”. This left him feeling abandoned and alone in his efforts to manage his IBD.

This theme of helplessness was also heard in how participants discussed their relationship with food; participants highlighted they were aware their pattern of eating was unhealthy yet felt stuck in a routine they could not break out of. Voicing they would like help

reinforced they felt they could not help themselves. However, further entrapment of this cycle ensued as they felt this help should come from IBD teams:

Ben: I don't know why it's like that, but that's, I think I've kind of, there's just no options because my, the way I'm just now just kind of feels like... [laughs]

Researcher: yeah you have to sort...it yourself on your own almost

Ben: Yeah which I'm fine doing, I'm quite...an independent person and I quite like you know, I do my own stuff but it's...yeah I mean if, I, I would be, if there was a service...I would be open to the service because you know...because where I am just now isn't healthy.

Despite this, it would appear some IBD teams were more receptive to listening to concerns surrounding management of diet. David had recently moved geographical location and his care had been transferred to a different team. He raised concerns in relation to diet and weight management with his new consultant, who recommended a referral to the team's psychological service to discuss these difficulties:

The new consultant did actually mention to me in the meeting that they do have in their unit a trained psychiatrist, Crohn's psychiatrist...and a nurse who...has been a gastro nurse for 15 years and trained as a psychologist and [I] made it clear to him if that was available I'd be interested. (David)

Therefore, it would appear resources available within a service were paramount to whether patients' concerns were addressed. If they were not, participants highlighted how lack of direct guidance on how to manage diet to try and control symptoms of IBD contributed to the development of difficulties with eating.

Discussion

The findings from this study provided new insight into a sparsely researched topic on IBD and explained how the experience of IBD contributed to experiences of psychological difficulties with eating. “Feeling helpless: nowhere to turn” is a novel theme which emerged. It highlighted how lack of support from IBD teams regarding diet and weight management, and a focus on physiological symptoms of IBD as opposed to the psychological impact of factors such as these, left participants feeling they were unable to turn to healthcare providers when they were struggling with these factors. Trying to find means of managing their diet and weight on their own left participants feeling overwhelmed and they consequently resorted to restricting their diet significantly. Participants also expressed feelings of abandonment by their IBD teams, which contributed to other difficult feelings such as low mood. Restricting diet can be a way individuals who experience psychological difficulties with eating manage difficult feelings, termed “mood modulatory behaviour” (Fairburn, 2008, p. 142). However, in restricting diet, this may increase feelings of low mood; Rao et al. (2008) cite nutrient deficiencies to be a contributing factor to psychological difficulties such as low mood and depression. Thus, a cycle of feeling unsupported, low in mood and restricting diet was seen.

This finding contradicted that of Quick et al (2012) who suggested individuals with DRCHC’s were twice as likely to have been diagnosed with an ED by a healthcare provider. The current findings suggested individuals with IBD did not discuss their psychological difficulties with eating with healthcare providers, thus making it possible that they were less likely to be identified as having these difficulties. This highlighted an issue of risk, as early detection and intervention are desired for all EDs (Treasure et al., 2015) as lengthier periods of illness before presentation for treatment is associated with reduced recovery rates (Keel & Brown, 2010; Pike, 1998; Richard et al., 2005).

The theme “increased intrinsic and extrinsic awareness: the impact on body image” also provided new insight into this topic. de Rooy et al. (2001) reported individuals with IBD

expressed body image concerns and highlighted this could suggest an association with IBD and psychological difficulties with eating, however they did not go as far as suggesting why this may occur. The current research identified individuals with IBD developed a preoccupation with body scanning, as well as experienced recurring thoughts about food and the impact this had on physical appearance due to ongoing physical changes within the body which caused discomfort, such as bloating. Resultantly, akin to those with EDs, these individuals developed an inward focus on the body (Fairburn, 2008) and avoided social situations. Fairburn (2008) suggested this desire to avoid others would likely be due to feelings of low mood, exacerbated by the brain being malnourished, alongside being focused on thoughts and behaviours associated with restricting dietary intake.

Similarities existed between previous research and the theme “responsibility, guilt and engagement: the experience of clinical interventions”. The experience of having to take prescribed steroid medication and the consequent bodily changes such as weight gain and facial swelling identified by Nicholas et al. (2007) and Meadows and Treasure, (1989) were also identified in this study as having an impact on psychological difficulties with eating due to dissatisfaction with body appearance. Yet the present study went further in exploring the impact of this and found participants would stop taking medication to meet body image goals. This presented a further issue of risk; it is dangerous to stop taking steroid medication without a period of titration, as physical health complications can occur. Furthermore, dramatic weight loss can lead to an exacerbation of IBD symptoms, as the body finds it difficult to digest food when reintroduced (Hearing, 2004). This finding is in line with Quick et al. (2012) who found participants with DRCHC’s controlled their weight through medicine misuse, however participants with IBD were not directly cited.

Whilst Van Balkom et al. (2012) suggested one factor which may affect poor body image could be the need for an ileo-anal pouch for individuals with severe cases of IBD, for

participants with an ileo-anal pouch in this study, whilst body image concerns were initially experienced, these were not longstanding, and thus were not thought to impact on the ongoing experience of eating difficulties.

A novel finding in relation to clinical interventions and the role this had on psychological difficulties with eating for those with IBD was also found in the current study; one participant received dietary therapy and denounced this led to feelings of guilt associated with eating foods deemed as “bad.” These feelings of shame, alongside increased feelings of responsibility, were also experienced when participants were having levels of calprotectin³ measured, as participants worried their diet would cause inflammation levels to be higher, encouraging them to further restrict. It has been suggested shame is associated with a fear of causing disgust in others (Gilbert, 1992; Miller, 1997; Power & Dagleish, 1997). In his evolutionary model of shame, Gilbert (1992, 1997) stated shame is anticipated from more powerful others, such as healthcare professionals. The experience of shame was then further conceptualised as external and internal shame (Gilbert, 1998). Gilbert (1998) described external shame as how an individual thinks they are perceived in the minds of others. Parallel to this exists internal shame, where the individual deems themselves as bad or morally defective as they failed to meet their own internalised standards (Tangney, 1993, 1995), such as those set out by participants in relation to foods deemed as good or bad. For individuals with EDs, both internal and external feelings of shame lead to restriction, which subsequently leads to weight loss and sometimes feelings of pride (Goss & Gilbert, 2002). Goss and Gilbert (2002) describe a shame-pride cycle exists where shame negatively reinforces restrictions and pride positively reinforces weight loss. This cycle is frequently cited by participants in this study.

³ Measure of inflammation within the body

The theme “the need to restrict and control” has previously been identified by other researchers in IBD including Ilzarbe et al. (2017), Quick et al. (2012), Nicholas et al. (2007) and Carlsson et al. (2011). However, again the qualitative nature of this study produced more detailed evidence, ascertaining reasons why dietary restrictions led to psychological difficulties with eating; escalations of restricting behaviours begin with participants attempting to navigate what works for them in terms of managing IBD symptoms, for example avoiding abdominal discomfort, as suggested by Ilzarbe et al. (2017). However, as Fairburn (2008) described for individuals with EDs, these restrictions and under-eating led to participants becoming inflexible and carrying out rigid routines, as described by participants being reluctant to attend friends’ houses for food. This can lead to individuals feeling detached and disconnected (Fairburn, 2008), as described by participants in this study who were unable to identify issues such as how their mental health was associated with dietary restrictions.

Clinical implications

All participants stated they would like to receive dietary education pertinent to IBD from healthcare professionals, alongside discussions specific to the psychological impact of having to manage a new diet. Dietary education could be provided by the IBD nurse specialist or dietician regularly found within IBD services. However, at present a disparity of access to clinical psychologists within IBD services exists, despite NICE guidelines (2015) stating all IBD teams should have access to one. Consequently, it may not be possible for individuals to receive assessment and intervention from a clinical psychologist pertaining to difficulties such as feelings of shame. This therefore highlights an area for commissioners of IBD teams to address; funding needs to be provided to give all IBD teams access to psychological services.

A further clinical implication exists in the form of risk; these individuals displayed experiences similar to those who experience EDs, yet these are not recognised by IBD teams

as discussions are not being held, further highlighting the assessment of these issues as standard is vital. This issue is exacerbated by appointments being held over the telephone, which prohibits healthcare professionals from being able to sufficiently assess the impact of the individuals IBD and diet on their weight due to not being able to observe the patient, alongside the reliance on the patient of providing an accurate weight measurement. This lack of detection and intervention could lead to escalation in ED behaviours, which in the most extreme situation could be fatal, although prevalence rates of this are currently unknown. Thus, discussions around diet and weight are extremely important, and the safety and proficiency of IBD consultations over the telephone should be assessed on individual bases.

Limitations

Although efforts were made to recruit participants from multiple avenues, all participants identified the study from the Crohn's and Colitis UK research website, and were actively looking for research to participate in. Thus, participants were highly motivated to engage and self-selection bias may be present. All participants who volunteered for the study were likely to have strongly identified with an IBD identity. Individuals with IBD who identify less strongly may have been less inclined to participate. Therefore, current findings likely represent the perspectives of individuals with IBD who have established self-acceptance of this identity, whilst other perspectives are underrepresented (Oppong, 2013), limiting the generalisability of the findings (Sharma, 2017).

Limited background information was gathered in relation to what additional experiences individuals have which predispose them to psychological difficulties with eating following the diagnosis of IBD. However, some information pointed to issues such as the age of diagnosis being significant; this was notable for those who were diagnosed with IBD during adolescence for whom factors such as body image and acceptance amongst peer groups were

particularly important. It would therefore be advised that healthcare professionals are mindful of this; a psychological formulation drawing these factors together would help to decipher this.

Limited gathering of background information also meant context relating to participants' current status of their IBD was lost, for example remission status, or structure presence. It is possible their relationship with food could fluctuate based on these factors, thus findings here remain representative of participants' experiences at the time of interview.

Future research

This research identified how individuals with IBD recount their experience of psychological difficulties with eating, and suggested reasons why these can occur in the context of having IBD. It is important to recognise that for individuals with IBD, it is often normal to restrict diet to manage symptoms. However, this study details how normal restrictions were exceeded, and became a cause for concern. The development of a tool which helps healthcare practitioners to assess this risk would be of benefit, for professionals to feel fully confident in their assessment, and prevent further escalation of behaviours.

Conclusion

For some individuals with IBD, the experience of having this condition impacts on their relationship with diet and eating. Although an element of change to diet is often experienced following the development of an IBD, this research has highlighted it is challenging for individuals to manage the emotional and psychological impact of this on their own, and appropriate support is needed.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-V*. American Psychiatric Association.
- Berndtsson, I., Carlsson, E., Perrson, E., & Lindholm, E. (2011). Long-term adjustment to living with an ileal pouch-anal anastomosis. *Diseases of the Colon and Rectum*, *54*, 193–9. <https://doi.org/10.1007/DCR.0b013e3181ff42d8>
- Caio, G., Lungaro, L., Caputo, F., Zoli, E., Giancola, F., Chiarioni, G., De Giorgio, R., & Zoli, G. (2021). *Nutritional Treatment in Crohn's Disease*. *Nutrients*, *13*(5), 1628. <https://doi.org/10.3390/nu13051628>
- de Rooy, E., Toner, B., Maunder, R., Greenberg, G.R., Baron, D., Steinhar, H., McLeod, R., & Cohen, Z. (2001). Concerns of patients with inflammatory bowel disease: results from a clinical population. *American Journal of Gastroenterology*, *96*, 1816–21. [https://doi.org/10.1016/S0002-9270\(01\)02440-6](https://doi.org/10.1016/S0002-9270(01)02440-6)
- Fairburn, C. G. (2008). *Cognitive behavior therapy and eating disorders*. Guilford Press.
- Gilbert, P. (1992). *Depression: The evolution of powerlessness*. LEA.
- Gilbert, P. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of Medical Psychology*, *70*, 113–147.
- Gilbert, P. (1998). *What is shame? Some core issues and controversies*. In P. Gilbert, & B. Andrews (Eds.), *Shame: Interpersonal behaviour, psychopathology and culture* (pp. 3–38). Oxford University Press.
- Goss, K., & Gilbert, P. (2002). *Eating disorders, shame and pride: A cognitive-behavioural functional analysis*. In P. Gilbert, & J. Miles (Eds.), *Body shame: Conceptualisation, research and treatment* (pp. 219–255). Brunner-Routledge
- Grilo, C. (2006). *Eating and weight disorders*. Psychology Press.

- Hoogkamer, A. B., Rowse, R., Brooks, A. J., & Lobo, A. J. (2018). Systematic review: predicting the development of psychological morbidity in inflammatory bowel disease. *UEG J*, 6(1), P0956
- Howitt, D., & Cramer, D. (2011). *Introduction to Research Methods in Psychology: Third Edition*. Pearson Education UK.
- Ilzarbe, L., Fàbregas, M., Quintero, R., Bastidas, A., Pintor, L., García-Campayo, J., Gomollón, F., & Ilzarbe, D. (2017). Inflammatory Bowel Disease and Eating Disorders: A systematized review of comorbidity. *Journal of Psychosomatic Research*, 102, 47–53. <https://doi.org/10.1016/j.jpsychores.2017.09.006>
- Karwautz A, Wagner G, Berger G, Sinnreich U, Grylli V, Huber W. (2008). Eating pathology in adolescents with celiac disease. *Psychosomatics*, 49, 399–406.
- Keel, P.K., & Brown, T.A. (2010). Update on course and outcome in eating disorders. *International Journal of Eating Disorder*, 43, 195–204. <https://doi.org/10.1002/eat.20810/abstract>.
- Larion, S., DeCecchis, P.D., Arnold, M.J., Vanslyke, A.J., and Tavakoli, R.H. (2015). Psychiatric Comorbidities in Inflammatory Bowel Disease. *Current Psychiatry Reviews*, 11(2), 124-129. <https://doi.org/10.2174/15734005110215050208333>
- Lewinson, P., Striegel-Moore, R., & Seeley, J. (2000). Epidemiology and natural course of eating disorders in young women from adolescent to young adulthood. *Journal of American Academy of Child and Adolescent Psychiatry*, 39, 1284-1292. <https://doi.org/10.1002/eat.10202>
- Meadows, G., & Treasure, J. (1989). Bulimia nervosa and Crohn's disease: two case reports. *Acta Psychiatrica Scandinavica*, 79, 413–4. <https://doi.org/10.1111/j.1600-0447.1989.tb10280.x>
- Miller, W. (1997). *The anatomy of disgust*. Harvard University Press.
- Molodecky, N.A., Soon, I.S., Rabi, D.M., Ghali, W.A., Ferris, M., Chernoff, G., Benchimol, E.I., Panaccione, R., Ghosh, S., Barkema, H.W., & Kaplan, G.G. (2012). Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on

systematic review. *Gastroenterology*, 142(1), 46–54, <http://dx.doi.org/10.1053/j.gastro.2011.10.001>

Murray, C.D., & Wilde, D. (2020). Thinking about, doing and writing up research using interpretative phenomenological analysis. In: Douglas, C., & Brearley, S. (Eds), *Handbook of Theory and Methods in Applied Health Research: Questions, Methods and Choices* (p. 140-166). Edward Elgar Publishing.

National Institute for Health and Care Excellence. (2014). *Inflammatory bowel disease briefing paper* [2]. <https://www.nice.org.uk/guidance/qs81/documents/inflammatory-bowel-disease-briefing-paper2>

National Institute for Health and Care Excellence. (2015). *Inflammatory bowel disease: QS81*. <https://www.nice.org.uk/guidance/qs81/chapter/quality-statement-2-multidisciplinary-team-support>.

Neuendorf, R., Harding, A., Stello, N., Hanes, D., & Wahbeh, H. (2016). Depression and anxiety in patients with inflammatory bowel disease: a systematic review. *Journal of Psychosomatic Research*, 87, 70–80. <https://doi.org/10.1016/j.jpsychores.2016.06.001>

Nicholas, D., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. (2007). Challenges and strategies of children and adolescents with inflammatory bowel disease: A qualitative examination. *Health and Quality of Life Outcomes*, 5(28), 1-8. <https://doi.org/10.1186/1477-7525-5-28>

Olendzki, B. C., Silverstein, T. D., Persuitt, G. M., Ma, Y., Baldwin, K. R., & Cave, D. (2014). An anti-inflammatory diet as treatment for inflammatory bowel disease: a case series report. *Nutrition journal*, 13(5). <https://doi.org/10.1186/1475-2891-13-5>

Opong, S. H. (2013). The Problem of Sampling in Qualitative Research. *Asian Journal of Management Sciences and Education*, 2(2), 202-210.

- Pike, K.M. (1998). Long-term course of anorexia nervosa: response, relapse, remission, and recovery. *Clinical Psychology Review, 18*, 447–475. [https://doi.org/10.1016/S0272-7358\(98\)00014-2](https://doi.org/10.1016/S0272-7358(98)00014-2)
- Power, M., & Dagleish, T. (1997). *Emotion: From order to disorder*. Psychology Press.
- Rao, T. S., Asha, M. R., Ramesh, B. N., & Rao, K. S. (2008). Understanding nutrition, depression and mental illnesses. *Indian journal of psychiatry, 50*(2), 77–82. <https://doi.org/10.4103/0019-5545.42391>
- Richard, M., Bauer, S., & Kordy, H. (2005). Relapse in anorexia and bulimia nervosa—a 2.5-year follow-up study. *European Eating Disorders Review, 13*, 180–190. <https://doi.org/10.1002/erv.638>
- Spiller, R., Aziz, Q., Creed, F., Emmanuel, A., Houghton, L., Hungin, P., Jones, R., Kumar, D., Rubin, G., Trudgill, N., & Whorwell, P. (2007). Guidelines on the irritable bowel syndrome: mechanisms and practical management. *Gut, 56*(12), 1770-1798.
- Quick, V. M., Byrd-Bredbenner, C., & Neumark-Sztainer, D. (2013). Chronic illness and disordered eating: A discussion of the literature. *Advances in Nutrition: An International Review Journal, 4*(3), 277–286. <https://doi.org/10.3945/an.112.003608>
- Quick, V. M., McWilliams, R., & Byrd-Bredbenner, C. (2012). Case–control study of disturbed eating behaviors and related psychographic characteristics in young adults with and without diet-related chronic health conditions. *Eating Behaviors, 13*(3), 207–213. <https://doi.org/10.1016/j.eatbeh.2012.02.003>
- Sharma, G. (2017). Pros and cons of different sampling techniques. *International journal of applied research, 3*(7), 749-752.
- Smith, J. A., & Osborn, M. (2003). *Interpretative Phenomenological Analysis*. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods* (pp. 53-80). Sage.

- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. SAGE.
- Tangney, J. P. (1993). *Shame and guilt*. In C. G. Costello (Ed.), *Symptoms of depression* (pp. 161–180). Wiley.
- Tangney, J. P. (1995). Recent advances in the empirical study of shame and guilt. *American Behavioral Scientist*, 38, 1132–1145.
- Torres, J., Mehandru, S., Colombel, J.F., & Peyrin-Biroulet, L. (2017). Crohn's disease. *Lancet*, 389(10080), 1741-1755.
- Treasure, J., Zipfel, S., Micali, N., Wade, T., Stice, E., Claudino, A., ... & Wentz, E. (2015). Anorexia nervosa. *Nature Reviews Disease Primers*, 1, 15074. <https://doi.org/10.1038/nrdp.2015.74>
- Van Balkom, K., Beld, M., Visschers, R., van Gemert, W., Breukink, S. (2012) Long-term results after restorative proctocolectomy with ileal pouch anal anastomosis at a young age. *Diseases of the Colon and Rectum*, 55, 939–47. <https://doi.org/10.1097/dcr.0b013e31825bd7f4>

Tables and Figures

Table 1. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<p>1) Individuals with a diagnosis of IBD who are aged 18 or over.</p> <p>2) Individuals who would describe themselves as having/having had psychological difficulties with eating but have not received a diagnosis of an ED, or individuals with a previous or current diagnosis of an ED.</p> <p>3) Individuals who currently reside in the UK to ensure similar service provision regarding IBD has been received.</p>	<p>1) Individuals with a diagnosis of IBS as this is not classified as a chronic health condition; it does not have a disease profile and does not result in the invasive treatment or surgery of IBD.</p>

Table 2. Participant Demographics

Pseudonym	Age	Gender	IBD Diagnosis	Age at IBD diagnosis	Age difficulties with eating relating to IBD started	Length of interview (hour: mins: secs)
Hayley	30	Female	Crohn's	26	27	1:26:02
Phil	27	Male	Ulcerative Colitis	24	24	0:44:12
Sarah	29	Female	Ulcerative Colitis	12	12	0:49:08
David	26	Male	Crohn's	18	18	0:47:23
Ben	19	Male	Crohn's Colitis	17	18	0:46:30
Stephen	37	Male	Crohn's	19	19	0:50:56

Table 3. Participant themes contributing to overall themes.

Participant Name	Theme 1- The need to restrict and control diet	Theme 2- Increased intrinsic and extrinsic awareness: the impact on body image.	Theme 3- Responsibility, guilt and engagement: The experience of clinical interventions.	Theme 4- Feeling helpless: nowhere to turn
Hayley	Guilt, low mood and avoidance: consequences of increased focus on food. Rules, restrictions and blurred lines: navigating the uncertain world of eating and IBD.	Increased focus on internal processes and consequent impact on visual appearance	Inconsistent support and advice from health services: the necessity to manage alone	Inconsistent support and advice from health services: the necessity to manage alone
Phil	Re-learning how to eat: restrictions and rules	Dramatic changes to physique: distaste and desire to transform Reduced awareness of the self and body: cutting off to feel safe	Triggering clinical interventions: extreme weight fluctuations and dietary changes	
Sarah	Teenage years and IBD onset: the perfect storm for eating difficulties All or nothing: complete dietary restriction or binge eating	Teenage years and IBD onset: the perfect storm for eating difficulties	Controlling diet to regain power after IBD diagnosis	Support vs lack of support: who offers it and how this variation impacts on the individuals relationship with her diet
David	The battle of self-control over dietary restrictions: the impact on mental wellbeing	Emergence of fixation over weight following IBD diagnosis Varying degrees of awareness between intrinsic and extrinsic processes	Emergence of fixation over weight following IBD diagnosis	The search for support with managing diet and IBD in lieu of this from health professionals
Ben	The desire to restrict diet to feel in control	Dramatic changes to body image: the impact on self-esteem	Dietary restrictions: the very real risk this poses to self	Feeling helpless: muddling through an unknown world of diet and IBD

Stephen	Evolving nature of food restrictions to master control over IBD symptoms	Significant weight loss: just as detrimental to mental wellbeing and bodily dissatisfaction as weight gain No respite: the relentlessness nature of thoughts and feelings related to diet	Where to turn when support from health professionals in relation to managing diet and IBD is lacking
---------	--	--	--

Appendix 2-A

Interview Schedule

Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.

This interview schedule outlines areas to be discussed in the interview with some example questions. The interview will use a narrative approach based on that set out by Anderson and Kirkpatrick (2016) and will therefore prioritise the participant's experiences. The interview will therefore start broad to try to gain the participant's story. Exact questions will depend on participants' responses and content that the individual being interviewed finds important and discusses. Below are some examples of possible questions and prompts if required. The interview schedule may be revised following the first interview if it is found that the required data is not being obtained.

Introduction

Introduce self. Cover participant information sheet, consent and purpose of interview. Check any necessary demographic information not already collected at point of consent and any changes in circumstances. Orientate participants to think about experiences IBD and ED. The interview will then begin with open questions asking the participants for their story. Following this, follow up questions will be used based on the content described by the participant. This may include questions about before, during and after the identification of an ED; some examples are outlined below.

Before identification

Example questions:

Thinking back to the time you were diagnosed with IBD, what was your relationship like with eating at this point?

What changes did you notice with your relationship with eating over time? How did this change?

What other changes did you notice aside from your relationship with eating?

During identification

Example questions:

How did the identification of difficulties with eating/ ED come about?

What differences did you first notice?

How did your experiences develop over time?

Were you able to talk to anyone about this? E.g. peers, family

In what way did/does your experience of difficulties with eating impact on your IBD?

Did you attend services? Which services? What was your experience of the meeting? Did you feel understood/ heard? Was the focus on your existing IBD or difficulties with eating? How did the service make sense of things?

After identification

Example questions:

Have you noticed any changes in your relationship with eating since this identification?

Have you noticed any changes in any other experiences since this identification?

Have you noticed any changes in the care you've received from services? And additional involvement from other services?

Conclusion

In this part of the interview the participant will be thanked for taking part. The interviewer will ensure the participant has not been distressed by the interview by asking how the participant feels. If necessary, participants will be directed to sources of support on the participant information sheet.

Appendix 2-B

Example Transcript with coding

Line	Transcript	Coding
96	R:...can you think what your relationship was like with eating at that point?	
97	P: I think I was just about getting to the age where I started	IBD started at an age when I recognised what I ate impacted on how my body felt and looked
98	To realise that what I ate had an impact On how my body felt and how my body looked	
99	R: okay	
100	P: Um, I'm at that age where everyone is particularly self	As a teenager I was self-conscious about body image and appearance
101	conscious about what Things sort of represent them So I was starting to develop a relationship With my body image and my appearance And being a teenager...	
102		
103	R: mm-hmmm	
104	P: ...and Perhaps not a particularly lean and fit one at that	
105	R: okay	
106	P: Um, and Became very very ill very suddenly when I was diagnosed And so actually ended up taking a lot Of	
107	steroids initially for quite a long time	
108	R: mmm-hmm	
109	P: And because I was a little bit perhaps too young to understand That steroids can cause you to swell up a little	Too young to understand that steroids make you swell and gain weight, so I focused on what I was eating rather than things that were out of my control
110	bit And to gain weight ...	
111	R: Yeah	
112	P: ...my focus was very much on what I was eating Rather than factors outside of my control. Really sorry about the	
113	cat	
114	R: it's OK it's OK. OK so you notice around sort of A similar time	
115	P: yeah	
116	R: Yeah okay	
117	P: It all came together in a big Perfect storm	IBD and age of onset were perfect storm for eating difficulties
118		
119		

Appendix 2-C

Example of Analysis for One participant

THEME	POST IT SUMMARIES	SUMMARY PARAGRAPH	QUOTES
Increased focus on internal processes and consequent impact on visual appearance	<p>Feeling bloated or experiencing digestive problems causes feelings of panic which makes her restrict diet - Pg 15, line 254</p> <p>Can fall into a restrict cycle when I feel bloated, but able to recognise more now that the bloating is due to IBD rather than weight gain, which helps- Pg 35, line 612</p> <p>Feels uncomfortable when she overeats- Pg 17, line 288</p> <p>Feels more anxious when not in a routine because she gets bloated and worries what people will say if they've previously noticed she's lost weight because of her IBD- Pg 18, line 305</p> <p>Body anxiety is related to how food makes me feel, like bloated stomach - Pg 33, line 588</p> <p>I think gluten makes me feel bloated, which makes me feel uncomfortable for example in certain clothes, like it does when you put weight on - Pg 34, line 602</p> <p>Feel more confident in my body when I've got a routine- Pg 39, line 685</p>	<p>Difficulties with eating also appear to stem from physical experiences which occur as a result of IBD. Participants find themselves scanning their bodies for physical symptoms of their IBD, one of which is bloating. As a result, they are more likely to notice when they feel bloated than an individual who does not experience IBD. This feeling of being bloated can then cause feelings of panic which appears to be related to body image, and how being bloated will make them look and also feel in their clothing. Participant's report worrying about having put on weight, or others perceiving that they have put on weight. This preoccupation with weight is likely to be precipitated by the extreme fluctuations in weight individuals with IBD experience;</p>	<p>if I start feeling like just bloated or digestive or, then I panic and then I think I don't know what it is that's causing it but it might be this, it might be that so then I just strip everything back that I added to it and then I feel like I'm back at square one again and then, yeah</p> <p>I did fall in like for a day like fall in the restrict cycle but then that's literally going to lead to like a restrict binge cycle that's literally pointless</p> <p>it feels really uncomfortable [if I overeat]</p> <p>when I get out of my routine that's when my body anxiety goes up a lot like higher because you're not eating such good food so you more likely to bloat in your face and bloat you out and if you have lost</p>

Focus on and aware of being bloated- Pg 34, line 596

the symptoms of the illness, such as frequent visits to the toilet, often result in weight loss, whilst certain medical treatments can result in weight gain. Participant one noted how others will voice when they notice that she has lost or gained weight, which she reports finding uncomfortable.

Consequently, participants report restricting their diet in order to manage bloating. They may also experience a preoccupation with thinking about what they have eaten which may have triggered this bloating. Again, a preoccupation with body scanning as well as recurring thoughts about food and the impact this has on the physical appearance of the body is an experience those with eating disorders experience.

weight previously like in relation to like you're just being like quite routine with just what you eating because you want to keep on the good tracks with your IBD like if people comment on like your weight loss and then it just really triggering it just throws me in the opposite direction for some reason I don't know why but

body anxiety is more results of the foods choices whether up or down like how that then effects like your body like is like if my stomach is bloated or

I think it's probably gluten I don't know but I'm quite highly certain cause it wasn't released in gluten before that and that leads to bloating so then like there's just I don't I don't feel that comfortable while probably like if somebody gains weight they aren't comfortable with it or comfortable in clothes sometimes that would like show your body shape or like those kind of things

I'd say I feel more confident and in like my body like like I'm fine with the other isn't a focus like oh it's like yeah like I'm more confident in my body because I know I'm fine like I've got a routine

bloating that's what yeah yeah there's definitely an awareness and focusing on that

Appendix 2-D

Author Guidelines

United European Gastroenterology Journal

Author guidelines

Aims and Scope

Providing an international forum for research in gastroenterology, United European Gastroenterology Journal (UEG Journal) publishes original peer reviewed articles which describe basic research, translational and clinical studies of interest to gastroenterologists and researchers in related fields.

Articles from across all fields of gastroenterology are welcomed by the Editors, including luminal, liver and pancreatic diseases, endoscopy, gastrointestinal surgery, digestive oncology, as well as paediatric gastroenterology and nutrition. Published article types include original research, reviews, guidelines papers, and news items related to United European Gastroenterology.

Manuscript Submission

Open Access and Article Publication Charges

As of January 2021, UEG Journal is a fully open access journal. Please visit this page to review the Article Publication Charges (APC).

Submission and Peer Review Process

Manuscripts should be submitted online at <http://mc.manuscriptcentral.com/UEGJ>.

For help with submissions, please contact: uegjournal@wiley.com.

Article Preparation Support

Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design, so you can submit your manuscript with confidence.

Also, check out our resources for Preparing Your Article for general guidance about writing and preparing your manuscript.

Free format submission

UEG Journal offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files—whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at <https://orcid.org>. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
 - Your co-author details, including affiliation and email address. (Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)
 - Statements relating to our ethics and integrity policies, which may include any of the following (Why are these important? We need to uphold rigorous ethical standards for the research we consider for publication):
 - data availability statement
 - funding statement
 - conflict of interest disclosure
 - ethics approval statement
 - patient consent statement
 - permission to reproduce material from other sources
 - clinical trial registration

To submit, login at <http://mc.manuscriptcentral.com/UEGJ> and create a new submission. Follow the submission steps as required and submit the manuscript.

Article Types

Original Research Papers

Original research papers should be no more than 3,000 words (excluding abstract, keywords, references, figures and table legends only, and the title page elements – including acknowledgement, COI and funding statements) and contain the following sections: Title page, Abstract, Introduction, Materials and Methods, Results, Discussion, Acknowledgements, References, Tables, Figures, and Figure legends.

The journal publishes a Key Summary alongside original research papers. The two points below require concise responses, presented in bullet points within the manuscript file

between the Abstract and the Introduction. Please use a maximum of four bullet points to each response.

Summarize the established knowledge on this subject

What are the significant and/or new findings of this study?

Review Papers

Review papers focus on specific subjects of current interest where there have been recent and significant advances, ranging from basic neuroscience to clinical and more ‘applied’ areas. They are short, factual, focused updates, comprising: Title page, an unstructured Abstract of 100-150 words, 5 or so Keywords, 2,500 words of text (excluding references), a limited number of relevant and recent references (up to 35 or so), and an illustrative figure if appropriate.

Guidelines

UEG Journal publishes guidelines commissioned by UEG and groups under the UEG umbrella.

Overview of the requirements for manuscript submissions to United European Gastroenterology Journal:

Article Type	Abstract Word Limit	Main Text Word Limit	References	Figures/Tables
Original Research Papers	300	3,000	Up to 35	Up to 7
Review Papers	100-150	2,500	Up to 50	Up to 5

* Excludes references, tables and legends

Visual Abstracts

At the revision stage, visual abstracts will be developed by a journal illustrator for all Original Articles and Reviews. You will be asked to review and approve a visual abstract for your paper prior to export to production. Should you wish to submit a visual abstract with your paper, please use this template.

Statements, Permissions and Signatures

Preprint policy

UEG Journal will consider for review articles previously available as preprints. You are requested to update any pre-publication versions with a link to the final published article. You may also post the final published version of the article immediately after publication.

Registered Reports

See the Registered Reports Author Guidelines for full details.

Data Sharing and Data Availability

UEG Journal expects data sharing. Review Wiley's Data Sharing policy where you will be able to see and select the data availability statement that is right for your submission.

Data Citation

Please review Wiley's Data Citation policy.

Data Protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication. Please review Wiley's Data Protection Policy to learn more.

Funding

You should list all funding sources in the Acknowledgments section. You are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature.

Authorship

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

- Make a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data
- Drafted the article or revised it critically for important intellectual content
- Approved the version to be published

Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicenter group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be listed in the Acknowledgments section. Please refer to the International Committee of Medical Journal Editors (ICMJE) authorship guidelines for more information on authorship.

In accordance with Wiley's Best Practice Guidelines on Research Integrity and Publishing Ethics and the Committee on Publication Ethics' guidance, UEG Journal will allow authors to correct authorship on a submitted, accepted, or published article if a valid reason exists to do so. All authors – including those to be added or removed – must agree to any proposed change. To request a change to the author list, please complete the Request for Changes to a Journal Article Author List Form and contact either the journal's editorial or production office, depending on the status of the article. Authorship changes will not be considered without a fully completed Author Change form.

Note that correcting the authorship is different from changing an author's name; the relevant policy for that can be found in Wiley's Best Practice Guidelines under "Author name changes after publication".

ORCID

This journal requires ORCID. Please refer to Wiley's resources on ORCID.

Manuscript Structure

Title Page

The title page should contain:

- A brief informative title containing the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
- A short running title of less than 40 characters;
- The full names of the authors;
- The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;

- Sources of funding, if any;
- Acknowledgments.

Main Text File

Abstract

The second page of the manuscript must contain only the abstract, which should be of no more than 300 words for original research papers, 150 for review papers, and 500 for guidelines papers. Your abstract must be clearly written and comprehensive to readers before they have to read the paper. An overview of the requirements for various article types can be found here.

The abstract should be structured according to the following subheadings: Background, Objective, Methods, Results and Conclusion. Abbreviations should be avoided, and reference citations are not permitted. See Wiley's guidance on writing for SEO here.

Any manuscripts submitted without a structured abstract will be returned to the author immediately without peer review, thus delaying the evaluation process of the manuscript.

Introduction

The introduction should assume that the reader is knowledgeable in the field and be as brief as possible.

Materials and Methods

Methods that have been published in detail elsewhere should not be described in detail. Avoid unnecessary detailed descriptions of widely used techniques. SI Units should be used throughout the text. Reports of experiments involving patients and healthy volunteers must describe the steps taken to obtain consent and to maintain confidentiality. Experiments involving animals must conform to accepted ethical standards.

Tables

Tables should be submitted in Word, typed on separate pages. Tables should be numbered consecutively with Arabic numerals and cited as such in the manuscript. The preferred placing of tables in the main text should be indicated. Tables should include a brief descriptive title and be self-explanatory. Footnotes to tables indicated by lower-case superscript letters are acceptable, but they should not include extensive experimental details.

Figures

Please review the basic figure requirements for manuscripts for peer review, as well as the more detailed post-acceptance figure requirements.

Figures should be supplied as separate files. All figures should be numbered using Arabic numerals and referred to in the text as Figure 1, etc. Please indicate the preferred placing of the figure in the main text. Symbols and keys should be given as a key on the figure, not in the legend. Magnification should be indicated by a scale bar on the photograph, not as a magnification factor in the legend.

Units, Symbols and Abbreviations

For detailed advice please refer to the guidelines in Baron, DN (1988). Units, symbols and abbreviations, 4th edn. (Obtainable from The Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE, UK). Note that the SI system of units is preferred. Because of the multidisciplinary nature of the readership and to avoid confusion, the number of abbreviations in the text should be kept to a minimum. Standard abbreviations acceptable without definition are limited to the following: CNS (central nervous system); CSF (cerebrospinal fluid); DNA (deoxyribonucleic acid); HLA (human leukocyte antigen; MRI (magnetic resonance imaging); CT (computerized tomography); UEGJ (United European Gastroenterology Journal); RNA (ribonucleic acid). Non-standard definitions must be defined in full at their first usage in the abstract and again at their first use in the text.

Supplemental material and Supporting Information

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc.) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplemental files. View Wiley's FAQs on supporting information.

Reference style

UEG Journal adheres to the Wiley Vancouver reference style. View the Wiley Vancouver guidelines to ensure your manuscript conforms to this reference style.

Peer Review

This journal operates under a single-blind peer review model. Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements.

In-house submissions, i.e. papers authored by Editors or Editorial Board members of the title, will be sent to Editors unaffiliated with the author or institution and monitored carefully to ensure there is no peer review bias.

Wiley's policy on the confidentiality of the review process is available [here](#).

As part of the submission process you will be asked to provide the names of two peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission
- The reviewer should not have recently collaborated with any of the authors
- Reviewer nominees from the same institution as any of the authors are not permitted

You will also be asked to nominate peers who you do not wish to review your manuscript (opposed reviewers).

Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

UEG Journal is committed to delivering high quality, fast peer-review for your paper, and as such has partnered with Publons. Publons is a third-party service that seeks to track, verify and give credit for peer review. Reviewers for United European Gastroenterology Journal can opt in to Publons in order to claim their reviews or have them automatically verified and added to their reviewer profile. Reviewers claiming credit for their review will be associated with the relevant journal, but the article name, reviewer's decision and the content of their review is not published on the site.

Search Engine Optimization

Search Engine Optimization is important to the discoverability of your article. UEG Journal has provided examples of articles that are fully optimized for SEO and those that are not. You can review them here.

Ethical Guidelines

Guidelines on Publishing and Research Ethics in Journal Articles

The journal requires that you include in the manuscript details IRB approvals, ethical treatment of human and animal research participants, and gathering of informed consent, as appropriate. You will be expected to declare all conflicts of interest, or none, on submission. Please review Wiley's policies surrounding human studies, animal studies, clinical trial registration, biosecurity, and research reporting guidelines.

It is the policy of United European Gastroenterology Journal to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

This journal follows the core practices of the Committee on Publication Ethics (COPE) and handles cases of research and publication misconduct accordingly (<https://publicationethics.org/core-practices>).

This journal uses iThenticate's CrossCheck software to detect instances of overlapping and similar text in submitted manuscripts. Where an article, for example, is found to have plagiarized other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve

the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

Research Ethics and Patient Consent

Manuscripts reporting data from research conducted on humans must include a statement of assurance in the methods section of the manuscript conforming to all four of the below points

- The study was approved by the ethical review board
- Name and date approval granted by the ethical board are included in the manuscript
- Written, informed consent was obtained from each patient included in the study
- The study protocol conforms to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in a priori approval by the institution's human research committee

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

All research involving animals submitted for publication must be approved by an ethics committee with oversight of the facility in which the studies were conducted. The journal has adopted the Consensus Author Guidelines on Animal Ethics and Welfare for Veterinary Journals published by the International Association of Veterinary Editors.

Clinical trials

The International Committee of Medical Journal Editors (ICMJE, <http://www.icmje.org/>) defines a clinical trial as any research project that prospectively assigns human participants to intervention or comparison groups to study the cause-and-effect relationship between an intervention and a health outcome. Interventions include but are not limited to drugs, surgical procedures, devices, behavioral treatments, process-of-care changes, and the like. All manuscripts reporting clinical trials must include a copy of the trial protocol including the complete statistical analysis plan (if the manuscript is accepted, the protocol will be published as an online supplement), a flow diagram (CONSORT flow diagram), and a completed trial checklist (the CONSORT checklist and template flow diagram can be found at <http://www.consort-statement.org/>). The trial registration number must be included at the end of the abstract and on the title page of the manuscript reporting a registered clinical trial.

Registration in a public trials registry is a condition for publication of clinical trials in UEG Journal in accordance with International Committee of Medical Journal Editors (ICMJE, <http://www.icmje.org/>) recommendations.

Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives.

After Acceptance

First Look

After your paper is accepted, your files will be assessed by the editorial office to ensure they are ready for production. You may be contacted if any updates or final files are required.

Otherwise, your paper will be sent to the production team.

Wiley Author Services

When an accepted article is received by Wiley's production team, the corresponding author will receive an email asking them to login or register with Wiley Author Services. You will be asked to sign a publication license at this point as well as pay for any applicable APCs.

Copyright & Licensing

UEG Journal is an Open Access journal: authors of accepted papers pay an Article Publication Charge and their papers are published under a Creative Commons license. This journal uses a CC-BY-NC-ND Creative Commons License. UEG offers CC BY and other licenses as mandated by certain funders; more information can be found here.

Information on the Article Publication Charges for publishing in UEG Journal is available here.

If a paper is accepted for publication, the author identified as the formal corresponding author will receive an email prompting them to login to Author Services, where via the Wiley Author Licensing Service (WALS), they will be able to complete the license agreement on behalf of all authors on the paper.

Proofs

Authors will receive an e-mail notification with a link and instructions for accessing HTML page proofs online. Authors should also make sure that any renumbered tables, figures, or references match text citations and that figure legends correspond with text citations and actual figures. Proofs must be returned within 48 hours of receipt of the email.

Appealing the publication decision

Editors have very broad discretion in determining whether an article is an appropriate fit for their journal. Many manuscripts are declined with a very general statement of the rejection decision. These decisions are generally not eligible for formal appeal unless the author provides strong evidence or new data that can respond to and alleviate the concerns of the editor and reviewers. The author may appeal the decision by providing the Editor with a detailed written description, strong evidence, or new data they believe have emerged. UEG journal will respond to a formal appeal and investigate whether key aspects of the submitted work have been overlooked or new arguments have come to light in the initial review phase.

If an author believes the decision regarding their manuscript was affected by a publication ethics breach, the author may contact the publisher with a detailed written description of their concern, and information supporting the concern, at uegjournal@wiley.com

Section 3 Critical Appraisal

Emma Mellor

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

Emma Mellor

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA14AT

Email: e.mellor@lancaster.ac.uk

Critical Appraisal

In this critical appraisal I will seek to summarise findings of the research and provide a more detailed explanation of how its conceptualisation occurred, with an emphasis on my own experience of Inflammatory Bowel Disease (IBD). My epistemological position will also be addressed, thinking about how this has interacted with my personal experience of the research topic. Finally, limitations of the research will be discussed further to pinpoint how future research can enhance current findings from this research.

Summary of Research

To explore how individuals with IBD recount their experience of difficulties with eating, semi-structured interviews were carried out with six participants. IPA was used to analyse transcripts, which revealed four themes; (1) The need to restrict and control diet; (2) Increased intrinsic and extrinsic awareness: the impact on body image; (3) Responsibility, guilt and engagement: the experience of clinical interventions; (4) Feeling helpless: nowhere to turn. This is the first study to use qualitative research methods to explore how difficulties with eating arise and are sustained within this population.

In the systemic literature review, I investigated how social support helps individuals with IBD to cope with their illness, and identified three major themes, with related subthemes; (1) Supportive peers, which emphasises how those around individuals with IBD help them to cope, namely through methods identified as subthemes which are (a) understanding, (b) recognition, (c) teamwork, and (d) presence; (2) Shared experiences, within which other individuals who also have IBD help those with IBD to cope, of which the identified subthemes were (a) advice taking and (b) advice giving; and (3) Openness, whereby the degree of which individuals with IBD are open with others impacts on their ability to cope with IBD, for which the identified subthemes were (a) reducing isolation, (b) stigma and (c) being a burden.

The findings from both papers highlighted the importance of the individual's system in coping with different challenges of having a lifelong health condition such as IBD; the literature review placed emphasis on the social system, whilst the empirical paper demonstrated the importance on healthcare professionals as a clinical system. Both studies emphasised the psychological implications a lack of support for IBD can have and point to clinical implications for healthcare professionals working with these individuals to be flexible and creative in the type of support they are offering and encourage the use of psychological provision to enhance this support where needed.

Reflections on the empirical paper

Recruitment

In a review of my proposed project by the Lancaster DCLinPsy Programme Research Team, I was advised to recruit individuals with IBD who have a pre-existing diagnosis of an ED (see initial ethics application in appendix 3-A). Unfortunately, this did not result in successful recruitment of any participants within a six-month period. Consequently, in a discussion with my research supervisor, I explained it was possible that challenges with recruitment were due to there being a sparsity of individuals with IBD who have received a diagnosis of an ED because of the lack of recognition or support these individuals get for their difficulties, which was a large part of the premise of the research. Thus, I amended my ethics application to allow me to recruit individuals with IBD who recognised that they had difficulties with eating, but whom might not have received a diagnosis of an ED. This resulted in a total of 43 participants volunteering to participate in the study within a six-month period. This may be of significance for individuals wishing to carry out future research in this area when determining an appropriate and effective recruitment strategy.

Reflexivity

Reflexivity is the concept that research will be influenced by the researcher's pre-existing ideas and experiences, which will inevitably impact on the findings. It is therefore important to acknowledge the potential impact of the researcher, whose position cannot remain neutral, particularly within qualitative research such as IPA (Palaganas et al., 2017). In line with this notion, it is important to discuss here how I generated the research topic. I was diagnosed with Ulcerative Colitis (UC) at the age of 18 and, over the course of the last ten years, I began to recognise how my thoughts had become dominated by food and meal planning in order to control how my body was going to feel physically. For example, I was keen to avoid feeling bloated, a sensation which I found was distorting my body image, as I was associating this with being overweight or out of shape. As a result, I began using an app to track my food, with a focus on macronutrient content, and would also attend the gym up to six times a week. Whilst I couldn't say that this was solely triggered by my experience of IBD, when I reflected on my journey, I was able to identify that my preoccupation and knowledge of food content to this extent began when I started trialling a FODMAP diet, a diet designed to reduce consumption of nondigestible carbohydrates to help control symptoms such as bloating, abdominal discomfort and altered bowel movement. Thus, akin to participants within this study, my own interests of fitness and body image goals merged with having a body that wouldn't always align with how I wanted it to look due to having IBD, which resulted in an escalation of restricting behaviours. There were also other experiences, such as having to be weighed by my IBD team, which I recognised as triggering difficulties with eating, as I found I would be keen for my weight to have decreased in between appointments.

I began to wonder if this experience was shared by other people and consequently joined the Crohn's and Colitis Forum on social media. At this point I discovered there were lots of threads with people discussing such difficulties and highlighting how these were impacting on their mental health, particularly because they felt alone in this journey with little

help from health care professionals in regard to diet. Many cited that they were being wrongly accused of having EDs, such as anorexia nervosa, which they did not feel represented their experience. Thus, when I was accepted onto the Lancaster Doctorate in Clinical Psychology (DClinPsy) training programme, I was keen to explore this further and give these individuals a platform to be heard on and have their experience explained sufficiently. A review of the literature carried out by myself as part of an assignment at the beginning of my training highlighted how previous research had specifically suggested a qualitative study which explored this experience of individuals with IBD was needed, and consequently, this journey seemed to fall perfectly into place.

However, due to my own investment and personal experience to the research topic, I had to be very much aware of my position of reflexivity throughout the study. Consequently, it was necessary to develop a semi-structured interview schedule and have this examined by experts by experience in order to ascertain that I was allowing for all elements of participants' experience to be captured, rather than those just in line with my own.

Furthermore, during the analysis of transcriptions, attempts were made to bracket my own beliefs and assumptions in order to be able to successfully capture the experience of participants, which can serve to enhance the validity of qualitative phenomenological research (Chan et al., 2013; Wall et al., 2004). However, it is likely that some of my own beliefs regarding the phenomenon lie unconsciously, therefore making it difficult to bracket away all of my existing biases or knowledge from the data. Consequently, I was mindful throughout that my own experience of IBD likely influenced my interpretation of the data. The hermeneutic nature of IPA endorses researcher reflexivity to facilitate interpretations of both the researcher's experience and the researched phenomenon (Shaw, 2010). Johnson (2009) states that as researchers are not without their own experience, bias, or assumptions, the use of reflection to evaluate the role of the researcher's own thoughts and feelings in qualitative

research assists to reduce the risk of misinterpreting the data. Despite this, the raw data has been re-visited several times to ensure the findings sit within participants' experiences.

Managing risk: My skills as a trainee clinical psychologist

Throughout the research process, I noticed my clinical skills as a trainee clinical psychologist (TCP) supported me in several ways. Firstly, drawing on person-centred skills such as summarising, paraphrasing and reflecting, as well as asking open-questions as part of the interview, enabled an authentic and mutually respectful relationship with participants (Sandvik & McCormack, 2018), which helped participants to feel comfortable sharing their experiences. This was particularly demonstrated when one participant shared information pertinent to risk; he disclosed that on some occasions he restricts his eating to the extent that he feels dizzy, and on one occasion fainted whilst with friends in his bedroom. At this moment, skills developed as a TCP were necessary to assess the level of risk that feeling dizzy and fainting could potentially cause for this participant, by ascertaining the level of severity and likelihood of this occurring again, as outlined by the Historical Clinical Risk Management-20 tool (HCR-20; Douglas et al., 2014). Having worked in forensic services for two years prior to starting my DClInPsy training, as well as carrying out a specialist placement in forensic services, I felt confident in being able to assess this risk and voice my concerns with the participant. This involved detailing how he could be in danger of causing harm to himself, for instance if he experienced an episode of fainting whilst in the gym. After this conversation, the participant stated that being able to voice his eating habits and his restrictive behaviours with myself for the first time had allowed him to recognise that what he was doing was actually harmful, and it had encouraged him to think about what he needs to do to change it. He stated that he would raise this during his next consultation with his IBD team, which was due in the following two weeks. Due to no current risk being present with the episode of fainting having occurred only on one occasion, several years ago, I felt comfortable with this arrangement.

Despite this, I documented my concerns in my reflective journal (appendix 1) and shared this with my research tutor.

Reflections on the literature review

Investigating the levels of social support individuals with IBD receive, and how this affects their ability to cope with the illness, appealed to me due to my own personal experience of support. I believe that I have been able to cope with the emotional impact of being diagnosed with a lifelong chronic health condition due to the approach my family and friends have adopted. There has never been a taboo culture to discussing bowel movements within my family, which I feel has allowed me to discuss my concerns and openly voice when I am experiencing difficulties. Prior to carrying out this review, I had begun to wonder what the impact of not being able to do this with those around you could have. This became apparent for participants in Ruan and Zhou's (2019) study, who described the psychological impact of not being able to be open with those around you due to cultural issues of bowel problems being taboo (Bischoff, 2011), alongside the notion of your worth being defined by what those around you think of you (Kim & Cohen, 2010).

The process of carrying out the literature review was separated by myself having a year off work to have a baby. Whilst this was undeniably wonderful, and I am so grateful for being able to have a little boy, and experience the joy he brings, it did bring about some challenges to carrying out the review. Prior to starting my maternity leave, I had reached the stage of having identified papers to include in the review. However, when I returned from maternity leave, my research supervisor suggested changes to enhance the SPIDER search. When I ran this search again, it understandably produced a new set of papers, and given the time which had lapsed between running the searches, I could not find a method I could be confident in which would decipher which papers had been newly identified. Thus, it was necessary to begin

the process of removing papers again. This experience, coupled with having written my introduction and methods section prior to maternity leave, and my results and discussion section after, has made it challenging to immerse myself in the data to the same extent as I was able to for my empirical paper. Having said that, it is also likely that this experience is akin to that of a lot of researchers, given that data collected for the empirical paper is collected by the researcher themselves.

Reflections on Epistemological Stance

A social constructionist stance was adopted for both the literature review and empirical paper, whilst drawing on ideas of critical realism often adopted in IPA, which Burr (2003) highlights encourages a greater emphasis on acknowledging that a reality exists within the physical and social world. This meant recognising that the findings would be impacted upon by my preconceived ideas and biases as described above but acknowledging and being open about this because it is not possible to prevent this from happening. Moreover, this is a phenomenon which occurs for all human beings, thus we all make sense of the world from our own viewpoint. Therefore, an objective truth cannot be found. IPA acknowledges this as the 'double hermeneutic' process which suggests the researcher's subjectivity and personal views and experiences have a fundamental role in shaping the data collection and analysis processes (Smith et al., 2009). Consequently, throughout the research I was aware of my own experience as an individual with IBD and how that will have influenced my interpretations of the data as a researcher.

A reflective diary was held throughout the research process to acknowledge my biases and their potential impact on the analysis of the data (Smith et al., 2009), thus assisting with the credibility and integrity of the findings of the study (Noble & Smith, 2015). It was particularly beneficial to have the reflective diary open to make notes during or after the

interviews in order to capture the specific thoughts and feelings participants were eliciting for me. This was particularly pertinent at times when I was unwell as a result of IBD myself; during the write up of the empirical paper, I had quite a significant flare up, which required steroid medication to control it. As the excerpt from my reflective diary found in appendix 2 highlights, I found carrying out research at this time difficult, firstly, due to the physical difficulties IBD brings with it, such as extreme exhaustion, but secondly because it was challenging hearing about other people's difficult experiences when I was struggling myself.

Limitations

Coronavirus

It is important to note that this research was for the most part carried out within the global pandemic, resulting in the necessity for interviews to be carried out either virtually via Skype, or over the telephone. It is unclear whether this impacted on the interviews and the quality of the data that was collected, however I noticed that at times I found it difficult not being face to face with participants. It is likely this experience was accentuated by my role as a trainee clinical psychologist, as both a researcher and a therapist; some overlap between these positions was recognised during the interviews, particularly concerning the use of common factors (Norcross & Lambert, 2019), such as nodding and providing reflections frequently in order to develop rapport. The pull to draw on therapy skills such as these was particularly felt when participants were experiencing some degree of emotional distress, as with the interviews being held virtually, it was much harder to provide comfort to them. In a study which explored the impact of COVID-19 on ED treatment, a theme of detached connection was identified (Vuillier et al., 2021); participants voiced how online treatment resulted in them not feeling connected to the therapist, whilst elements such as artificial screen backgrounds made the experience feel unprofessional. Whilst these findings are pertinent to my own experience of

carrying out research interviews virtually, and the overlap with therapy skills, they are also pertinent to findings from my empirical paper. In Vuillier et al.'s (2021) study, participants also identified how online treatment introduced a barrier to disclosure, for example in regard to providing accurate weight measurements. This finding corresponds to the theme of "Responsibility, guilt and engagement: The experience of clinical interventions" identified in my empirical paper, where some participants highlighted that telephone consultations facilitated them to be able to not cause concern with health professionals, as they were not able to observe their weight loss.

That being said, it is likely geographical limitations would have resulted in some interviews being held virtually despite the pandemic. For some participants in Vuilliers et al.'s (2021) study, the ease of access to online sessions in fact increased their engagement, as it reduced lengthy travel times, thus it is possible more participants volunteered to participate in the present study for the same reason. Prior to commencing my maternity leave, the study was advertised on the Crohn's and Colitis UK research website from January to July 2020, and interviews were offered as both face to face or virtually (via skype or telephone), yet no participants volunteered at this time. However, upon returning to work in August 2021 and recommencing recruitment via the same means, with the exception of interviews being solely offered as virtual, a total of 43 participants contacted myself in a six-month period. Although the adaptation to the recruitment strategy is likely to be predominantly responsible for this increase in recruitment, it is also possible that following the dramatic growth in the use of online platforms to engage with others and remain connected, this resulted in more individuals feeling comfortable to volunteer to participate in the study who otherwise wouldn't have been able to due to geographical distance. This is again in line with Vuillier et al.'s (2021) findings which suggested online treatment removed some degree of anxiety experienced from attending

face to face sessions, such as sessions feeling like less of a commitment, which consequently enabled participants to seek help to a greater extent.

Participant Demographics

Participant demographics relating to race and culture were unfortunately not collected, which in hindsight would have been useful data to obtain in order to ascertain if differences exist in the experience of individuals with IBD amongst different races and cultures. For example, it is possible that the cultural relationship to diet and food could have had an impact on how the individuals recounted their experience of IBD and difficulties with eating. One participant did however inform me that he was not originally from England, but moved here during high school, and noticed how his relationship with food changed at this point, including the types of foods that he would eat. Yet given that data pertaining to this was not obtained from all participants, conclusions cannot be drawn from this. Future research should seek to gather this data, to ascertain to what extent differences exist for individuals with IBD who experience difficulties with eating, particularly in light of the findings from the literature review which highlighted how race differences existed in regard to what type of support was found beneficial.

Demographics relating to what eating disorder (ED) participants could identify with were collected however, following advice from the university research team. However, on reflection, during the interviews this felt like a difficult conversation to have with participants, as many had not thought about their difficulties with eating in line with an ED. For that reason, the researcher chose not to include these details in the patient demographic table, as they did not feel truly representative of the participants' experiences. Interestingly, those that were able to more easily identify an ED in line with their experience were the two female participants.

These participants generally had more vocabulary relating to EDs, and their discussion of their experience came more readily.

In comparison, male participants appeared to need more time to get used to talking about their experience of difficulties with eating. This could be representative of the gender culture bias which exists within the ED population; there is consensus within the ED literature that males with EDs are underreported and underdiagnosed (Murray et al., 2017). Research suggests males find it more difficult to disclose EDs due to the impact this could have on their masculine identity (Robinson et al., 2013). Therefore, the lack of vocabulary male participants had for EDs perhaps reflects an absence of discussion surrounding EDs for males. Despite this, there were a greater number of male participants in the current study, although there was a small sample size of six participants.

Final reflections

I have learnt a vast amount about the process of carrying out qualitative research, having only previously carried out a piece of quantitative research for the purpose of my undergraduate psychology degree. It was a big leap to go on to complete research for the purpose of a doctorate qualification and felt daunting at first. Despite this, I have found I really enjoy carrying out research when I have dedicated time to do this, particularly getting the opportunity to speak to individuals who I would have otherwise never made contact and giving them a platform from which to voice their experiences. Whilst I acknowledge that there is not one diet that will suit all individuals with IBD, I do not feel that it is acceptable to continue to use this as an excuse to not provide support pertaining to managing diet. This research has highlighted the detrimental impact not having this support can have.

I have also learned a lot about myself, and what I am capable of achieving. Returning to work after having had a baby in a global pandemic felt extremely overwhelming, with new

challenges to overcome on top of those that already exist with the completion of the DClinPsy programme, which prior to having a baby felt like the most important thing. In the first instance I had to navigate feelings of guilt for what felt like abandoning my baby boy; we had spent so much time together within a lock down situation that I wasn't sure how he was going to manage without me, or me without him. On top of that, he was still breastfeeding regularly throughout the day, and so a further challenge presented itself as to how he was going to feed, and what he was going to eat, being a very fussy baby with solid food. As he grew older and my necessity to work from home due to taking my study block and not being able to attend placement due to taking immunosuppressants amidst the pandemic increased, new hurdles to overcome presented themselves. His awareness of me being in the house sometimes made it difficult for me to work without being disturbed, but I soon learned how to work efficiently when he wasn't there, despite him not sleeping through the night until he reached seventeen months old. Overall however, this experience has taught me to value every bit of time we get together, for every moment is so precious, and they change so quickly. It has also taught me that aside from being a mum, I value myself as a professional working female, and that both of these things now represent my identity.

Participants will be offered a summary of the findings upon completion of the thesis, which they expressed an interest in receiving. I also plan to share the findings with the Crohn's and Colitis Research UK charity that supported the recruitment of participants for the study, and to present the findings to Trainee Clinical Psychologists and staff of the DClin Programme at Lancaster University. The two papers will also be prepared for submission to the IBD journal to be accessible to a wider audience.

References

- Bischoff, S.C. (2011). 'Gut health': a new objective in medicine? *BMC Medicine*, 4(9), 24.
<https://doi.org/10.1186/1741-7015-9-24>
- Burr, V. (2003). *Social Constructionism* (2nd ed.). Routledge.
<https://doi.org/10.4324/9780203694992>
- Chan, Z. C., Fung, Y.-l., & Chien, W.-t. (2013). Bracketing in Phenomenology: Only Undertaken in The Data Collection and Analysis Process. *The Qualitative Report*, 18(30), 1-9. <https://doi.org/10.46743/2160-3715/2013.1486>
- Douglas, K. S., Hart, S. D., Webster, C. D., Belfrage, H., Guy, L. S., & Wilson, C. M. (2014). Historical-clinical-risk management-20, version 3 (HCR-20V3): development and overview. *International Journal of forensic mental health*, 13(2), 93-108.
- Johnson, N. (2009). The Role of Self and Emotion within Qualitative Sensitive Research: A Reflective Account. *ENQUIRE*, 2, (2), 191-214.
- Kim Y-H, & Cohen D. (2010). Information, Perspective, and Judgments About the Self in Face and Dignity Cultures. *Personality and Social Psychology Bulletin*, 36(4), 537-550.
<https://doi.org/10.1177/0146167210362398>
- , Blashill AJ, Mond JM.
- Murray, S.B., Nagata, J.M., Griffiths, S., Calzo, J.P., Brown, T.A., Mitchison, D Blashill, A.J., & Mond, J.M. (2017). The enigma of male eating disorders: A critical review and synthesis. *Clinical Psychology Review*, 57, 1-11. <https://doi.org/10.1016/j.cpr.2017.08.001>
- Noble, H., & Smith, J. (2015). Issues of Validity and Reliability in Qualitative Research. *Evidence Based Nursing*, 18(2), 34. <https://doi.org/10.1136/eb-2015-102054>
- Norcross, J. C., & Lambert, M. J. (Eds.). (2019). *Psychotherapy relationships that work evidence-based therapist contributions (3rd ed.)*. Oxford University Press.
<https://doi.org/10.1093/med-psych/9780190843953.001.0001>

- Palaganas, E. C., Sanchez, M. C., Molintas, V. P., & Caricativo, R. D. (2017). Reflexivity in qualitative research: A journey of learning. *Qualitative Report*, 22(2).
- Robinson, K.J., Mountford, V.A, & Sperlinger, D.J. (2013). Being men with eating disorders: Perspectives of male eating disorder service-users. *Journal of Health Psychology*, 18(2), 176-186. <https://doi.org/10.1177/1359105312440298>
- Ruan, J. Y. & Zhou, Y. X. (2019). Regaining normality: A grounded theory study of the illness experiences of Chinese patients living with Crohn's disease. *International Journal of Nursing Studies*, 93, 87-96. <https://doi.org/10.1016/j.ijnurstu.2019.02.015>.
- Sandvik, B. M., & McCormack, B. (2018). Being Person-Centred in Qualitative Interviews: Reflections on a Process. *International Practice Development Journal*, 8 (2), 1-8. <https://doi.org/10.19043/ipdj.82.008>
- Shaw, R. (2010). Embedding Reflexivity Within Experiential Qualitative Psychology. *Qualitative Research in Psychology*, 7(3), 233-243. <https://doi.org/10.1080/14780880802699092>
- Smith, J. S., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE Publications Ltd
- Vuillier, L., May, L., Greville-Harris, M., Surman, R., & Moseley, R.L. (2021). The impact of the COVID-19 pandemic on individuals with eating disorders: the role of emotion regulation and exploration of online treatment experiences. *Journal of Eating Disorders*, 9(10). <https://doi.org/10.1186/s40337-020-00362-9>
- Wall, C., Glenn, S., Mitchinson, S., & Poole, H. (2004). Using a Reflective Diary to Develop Bracketing Skills During a Phenomenological Investigation. *Nurse Researcher*, 11(4), 20-29. <https://doi.org/10.7748/nr2004.07.11.4.20.c6212>

Appendix 3-A**Original ethics application****Faculty of Health and Medicine Research Ethics Committee (FHMREC)****Lancaster University****Application for Ethical Approval for Research****Guidance on completing this form is also available as a word document**

Title of Project: Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and who self-report having, or have received a diagnosis of, an Eating Disorder (ED).

Name of applicant/researcher: Emma Mellor

ACP ID number (if applicable)*:

Funding source (if applicable)

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist.**

Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects. **Complete sections one, three and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist
– Division of Clinical Psychology

2. Contact information for applicant:

E-mail: e.mellor@lancaster.ac.uk

Telephone: 07735438095 (please give a number on

which you can be contacted at short notice)

Address: 37 Mosses Farm Road, Longridge, Preston, PR3 2BG

3. Names and appointments of all members of the research team (including degree where applicable)

Dr Craig Murray – (Research Supervisor) – Senior Lecturer/ Health Psychologist, Doctorate in Clinical Psychology, Lancaster University

Dr Georgina Rowse – (Field Supervisor) – Senior Lecturer/ Clinical Psychologist, Doctorate in Clinical Psychology Programme at Sheffield University

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma Masters by research PhD Thesis PhD Pall. Care

PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD

DClinPsy SRP [if SRP Service Evaluation, please also indicate here: DClinPsy Thesis

4. Project supervisor(s), if different from applicant:

Dr Craig Murray – (Research Supervisor)

Dr Georgina Rowse – (Field Supervisor)

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Dr Craig Murray - Lecturer in Health Research, Doctorate in Clinical Psychology, Lancaster University

Dr Georgina Rowse- Senior Lecturer/ Clinical Psychologist, Doctorate in Clinical Psychology Programme at University of Sheffield

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date:

End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'?

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects**1. Summary of research protocol in lay terms (indicative maximum length 150 words):**

A lot of research thus far has looked at how individuals with IBD experience depression and anxiety. It has been suggested that the impact of being diagnosed with a life long illness, such as IBD, coupled with the necessity to adapt one's lifestyle to manage the illness, may contribute to the likelihood of an individual experiencing mental health difficulties such as these.

However, there are few research studies on the relationship between EDs and IBD. It is felt that this is important research to carry out, as it is likely individuals with IBD are at a greater risk than the general population of developing an ED. One possible reason for this relates to having to follow a strict diet; indeed this has been reported within the ED literature as a contributing factor to the development of an ED. Therefore, I plan to explore the experiences of individuals with a diagnosis of IBD and who self-report or have received a formal diagnosis of an ED, to establish if participants experience and recount a relationship between their IBD and ED experiences.

2. Anticipated project dates (month and year only)

Start date: December 2019

End date: March 2021

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

I aim to recruit individuals who have received a diagnosis of IBD and self-report or have received a diagnosis of an ED. There is consensus within the literature that the age of onset for EDs lies within adolescence and young adulthood (Halmi, 2005); Volpe et al (2016) sought to more clearly define this, and through a large scale study of 806 participants, found that for all types of EDs, the average age of onset was 18 years old. Therefore, I will aim to recruit individuals from 18 years onwards. IBD will refer to all variations of the disease, specifically Crohn's Disease and all forms of Ulcerative Colitis. EDs will refer to all illnesses which meet diagnosable criteria and are defined as "clinically meaningful behavioural or psychological pattern having to do with eating or weight that is associated with distress, disability, or with substantially increased risk of morbidity or mortality" (Grilo, 2006, p.3). As defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013), these include anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), or avoidant restrictive food intake disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). Due to the exploratory nature of this study, with no similar research having been conducted previously, IPA will be used; IPA calls for an in-depth idiographic analysis, therefore I will aim to recruit a small sample size of 6-10 participants.

Inclusion criteria:

- Individuals with a diagnosis of IBD who are aged 18 and over.
- Individuals with a previous or current diagnosis of an ED.
- Individuals who would describe themselves as having/ having had disordered eating but have not received a diagnosis of an ED.
- Individuals who currently reside in the UK; this is to ensure individuals have received similar service provision in regards to their IBD.

Exclusion criteria:

- Individuals with a diagnosis of Irritable Bowel Syndrome as IBS is not classified as a chronic health condition; it does not have a disease profile and does not result in the invasive treatment or surgery of IBD.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (e.g. adverts, flyers, posters).

Purposive sampling will be used to recruit individuals. Targeted recruitment efforts will be employed; online support groups such as Crohns & Colitis UK will be contacted via email (appendix 4) in the first instance via the contact details provided on their website to obtain permission to advertise the research on their website, and on their social media platforms, specifically Facebook, Twitter and Instagram. A handle (appendix 5) will be requested to be advertised on social media platforms. The researcher will also advertise the research on their own social media platforms, which will again be Facebook, Twitter and Instagram, as the researcher has contacts with individuals with IBD on these platforms.

The researcher's field supervisor will also send a dictated email (appendix 6) to individuals who stated following a previous piece of research, that they would be happy for their contact details to be stored in order to be contacted about participation in future research.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

In order for key topic areas to be covered, whilst also facilitating the researcher to have some degree of flexibility, semi-structured interviews will be used. The interview will consider individuals' experiences since being diagnosed with IBD up to the point of diagnosis/identification of an ED, and their experience from this point onwards up to the present day. Questions to be used within the interview (appendix 3) have been informed by experts by experience, alongside the participant information sheet (appendix 1), consent form (appendix 2), expression of interest/opt in form (appendix 7) and email to participants (appendix 6) social media handle (appendix 5), to ensure the appropriateness of these materials.

During the interview, participants will be asked to complete the Inflammatory Bowel Disease Questionnaire (IBDQ) (Irvine, 1999) (appendix 10) and the Eating Disorder Examination Questionnaire (EDE-Q) (Fairburn & Beglin, 1994) (appendix 9) in order to obtain a current clinical picture of the sample. This will be particularly useful in relation to individuals current experience of EDs, as it is possible that not all individuals will have received a diagnosis of an ED. Both the IBDQ

and EDE-Q are well-validated and widely used to assess symptomology through the use of self-report measures (Pallis, Mouzas, Vlachonikolis, Phil, 2004; Berg, Peterson, Frazier, & Crow, 2012). The EDE-Q (Fairburn & Beglin, 1994) assesses symptoms of an ED within the last 28 days; it is possible that some individuals will have recovered from their experience of an ED and therefore the EDE-Q (Fairburn & Beglin, 1994) will not capture their experience. These individuals will not be expected to complete a screening questionnaire as it is felt it is not appropriate to screen participants who no longer have an eating disorder as the questions asked could be triggering and therefore psychological harm could be caused. These individuals will not be expected to complete a screening questionnaire as it is felt it is not appropriate to screen participants who no longer have an eating disorder as the questions asked could be triggering and therefore psychological harm could be caused. These individuals will not be excluded from participating in the research; a self-report disclosure will be accepted in these instances. In order to assist with this, participants will be provided with a definition of each ED, as defined by the DSM-V (2013), and asked to state which one they most identify with. Specifically, these include:

- **Anorexia Nervosa:** Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health); Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight); Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.
- **Bulimia nervosa:** Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise; The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months; Self-evaluation is unduly influenced by body shape and weight; The disturbance does not occur exclusively during episodes of Anorexia Nervosa.
- **Binge-eating disorder:** Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); The binge eating episodes are associated with three or more of the following: eating much more rapidly than normal, eating until feeling uncomfortably full, eating large amounts of food when not feeling physically hungry, eating alone because of feeling embarrassed by how much one is eating, feeling disgusted with oneself, depressed or very guilty afterward; Marked distress regarding binge eating is present; Binge eating occurs, on average, at least once a week for three months; Binge eating not associated with the recurrent use of inappropriate compensatory behaviours as in Bulimia Nervosa and does not occur exclusively during the course of Bulimia Nervosa, or Anorexia Nervosa methods to compensate for overeating, such as self-induced vomiting.
- **Avoidant restrictive food intake disorder:** An Eating or Feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: Significant loss of weight (or failure to achieve expected weight gain or

faltering growth in children), Significant nutritional deficiency, Dependence on enteral feeding or oral nutritional supplements, Marked interference with psychosocial functioning; The behaviour is not better explained by lack of available food or by an associated culturally sanctioned practice; The behaviour does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is experienced; The eating disturbance is not attributed to a medical condition, or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behaviour exceeds what is usually associated, and warrants additional clinical attention.

- **Other Specified Feeding or Eating Disorder:** A person must present with a feeding or eating behaviours that cause clinically significant distress and impairment in areas of functioning, but do not meet the full criteria for any of the other feeding and eating disorders. A diagnosis might then be allocated that specifies a specific reason why the presentation does not meet the specifics of another disorder (e.g. Bulimia Nervosa- low frequency).
- **Unspecified Feeding or Eating Disorder:** This category applies to where behaviours cause clinically significant distress/impairment of functioning, but do not meet the full criteria of any of the Feeding or Eating Disorder criteria. This category may be used by clinicians where a clinician chooses not to specify why criteria are not met, including presentations where there may be insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

IPA will be used to analyse the data, guided by the approach outlined by Smith and Osborn (2003). IPA has been chosen as it allows for the context and personal meanings of an individual's experience to be analysed in detail, whilst acknowledging the process will be influenced by the researcher's own interpretations. Ilzarbe et al. (2017) suggested research is needed to further consolidate the link between IBD and EDs and identify possible clinical markers which could assist in the earlier identification of EDs in the IBD population. Therefore, I plan to use IPA to explore how participants have experienced factors related to developing an ED, such as dietary management, embodied sensations (such as discomfort from eating food), weight and body satisfaction.

Interviews will be audio recorded and transcribed verbatim (Smith & Osborn, 2003). The transcripts will be frequently read and a left-hand margin used to annotate what is interesting or significant about what the respondent said. The right-hand side margin will then be used to document emerging theme titles. I will attempt to connect the themes and cluster them together, checking the transcript to ensure the concepts fit with the original transcript. Once themes have been identified for each transcript, I will look for convergences and divergences across the transcripts. A table will be devised, with themes ordered coherently. At this stage, themes which do not fit well in the emerging structure or do not have substantive evidence within the transcript may be dropped. Once the final themes are collated, a write up will be carried out which aims to explain the themes within a narrative account.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Interviews will be recorded onto a voice recording device. This will not be encrypted, or password protected but will be kept securely by the researcher. Recordings will be transferred to the secure, encrypted Lancaster University drive at the earliest opportunity, and transcribed into anonymous

transcripts, both of which will be password protected. The research supervisor will look at excerpts from these. Audio recordings will be deleted following the successful examination of the thesis project.

7. Will audio or video recording take place? no audio video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. Identifiable data will be stored on the Lancaster University encrypted drive.

Interviews will be recorded onto a voice recording device. This will not be encrypted, or password protected but will be kept securely by the researcher. Recordings will be transferred to the secure, encrypted Lancaster University drive at the earliest opportunity, and transcribed into anonymous transcripts, both of which will be password protected. The research supervisor will look at excerpts from these. Audio recordings will be deleted following the successful examination of the thesis project.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings will be transferred onto the secure, encrypted Lancaster university drive and will be anonymously transcribed, both of which will be password protected. Recordings will then be stored on the researcher's university drive until the successful examination of the thesis project is complete. Following this, recordings will be deleted.

All other data will be stored electronically, including consent forms which will be scanned and saved, and the paper copies destroyed. All electronic files will be encrypted and transferred via the University's secure file transfer software to the research coordinator who will save the files in password-protected file space on the university server where they will be stored for 10 years after the study has finished or after it is published, whichever is longer. At the end of this time, they will be permanently deleted.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

All other data will be saved electronically, including consent forms which will be scanned and saved, and the paper copies destroyed. All electronic files will be encrypted and transferred via the University's secure file transfer software to the research coordinator who will save the files in password-protected file space on the university server where they will be stored for 10 years after the study has finished or after it is published, whichever is longer. At the end of this time, they will be permanently deleted.

8b. Are there any restrictions on sharing your data?

Due to the small sample size, even after full anonymisation, there is a small risk that participants could still be identifiable following anonymisation. Therefore, sharing supporting data will be considered on a case by case basis by the DCLinPsy Research Director.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?

b. Detail the procedure you will use for obtaining consent?

Information packs (appendix 6) will be provided to potential participants via email from the researcher, once participants have identified their interest via advertisements placed on the Crohns and Colitis website or social media platforms, or the researcher's individual social media platforms. When potential participants identify they might be interested, they can contact the researcher with any questions if needed. Once participants have been provided with information packs, the earliest point of participation will be 48 hours following this. Informed consent forms will be completed with the researcher and participant; if the interview is taking place in person, this will be completed on paper prior to commencement of the interview. However, if the interview is being conducted via skype, verbal consent will be obtained at the time of interview and audio-recorded separately to the rest of the interview and stored; consent will be gained by reading out each item from the consent form for the participant to verbally agree.

After participation, participants will have 48 hours to withdraw their consent to participate.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Minimal risks are associated with taking part in this study. However, participants may find the discussion of their experiences distressing. If participants become distressed during the interview, the researcher will offer to pause or stop the interview. If this occurs during or after participation in the study, participants will have the opportunity to discuss it with the interviewer, or use the resources provided on the Participant Information Sheet (appendix 7). Information has been incorporated into the participant information sheet for the event that any participants feel they would like to seek support following their participation in the study.

Confidentiality and its limits will be clearly explained prior to the interview taking place and participation in the project. If serious concerns are raised such as concerns about wellbeing and/or risk, it will be important for the researcher to ascertain if it is necessary to inform the appropriate services of this, such as services supporting the individual at that time or the relevant crisis teams within the area. However, if it was felt that this was necessary, this would be collaboratively discussed with the participant about how to best share this information.

Participants are welcome to withdraw from the study at any time. However, the removal of their data will have a time limit of two weeks following their interview. After this, it may not be possible to remove data once analysis is started and the data has been pooled.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

It is likely to be necessary to provide participants with the researchers email address for recruitment purposes. In the interest of risk, the researcher's university email will be used. If a mobile phone is needed for the same purpose, a non-personal (research project) phone will be used.

Whilst it is foreseen that the majority of interviews will be conducted via skype, interviews will be offered on a face to face location if the geographical location permits this. At this point the university's lone working policy will be adhered to, taking into account section 2 of field work planning, particular in regards to risks present in the geographical location, as well as section 3.1 in regards to personal safety. A peer of the researcher will be advised when, where and at what time the interviews will take place and will be informed when the interviews are complete. It is hoped that a 'Skyguard' alarm device will also be used in order to raise an alarm if a dangerous situation should arise. The 'Skyguard' device will be linked with an online account which will be updated with details of the interview including time and location. In the event of a dangerous situation, the device will be activated and a Skyguard representative will be able to access the account information to take the necessary steps such as contacting the appropriate authorities.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

Taking part gives participants the opportunity for their opinions and experiences to be heard and this could provide valuable information about how to change and improve services for the benefit of both staff and patients.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Interviews are planned to take at a place of participant's convenience if geographical location permits this or via telephone or skype call. If travelling is necessary, travel expenses incurred will be reimbursed, up to a maximum of £20.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Confidentiality and its limits will be clearly explained prior to the interview taking place and participation in the project. If serious concerns are raised such as concerns about wellbeing and/or risk, it will be important for the researcher to ascertain if it is necessary to inform the appropriate services of this, such as services supporting the individual at that time or the relevant crisis teams within the area. However, if it was felt that this was necessary, this would be collaboratively discussed with the participant about how to best share this information.

Another possible limit of confidentiality is that it might be difficult to make quotes fully anonymous in the report. Personal details will not be used but there is a chance that people could be identified due to the small sample size.

If skype is used for interviews, a dedicated Skype account will be set up and not used for any other purpose. At the start of the skype interview, participants will be alerted to the fact that the internet is not secure and will be offered the option of withdrawing from the research. This information will also be included in the Participant Information Sheet.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The target participant group has been consulted on practicalities involved in supporting recruitment, such as social media handles (appendix 2).

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The findings will form part of the lead researcher's thesis and will be written in a report for submission to Lancaster University in partial fulfilment of a Doctorate in Clinical Psychology The findings may also be published in an academic/professional journal and may be presented at conferences. Participants will also receive a copy of the findings or a summary at their request.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

N/A

SECTION FOUR: signature**Applicant electronic signature:** Date

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable):

Date application discussed

Appendix 3-B

Extract from reflective journal

REFLECTIONS

██████: Difficult convo's v.c. ix → what that feels like v.e. geography + being so far away → good conclusion: MMac said wicing eating habits + what he's doing for first time has made him recognize it is actually harmful, + encouraged him to think about what he needs to do to change it.

Appendix 3-C

Extract from reflective journal

info from men, but presented with higher
risks

Difficulties of doing research whilst having
a flare up myself → provokes anxiety, i.e.
what pts say about steroids + side effects

22.03.22

Can't do it today. Exhausted from fatigue
and have the most extreme brain fog,
which feels like I can't see properly.
Don't feel up to reading and hearing
about other people's experiences of this
illness, don't feel like I can take on
anymore.

Section 4 Ethics Section

Emma Mellor

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

Emma Mellor

Doctorate in Clinical Psychology

Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

Email: e.mellor@lancaster.ac.uk

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

Title of Project: Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.

Name of applicant/researcher: Emma Mellor

ACP ID number (if applicable)*:

Funding source (if applicable)

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

Type of study

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects. **Complete sections one, three and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist –
Division of Clinical Psychology

2. Contact information for applicant:

E-mail: e.mellor@lancaster.ac.uk
 be contacted at short notice)

Telephone: (please give a number on which you can

Address:

3. Names and appointments of all members of the research team (including degree where applicable)

Dr Craig Murray – (Research Supervisor) – Senior Lecturer/ Health Psychologist, Doctorate in Clinical Psychology, Lancaster University

Dr Georgina Rowse – (Field Supervisor) – Senior Lecturer/ Clinical Psychologist, Doctorate in Clinical Psychology Programme at Sheffield University

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete FHMREC form UG-tPG, following the procedures set out on the [FHMREC website](#))

PG Diploma Masters by research PhD Thesis PhD Pall. Care

PhD Pub. Health PhD Org. Health & Well Being PhD Mental Health MD

DClinPsy SRP [if SRP Service Evaluation, please also indicate here: DClinPsy Thesis

4. Project supervisor(s), if different from applicant:

Dr Craig Murray – (Research Supervisor)

Dr Georgina Rowse – (Field Supervisor)

5. Appointment held by supervisor(s) and institution(s) where based (if applicable):

Dr Craig Murray - Lecturer in Health Research, Doctorate in Clinical Psychology, Lancaster University

Dr Georgina Rowse- Senior Lecturer/ Clinical Psychologist, Doctorate in Clinical Psychology Programme at University of Sheffield

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date:

End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'?

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

A lot of research thus far has looked at how individuals with IBD experience depression and anxiety. It has been suggested that the impact of being diagnosed with a life long illness, such as IBD, coupled

with the necessity to adapt one's lifestyle to manage the illness, may contribute to the likelihood of an individual experiencing mental health difficulties such as these.

Individuals with IBD often have to manage their dietary intake to minimise risk of a deterioration in their illness. Increased focus on diet management is associated with the risk of developing an eating disorder (ED). Previous research has also suggested psychological comorbidities are higher for individuals with EDs. Therefore, it is theorised the possibility of developing an ED is higher in the IBD population. A small number of studies have investigated IBD and EDs, and these support the claim that disordered eating practices occur within this population. However, the prevalence and risk factors associated with this are currently unknown. Consequently, I plan to explore the experiences of individuals with a diagnosis of IBD and their experience of difficulties with eating, to establish if they recount a relationship between their IBD and eating difficulties.

2. Anticipated project dates (month and year only)

Start date: December 2019

End date: March 2022

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

I aim to recruit individuals who have received a diagnosis of IBD and who self-report experiencing difficulties with eating relating to the onset of IBD; this may also include individuals who have received a formal diagnosis of an ED. There is consensus within the literature that the age of onset for EDs lies within adolescence and young adulthood (Halmi, 2005); Volpe et al (2016) sought to more clearly define this, and through a large scale study of 806 participants, found that for all types of EDs, the average age of onset was 18 years old. Therefore, I will aim to recruit individuals from 18 years onwards. IBD will refer to all variations of the disease, specifically Crohn's Disease and all forms of Ulcerative Colitis. Difficulties with eating will refer to individuals who may experience disordered eating behaviours associated with EDs which would be described as abnormal, including restraint eating and controlling body weight and shape through unsuitable compensatory behaviours, that would not meet criteria for an ED as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013). EDs will refer to all illnesses which meet diagnosable criteria and are defined as "clinically meaningful behavioural or psychological pattern having to do with eating or weight that is associated with distress, disability, or with substantially increased risk of morbidity or mortality" (Grilo, 2006, p.3). As defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) (2013), these include anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), or avoidant restrictive food intake disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). Due to the exploratory nature of this study, with no similar research having been conducted previously, IPA will be used; IPA calls for an in-depth idiographic analysis, therefore I will aim to recruit a small sample size of 6-10 participants.

Inclusion criteria:

- Individuals with a diagnosis of IBD who are aged 18 and over.
- Individuals who would describe themselves as having/ having had disordered eating but have not received a diagnosis of an ED, or individuals with a previous or current diagnosis of an ED.
- Individuals who currently reside in the UK; this is to ensure individuals have received similar service provision in regards to their IBD.

Exclusion criteria:

- Individuals with a diagnosis of Irritable Bowel Syndrome as IBS is not classified as a chronic health condition; it does not have a disease profile and does not result in the invasive treatment or surgery of IBD.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (e.g. adverts, flyers, posters).

Purposive sampling will be used to recruit individuals. Targeted recruitment efforts will be employed; online support groups such as Crohns & Colitis UK and Beat Eating Disorders will be contacted via email (appendix 4) in the first instance via the contact details provided on their website to obtain permission to advertise the research on their website, and on their social media platforms, specifically Facebook, Twitter and Instagram. A handle (appendix 5) will be requested to be advertised on social media platforms researchers professional twitter account.

The researcher's field supervisor will also send a dictated email (appendix 6) to individuals who stated following a previous piece of research, that they would be happy for their contact details to be stored in order to be contacted about participation in future research.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

In order for key topic areas to be covered, whilst also facilitating the researcher to have some degree of flexibility, semi-structured interviews will be used. The interview will consider individuals' experiences since being diagnosed with IBD up to the point of diagnosis/identification of an ED or difficulties with eating, and their experience from this point onwards up to the present day. Questions to be used within the interview (appendix 3) have been informed by experts by experience, alongside the participant information sheet (appendix 1), consent form (appendix 2), expression of interest/opt in form (appendix 7) and email to participants (appendix 6) social media handle (appendix 5), to ensure the appropriateness of these materials.

Participants will be asked to inform the researcher what diagnosis of IBD they received, and when they received this. Participants will also be asked if they have received a formal diagnosis of an ED or if they associate themselves with having difficulties with eating relating to IBD (appendix 8). If participants have received a formal diagnosis of an ED, they will also be asked when this diagnosis of an ED was received and if the ED is still current. In regards to participants who recount having difficulties with eating, participants will be provided with a definition of each ED, as defined by the DSM-V (2013) and asked to state which one they most identify with. Specifically, these include:

Anorexia Nervosa: Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health); Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight); Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Bulimia nervosa: Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise; The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months; Self-evaluation is unduly influenced by body shape and weight; The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

Binge-eating disorder: Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); The binge eating episodes are associated with three or more of the following: eating much more rapidly than normal, eating until feeling uncomfortably full, eating large amounts of food when not feeling physically hungry, eating alone because of feeling embarrassed by how much one is eating, feeling disgusted with oneself, depressed or very guilty afterward; Marked distress regarding binge eating is present; Binge eating occurs, on average, at least once a week for three months; Binge eating not associated with the recurrent use of inappropriate compensatory behaviours as in Bulimia Nervosa and does not occur exclusively during the course of Bulimia Nervosa, or Anorexia Nervosa methods to compensate for overeating, such as self-induced vomiting.

Avoidant restrictive food intake disorder: An Eating or Feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: Significant loss of weight (or failure to achieve expected weight gain or faltering growth in children), Significant nutritional deficiency, Dependence on enteral feeding or oral nutritional supplements, Marked interference with psychosocial functioning; The behaviour is not better explained by lack of available food or by an associated culturally sanctioned practice; The behaviour does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is experienced; The eating disturbance is not attributed to a medical condition, or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behaviour exceeds what is usually associated, and warrants additional clinical attention.

Other Specified Feeding or Eating Disorder: A person must present with a feeding or eating behaviours that cause clinically significant distress and impairment in areas of functioning, but do not meet the full criteria for any of the other feeding and eating disorders. A diagnosis might then be allocated that specifies a specific reason why the presentation does not meet the specifics of another disorder (e.g. Bulimia Nervosa- low frequency).

Unspecified Feeding or Eating Disorder: This category applies to where behaviours cause clinically significant distress/impairment of functioning, but do not meet the full criteria of any of the Feeding or Eating Disorder criteria. This category may be used by clinicians where a clinician chooses not to specify why criteria are not met, including presentations where there may be insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

IPA will be used to analyse the data, guided by the approach outlined by Smith and Osborn (2003). IPA has been chosen as it allows for the context and personal meanings of an individual's experience to be analysed in detail, whilst acknowledging the process will be influenced by the researcher's own interpretations. Ilzarbe et al. (2017) suggested research is needed to further consolidate the link between IBD and EDs and identify possible clinical markers which could assist in the earlier identification of EDs in the IBD population. Therefore, I plan to use IPA to explore how participants have experienced factors related to developing an ED, such as dietary management, embodied sensations (such as discomfort from eating food), weight and body satisfaction.

Interviews will be audio recorded and transcribed verbatim (Smith & Osborn, 2003). The transcripts will be frequently read and a left-hand margin used to annotate what is interesting or significant about what the respondent said. The right-hand side margin will then be used to document emerging theme titles. I will attempt to connect the themes and cluster them together, checking the transcript to ensure the concepts fit with the original transcript. Once themes have been identified for each transcript, I will look for convergences and divergences across the transcripts. A table will be devised, with themes ordered coherently. At this stage, themes which do not fit well in the emerging structure or do not have substantive evidence within the transcript may be dropped. Once the final themes are collated, a write up will be carried out which aims to explain the themes within a narrative account.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Interviews will be recorded onto a voice recording device. This will not be encrypted, or password protected but will be kept securely by the researcher. Recordings will be transferred to the secure, encrypted Lancaster University drive at the earliest opportunity, and transcribed into anonymous transcripts, both of which will be password protected. The research supervisor will look at excerpts from these. Audio recordings will be deleted following the successful examination of the thesis project.

7. Will audio or video recording take place? no audio video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. Identifiable data will be stored on the Lancaster University encrypted drive.

Interviews will be recorded onto a voice recording device. This will not be encrypted, or password protected but will be kept securely by the researcher. Recordings will be transferred to the secure, encrypted Lancaster University drive at the earliest opportunity, and transcribed into anonymous transcripts, both of which will be password protected. The research supervisor will look at excerpts

from these. Audio recordings will be deleted following the successful examination of the thesis project.

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio recordings will be transferred onto the secure, encrypted Lancaster university drive and will be anonymously transcribed, both of which will be password protected. Recordings will then be stored on the researcher's university drive until the successful examination of the thesis project is complete. Following this, recordings will be deleted.

All other data will be stored electronically, including consent forms which will be scanned and saved, and the paper copies destroyed. All electronic files will be encrypted and transferred via the University's secure file transfer software to the research coordinator who will save the files in password-protected file space on the university server where they will be stored for 10 years after the study has finished or after it is published, whichever is longer. At the end of this time, they will be permanently deleted.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

All other data will be saved electronically, including consent forms which will be scanned and saved, and the paper copies destroyed. All electronic files will be encrypted and transferred via the University's secure file transfer software to the research coordinator who will save the files in password-protected file space on the university server where they will be stored for 10 years after the study has finished or after it is published, whichever is longer. At the end of this time, they will be permanently deleted.

8b. Are there any restrictions on sharing your data ?

Due to the small sample size, even after full anonymisation, there is a small risk that participants could still be identifiable following anonymisation. Therefore, sharing supporting data will be considered on a case by case basis by the DClinPsy Research Director.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Information packs (appendix 6) will be provided to potential participants via email from the researcher, once participants have identified their interest via advertisements placed on charity organisation websites or social media platforms, such as Crohns and Colitis and Beat Eating Disorders, or the researchers professional twitter account. When potential participants identify they might be

interested, they can contact the researcher with any questions if needed. Once participants have been provided with information packs, the earliest point of participation will be 48 hours following this. Informed consent forms will be completed with the researcher and participant; if the interview is taking place in person, this will be completed on paper prior to commencement of the interview. However, if the interview is being conducted via skype, verbal consent will be obtained at the time of interview and audio-recorded separately to the rest of the interview and stored; consent will be gained by reading out each item from the consent form for the participant to verbally agree.

Participants will be informed that they are welcome to withdraw from the study at any time. However, the removal of their data will have a time limit of two weeks following their interview. After this, it may not be possible to remove data once analysis is started and the data has been pooled.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Minimal risks are associated with taking part in this study. However, participants may find the discussion of their experiences distressing. If participants become distressed during the interview, the researcher will offer to pause or stop the interview. If this occurs during or after participation in the study, participants will have the opportunity to discuss it with the interviewer, or use the resources provided on the Participant Information Sheet (appendix 7). Information has been incorporated into the participant information sheet for the event that any participants feel they would like to seek support following their participation in the study.

Confidentiality and its limits will be clearly explained prior to the interview taking place and participation in the project. If serious concerns are raised such as concerns about wellbeing and/or risk, it will be important for the researcher to ascertain if it is necessary to inform the appropriate services of this, such as services supporting the individual at that time or the relevant crisis teams within the area. However, if it was felt that this was necessary, this would be collaboratively discussed with the participant about how to best share this information.

Participants are welcome to withdraw from the study at any time. However, the removal of their data will have a time limit of two weeks following their interview. After this, it may not be possible to remove data once analysis is started and the data has been pooled.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

It is likely to be necessary to provide participants with the researchers email address for recruitment purposes. In the interest of risk, the researcher's university email will be used. If a mobile phone is needed for the same purpose, a non-personal (research project) phone will be used.

Whilst it is foreseen that the majority of interviews will be conducted via skype, interviews will be offered on a face to face location if the geographical location permits this. At this point the university's lone working policy will be adhered to, taking into account section 2 of field work planning, particular in regards to risks present in the geographical location, as well as section 3.1 in regards to personal

safety. A peer of the researcher will be advised when, where and at what time the interviews will take place and will be informed when the interviews are complete. It is hoped that a 'Skyguard' alarm device will also be used in order to raise an alarm if a dangerous situation should arise. The 'Skyguard' device will be linked with an online account which will be updated with details of the interview including time and location. In the event of a dangerous situation, the device will be activated and a Skyguard representative will be able to access the account information to take the necessary steps such as contacting the appropriate authorities.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

Taking part gives participants the opportunity for their opinions and experiences to be heard and this could provide valuable information about how to change and improve services for the benefit of both staff and patients.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

Interviews are planned to take at a place of participant's convenience if geographical location permits this or via telephone or skype call. If travelling is necessary, travel expenses incurred will be reimbursed, up to a maximum of £20.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Confidentiality and its limits will be clearly explained prior to the interview taking place and participation in the project. If serious concerns are raised such as concerns about wellbeing and/or risk, it will be important for the researcher to ascertain if it is necessary to inform the appropriate services of this, such as services supporting the individual at that time or the relevant crisis teams within the area. However, if it was felt that this was necessary, this would be collaboratively discussed with the participant about how to best share this information.

Another possible limit of confidentiality is that it might be difficult to make quotes fully anonymous in the report. Personal details will not be used but there is a chance that people could be identified due to the small sample size.

If skype is used for interviews, a dedicated Skype account will be set up and not used for any other purpose. At the start of the skype interview, participants will be alerted to the fact that the internet is not secure and will be offered the option of withdrawing from the research. This information will also be included in the Participant Information Sheet.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The target participant group has been consulted on practicalities involved in supporting recruitment, such as social media handles (appendix 2).

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The findings will form part of the lead researcher's thesis and will be written in a report for submission to Lancaster University in partial fulfilment of a Doctorate in Clinical Psychology. The findings may also be published in an academic/professional journal and may be presented at conferences. Participants will also receive a copy of the findings or a summary at their request.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

N/A

SECTION FOUR: signature

Applicant electronic signature:

Date

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable):

Date application discussed

Appendix 4-A

Governance Checklist

Please remember to allow sufficient time for the review process if it is awarded. The ethical review process can accommodate phased applications, multiple applications and generic applications (e.g. for a suite of projects), where appropriate; the [Research Ethics Officer](#) will advise on the most suitable method according to the specific circumstances.

1.2 Please indicate which item(s) listed in section 1A apply to this project (use the appropriate letter(s), eg. a,c,f)

Items: a

1.3 Please indicate which committee you anticipate submitting the application to:

- NHS ethics committee
- Other external committee
- LU FASS/LUMS Research Ethics committee
- LU FST Research Ethics committee
- LU FHM Research Ethics committee
- LU AWERB (animals)

Section	2:	Project	Information
This information in this section is required by the Research Support Office (RSO) to expedite your proposal.			

2.1 If the establishment of a research ethics committee is required as part of your collaboration, please indicate below. (This is a requirement for some large-scale European Commission funded projects, for example.)

- Establishment of a research ethics committee required

2.2 If the research involves either the nuclear industry or an aircraft or the aircraft industry (other than for transport), please provide details below. This information is required by the university insurers.

[Click here to enter text.](#)

Section	3:	Guidance
The following information is intended as a prompt and to provide guidance on where to find further information. Where appropriate consider addressing these points in the proposal.		
<ul style="list-style-type: none"> • If relevant, guidance on data protection issues can be obtained from the Data Protection Officer - see Data Protection website • If relevant, guidance on the Freedom of Information Act can be obtained from the FOI Officer - see FOI website • The University's Research Data Policy can be downloaded here • The health and safety requirements of each research project must be considered, further information is available from the Safety Office website 		

- If any of the research team will be working with an NHS Trust, consider who will be named as the Sponsor (if applicable) and seek agreement in principle. Contact the [Research Ethics Officer](#) for further information
- If you are involved in any other activities that may result in a conflict of interest with this research, please contact the [Head of Research Services](#) (ext. 94905)
- If any of the intellectual property to be used in the research belongs to a third party (e.g. the funder of previous work you have conducted in this field), please contact the [Intellectual Property Development Manager](#) (ext. 93298)
- If you intend to make a prototype or file a patent application on an invention that relates in some way to the area of research in this proposal, please contact the [Intellectual Property Development Manager](#) (ext. 93298)
- If your work involves [animals](#) you will need authorisation from the University Secretary and may need to submit an application to AWERB, please contact the [University Secretary](#) for further details
- Online Research Integrity training is available for staff and students [here](#) along with a Research Integrity self-assessment exercise.

3.1 I confirm that I have noted the information provided in section 3 above and will act on those items which are relevant to my project.

Confirmed

Section 4: Statement

4.2 I understand that as researcher I have overall responsibility for the ethical management of the project and confirm the following:

- I have read the Code of Practice, [Research Ethics at Lancaster: a code of practice](#) and I am willing to abide by it in relation to the current proposal
- I have completed the [ISS Information Security training](#) and passed the assessment
- I will manage the project in an ethically appropriate manner according to: (a) the subject matter involved; (b) the code of practice of any relevant funding body; and (c) the Code of Practice and Procedures of the university.
- On behalf of the [institution](#) I accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- On behalf of the [institution](#) I accept responsibility for the project in relation to the observance of the rules for the exploitation of intellectual property.
- I will give all staff and students involved in the project guidance on the good practice and ethical standards expected in the project in accordance with the university Code of Practice. (Online Research Integrity training is available for staff and students [here](#).)
- I will take steps to ensure that no students or staff involved in the project will be exposed to inappropriate situations.


Confirmed

Please note: If you are not able to confirm the statement [above](#) please contact [Faculty Research Ethics Officer](#) and provide an explanation

Applicant

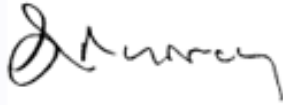
Name: Emma Mellor

Date: 20.11.2019

Signature: 

***Supervisor (if applicable):** Name: Craig Murray Date: 22.11.2019

Signature:



**I declare that I have reviewed this application, and discussed it with the applicant as appropriate. I am happy for this application to proceed to ethical review.*

Head **of** **Department**
(or delegated representative) Name: Bill Sellwood Date: 20.11.2019

Signature:



Please return this form to your Faculty Research Ethics Officer

Appendix 4-B

Research Protocol

Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.

Principal Investigator

Emma Mellor

Trainee Clinical Psychologist, Lancaster University, Lancaster, LA1 4YG

Phone: [Research phone number to be confirmed]

Email: e.mellor@lancaster.ac.uk

Co-investigators

Dr Craig Murray

Lecturer in Health Research, Clinical Psychology, Division of Health Research, Lancaster University, Lancaster, LA1 4YG

Phone:

Email: c.murray@lancaster.ac.uk

Dr Georgina Rowse

Clinical Psychologist, Doctorate in Clinical Psychology, Sheffield University, 1 Vicar Lane, Sheffield S1 1HD Phone:

Email: g.rowse@sheffield.ac.uk

Introduction/Rationale

Previous research has examined the link between Inflammatory Bowel Disease (IBD) and mood disorders, such as anxiety and depressive disorders (Larion et al., 2015; Neuendorf et al., 2016). Neuendorf et al. (2016) suggested the prevalence of anxiety and depressive disorders in IBD is 21% and 15%. Lewinson et al. (2000) have suggested eating disorders (EDs) often co-occur in individuals with high levels of depression and anxiety severity, yet despite this, Ilzarbe et al. (2017) highlight the relationship between EDs and IBD has not been extensively studied.

In an initial investigation into diet related chronic health conditions (DRCHC), including IBD, Quick et al. (2012) sought to identify whether psychographic characteristics in healthy young adults with disturbed eating behaviours are different to those with DRCHCs. Results suggested participants with DRCHCs had higher rates of ED diagnoses. They concluded the findings called for disturbed eating behaviours in young adults with DRCHCs to be screened and monitored so an early intervention can be provided when these behaviours are easiest to modify (Rosen, 2010).

In a further study in 2013, Quick et al. sought to investigate the prevalence and risk factors for developing an ED in individuals with DRCHC's, again including the population of IBD, by carrying out a literature review. Their findings suggested there is currently not enough evidence to do this (Sullivan et al., 1997; Perkins et al., 2005) due to the sparsity of research, but disordered eating practices occur (Bayle & Bouvard, 2003). They therefore suggested that "qualitative work such as conducting focus groups with health care providers of DRCHC patients and DRCHC patients themselves would increase understanding of how eating

disorders develop in DRCHC populations and lead to a suitable theoretical framework for patient interventions” (Quick et al., 2013).

More recent research carried out by Ilzarbe et al. (2017) included a case study of a female with a comorbid diagnosis of IBD and ED, as well as a systematized review of published cases of patients with the same condition. Their findings highlighted a possible association between IBD and ED and suggested several risk factors to associate EDs with IBD, such as “preoccupation with dietary management, fear of abdominal discomfort from eating food, weight and body shape concerns and poor body image”. They went on to suggest clinical implications relevant to the field of clinical psychology, including suggesting a multi-disciplinary team approach is necessary to provide adequate therapeutic interventions, due to the complexity of these cases. They also suggested a screening tool which evaluates eating attitudes early on in patients with IBD is needed, as the review found the association between IBD and ED may cause a deterioration in both conditions. Before this can be carried out, Ilzarbe et al. (2017) suggested research is needed to further consolidate the link between IBD and EDs and identify possible clinical markers which could assist in the earlier identification of EDs in the IBD population; this is the research I aim to carry out.

Method

Participants

I aim to recruit individuals who have received a diagnosis of IBD and who self-report experiencing difficulties with eating relating to the onset of the IBD; this may also include individuals who have received a formal diagnosis of an ED. There is consensus within the literature that the age of onset for EDs lies within adolescence and young adulthood (Halmi, 2005); Volpe et al. (2016) sought to more clearly define this, and through a large scale study

of 806 participants, found that for all types of EDs, the average age of onset was 18 years old. Therefore, I will aim to recruit individuals from 18 years onwards. IBD will refer to all variations of the disease, specifically Crohn's Disease and all forms of Ulcerative Colitis. Difficulties with eating will refer to individuals who may experience disordered eating behaviours associated with EDs which would be described as abnormal, including restraint eating and controlling body weight and shape through unsuitable compensatory behaviours, that would not meet criteria for an ED as defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013). EDs will refer to all illnesses which meet diagnosable criteria and are defined as "clinically meaningful behavioural or psychological pattern having to do with eating or weight that is associated with distress, disability, or with substantially increased risk of morbidity or mortality" (Grilo, 2006, p.3). As defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013), these include anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), or avoidant restrictive food intake disorder (ARFID), Other Specified Feeding or Eating Disorder (OSFED) and Unspecified Feeding or Eating Disorder (UFED). Due to the exploratory nature of this study, with no similar research having been conducted previously, IPA will be used; IPA calls for an in-depth idiographic analysis, therefore I will aim to recruit a small sample size of 10 participants.

Inclusion criteria:

- Individuals with a diagnosis of IBD who are aged 18 or over.
- Individuals who would describe themselves as having/having had disordered eating but have not received a diagnosis of an ED, or Individuals with a previous or current diagnosis of an ED.

- Individuals who currently reside in the UK; this is to ensure individuals have received similar service provision in regards to their IBD.

Exclusion criteria:

- Individuals with a diagnosis of Irritable Bowel Syndrome as IBS is not classified as a chronic health condition; it does not have a disease profile and does not result in the invasive treatment or surgery of IBD.

Design

Individual semi-structured interviews will be conducted with participants, using a narrative approach. Due to the exploratory nature of this study, with no similar research having been conducted previously, IPA (Smith & Osborn, 2003) will be used; IPA calls for an in-depth idiographic analysis, therefore I will aim to recruit a small sample size of 6-10 participants.

Materials

In order for key topic areas to be covered, whilst also facilitating the researcher to have some degree of flexibility, semi-structured interviews will be used. The interview questions will ask participants to focus on their experience from the point of receiving a diagnosis of IBD to the current date, such as “How did the identification of an ED come about?” and “Have you noticed any changes in your relationship with eating since this identification?” The aim of this is to establish if participants experience and recount a relationship between their IBD and ED experiences. Questions to be used within the interview (appendix 3) have been screened by experts by experience, alongside the participant information sheet (appendix 1), the consent form (appendix 2), the email for participants (appendix 6) and social media handle (appendix 5), to ensure the appropriateness of these materials.

Participants will be asked to inform the researcher what diagnosis of IBD they received, and when they received this. Participants will also be asked if they have received a formal diagnosis of an ED or if they associate themselves with having difficulties with eating relating to the onset of an IBD (appendix 8). If participants have received a formal diagnosis of an ED, they will also be asked when this diagnosis of an ED was received and if the ED is still current. In regards to participants who recount having difficulties with eating, participants will be provided with a definition of each ED, as defined by the DSM-V (2013) and asked to state which one they most identify with.

Consent

Ethical approval from Lancaster University FHMREC will be sought; in order to do this, a detailed ethics form will be sent via email to the FHMREC administrator, alongside the supporting documents. Specifically, these include the participant information sheet (appendix 1), consent form (appendix 2), interview schedule (appendix 3), email to be sent to identified individuals on online forums/websites (appendix 4), the social media handle (appendix 5), the email to be sent to the list of individuals who have previously registered interest in taking part in future research (appendix 6), the expression of interest/opt in form (appendix 7), and demographic data collection sheet (appendix 8).

Consent from participants to participate in the research will also be sought. Information packs (appendix 6) will be provided to potential participants via email from the researcher, once participants have identified their interest via advertisements placed on the Crohns and Colitis website, Beat Eating Disorders website or social media platforms, or the researcher's individual social media platforms. When potential participants identify they might be interested, they can contact the researcher with any questions if needed. Once

participants have been provided with information packs, the earliest point of participation will be 48 hours following this. Informed consent forms will be completed with the researcher and participant; if the interview is taking place in person, this will be completed on paper prior to commencement of the interview. However, if the interview is being conducted via skype, verbal consent will be obtained at the time of interview and audio-recorded separately to the rest of the interview and stored; consent will be gained by reading out each item from the consent form for the participant to verbally agree.

Procedure

Purposive sampling will be used to recruit individuals. Targeted recruitment efforts will be employed; an email (appendix 4) will be sent to an identified contact person from online forums such as Crohns & Colitis UK and Beat Eating Disorders will be contacted in the first instance via the contact details provided on their website to obtain permission to advertise the research on their website, and on their social media platforms, specifically Facebook, Twitter and Instagram. A handle (appendix 5) will be requested to be advertised on social media platforms, which will also be advertised on the researcher's professional twitter account. The researcher's field supervisor will also send a dictated email (appendix 6) to individuals who stated following a previous piece of research, that they would be happy for their contact details to be stored in order to be contacted about participation in future research.

Participants will identify potential interest via the contact information provided or using the expression of interest form (appendix 7). The researcher will then provide them with information packs about the study, including the participant information sheet (appendix 1) and consent form (appendix 2).

Participants will be able to indicate whether they would be interested in taking part in the project and if they would like to discuss the project further. Participants will not have to do this immediately and they will be given time to consider whether they wish to take part in the research, however, if participants do decide to take part immediately, this will be possible, within 48 hours. If participants express their interest and are happy to participate, arrangements can be made to gain full consent and conduct an interview. If interest is maintained, arrangements will be made to go through the participant information sheet, obtain informed consent and conduct a semi-structured interview at a site convenient to the participant if geographical location permits this or via telephone/skype call. This interview will be audio recorded. This process may be repeated with a second call to recruit if necessary to support recruitment.

Once recruited, participants will be asked to attend a single interview session which is expected to last approximately 1 hour. In order for key topic areas to be covered, whilst also facilitating the researcher to have some degree of flexibility, semi-structured interviews will be used. The interview will ask participants to focus on their experience from the point of receiving a diagnosis of IBD to the current date, to establish if participants experience and recount a relationship between their IBD and ED experiences. Questions to be used within the interview (appendix 3) have been screened by experts by experience, alongside the participant information pack and social media handle (appendix 5), to ensure the appropriateness of these materials.

Participants will be asked to inform the researcher what diagnosis of IBD they received, and when they received this. Participants will also be asked if they have received a formal diagnosis of an ED or if they associate themselves with having difficulties with eating relating to the onset of IBD (appendix 8). If participants have received a formal diagnosis of an ED,

they will also be asked when this diagnosis of an ED was received and if the ED is still current. In regards to participants who recount having difficulties with eating, participants will be provided with a definition of each ED, as defined by the DSM-V (2013) and asked to state which one they most identify with. Specifically, these include:

- **Anorexia Nervosa:** Persistent restriction of energy intake leading to significantly low body weight (in context of what is minimally expected for age, sex, developmental trajectory, and physical health); Either an intense fear of gaining weight or of becoming fat, or persistent behaviour that interferes with weight gain (even though significantly low weight); Disturbance in the way one's body weight or shape is experienced, undue influence of body shape and weight on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.
- **Bulimia nervosa:** Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting, misuse of laxatives, diuretics, or other medications, fasting, or excessive exercise; The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for three months; Self-evaluation is unduly influenced by body shape and weight; The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

- **Binge-eating disorder:** Recurrent episodes of binge eating. An episode of binge eating is characterised by both of the following: Eating, in a discrete period of time (e.g. within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances AND a sense of lack of control over eating during the episode (e.g. a feeling that one cannot stop eating or control what or how much one is eating); The binge eating episodes are associated with three or more of the following: eating much more rapidly than normal, eating until feeling uncomfortably full, eating large amounts of food when not feeling physically hungry, eating alone because of feeling embarrassed by how much one is eating, feeling disgusted with oneself, depressed or very guilty afterward; Marked distress regarding binge eating is present; Binge eating occurs, on average, at least once a week for three months; Binge eating not associated with the recurrent use of inappropriate compensatory behaviours as in Bulimia Nervosa and does not occur exclusively during the course of Bulimia Nervosa, or Anorexia Nervosa methods to compensate for overeating, such as self-induced vomiting.
- **Avoidant restrictive food intake disorder:** An Eating or Feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with one (or more) of the following: Significant loss of weight (or failure to achieve expected weight gain or faltering growth in children), Significant nutritional deficiency, Dependence on enteral feeding or oral nutritional supplements, Marked interference with psychosocial functioning; The behaviour is not better explained by lack of available food or by an associated culturally sanctioned practice; The behaviour does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no evidence of a disturbance in the way one's body weight or shape is

experienced; The eating disturbance is not attributed to a medical condition, or better explained by another mental health disorder. When it does occur in the presence of another condition/disorder, the behaviour exceeds what is usually associated, and warrants additional clinical attention.

- **Other Specified Feeding or Eating Disorder:** A person must present with a feeding or eating behaviours that cause clinically significant distress and impairment in areas of functioning, but do not meet the full criteria for any of the other feeding and eating disorders. A diagnosis might then be allocated that specifies a specific reason why the presentation does not meet the specifics of another disorder (e.g. Bulimia Nervosa-low frequency).
- **Unspecified Feeding or Eating Disorder:** This category applies to where behaviours cause clinically significant distress/impairment of functioning, but do not meet the full criteria of any of the Feeding or Eating Disorder criteria. This category may be used by clinicians where a clinician chooses not to specify why criteria are not met, including presentations where there may be insufficient information to make a more specific diagnosis (e.g. in emergency room settings).

Interviews will be recorded onto a voice recording device. This will not be encrypted, or password protected but will be kept securely by the researcher. Recordings will be transferred to the secure, encrypted Lancaster University drive at the earliest opportunity, and transcribed into anonymous transcripts, both of which will be password protected. The research supervisor will look at excerpts from these.

Potential Barriers

Recruitment difficulties may exist as IBD and its association with EDs is currently under researched and is often not picked up on by health care professionals (Quick et al., 2013).

Therefore, there may be a limited number of individuals who have received both diagnoses. To account for this, previous research has included participants with disordered eating which is described by Quick et al. (2013) as “abnormal behaviours associated with eating disorders, such as restraint eating; emotional eating; disinhibited eating...that do not warrant a psychiatric diagnosis of an ED”. Therefore, the current research will also include individuals who experience disordered eating.

Management of Professional Role and Researcher Role

It is acknowledged that the researcher’s role transcends two areas, due to simultaneously holding positions as a mental health professional and a researcher. The researcher’s professional role does not sit within the network in which the research is being carried out. In circumstances where the researcher believes it to be appropriate or necessary, such as if there are concerns about a participant’s wellbeing or risk, information will be shared using the appropriate structures available, such as the researcher’s field supervisor, research supervisor, safeguarding etc. If possible, this will be agreed with the participant in the first instance.

Analysis

IPA will be used to analyse the data, guided by the approach outlined by Smith and Osborn (2003). IPA has been chosen as it allows for the context and personal meanings of an individual’s experience to be analysed in detail, whilst acknowledging the process will be influenced by the researcher’s own interpretations. Ilzarbe et al. (2017) suggested research is needed to further consolidate the link between IBD and EDs and identify possible clinical markers which could assist in the earlier identification of EDs in the IBD population. Therefore, I plan to use IPA to explore how participants have experienced factors related to developing

an ED, such as dietary management, embodied sensations (such as discomfort from eating food), weight and body satisfaction.

Interviews will be audio recorded and transcribed verbatim (Smith & Osborn, 2003). The transcripts will be frequently read and a left-hand margin used to annotate what is interesting or significant about what the respondent said. The right-hand side margin will then be used to document emerging theme titles. I will attempt to connect the themes and cluster them together, checking the transcript to ensure the concepts fit with the original transcript. Once themes have been identified for each transcript, I will look for convergences and divergences across the transcripts. A table will be devised, with themes ordered coherently. At this stage, themes which do not fit well in the emerging structure or do not have substantive evidence within the transcript may be dropped. Once the final themes are collated, a write up will be carried out which aims to explain the themes within a narrative account.

Dissemination

The findings will be written in a report for submission to Lancaster University in partial fulfilment of a Doctorate in Clinical Psychology. The findings may also be published in an academic/professional journal and may be presented at conferences. Participants will also receive a copy of the findings or a summary at their request.

Ethical concerns

Risk to participants

Minimal risks are associated with taking part in this study. However, participants may find discussing their experiences to cause distress. If participants become distressed during the interview, the researcher will offer to pause or stop the interview. If this occurs during or after participation in the study, participants will have the opportunity to discuss it with the

interviewer, or use the resources provided on the Participant Information Sheet. Information has been incorporated into the participant information sheet for the event that any participants feel they would like to seek support following their participation in the study.

Confidentiality and its limits will be clearly explained prior to the interview taking place and participation in the project. If serious concerns are raised such as concerns about wellbeing and/or risk, it will be important for the researcher to ascertain if it is necessary to inform the appropriate services of this, such as services supporting the individual at that time or the relevant crisis teams within the area. However, if it was felt that this was necessary, this would be collaboratively discussed with the participant about how to best share this information.

Participants are welcome to withdraw from the study at any time. However, the removal of their data will have a time limit of two weeks following their interview. After this, it may not be possible to remove data once analysis is started and the data has been pooled.

Risk to researchers

It is likely to be necessary to provide participants with the researchers email address for recruitment purposes. In the interest of risk, the researcher's university email will be used. If a mobile phone is needed for the same purpose, a non-personal (research project) phone will be used.

Whilst it is foreseen that the majority of interviews will be conducted via skype, interviews will be offered on a face to face location if the geographical location permits this. At this point the university's lone working policy will be adhered to, taking into account section 2 of field work planning, particular in regards to risks present in the geographical location, as well as section 3.1 in regards to personal safety. A peer identified by the researcher will be advised when, where and at what time the interviews will take place, and

will be informed when the interviews are complete. It is hoped that a 'Skyguard' alarm device will also be used in order to raise an alarm if a dangerous situation should arise. The 'Skyguard' device will be linked with an online account which will be updated with details of the interview including time and location. In the event of a dangerous situation, the device will be activated and a Skyguard representative will be able to access the account information to take the necessary steps such as contacting the appropriate authorities.

Approximate Timescale

ACTIVITY	DATE
Submit ethics proposal	November 2019
Data collection	July 2021-September 2021
Data analysis	September 2021
Submit Thesis	March 2022

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-V*. American Psychiatric Association.
- Anderson, C., & Kirkpatrick, S. (2016). Narrative interviewing. *International Journal of Clinical Pharmacology*, 38, 631–634. <https://doi.org/10.1007/s11096-015-0222-0>
- Bayle, F., & Bouvard, M. (2003). Anorexia nervosa and Crohn's disease dual diagnosis: a case study. *European Psychiatry*, 18, 421–2.
- Grilo, C. (2006). *Eating and weight disorders*. Psychology Press.
- Halmi, K.A. (2005). The multimodal treatment of eating disorders. *World Psychiatry*, 4, 69-73.
- Ilzarbe, L., Fàbregab, M., Quinteroc, R., Bastidasd, A., Pintorc, L., García-Campayoa, J., Gomollón, F., Ilzarbe, D. (2017). Inflammatory Bowel Disease and Eating Disorders: A systematized review of comorbidity. *Journal of Psychosomatic Research*, 102, 47–53.
- Larion, S., DeCecchis, P.D., Arnold, M.J., Vanslyke, A.J., & Tavakoli, R.H. (2015). Psychiatric Comorbidities in Inflammatory Bowel Disease. *Current Psychiatry Reviews*, 11(2), 124-129.
- Lewinson, P., Striegel-Moore, R., & Seeley, J. (2000). Epidemiology and natural course of eating disorders in young women from adolescent to young adulthood. *Journal of American Academy of Child and Adolescent Psychiatry*, 39, 1284-1292.
- Neuendorf, R., Harding, A., Stello, N., Hanes, D., & Wahbeh, H. (2016). Depression and anxiety in patients with inflammatory bowel disease: a systematic review. *Journal of Psychosomatic Research*, 87, 70–80, <http://dx.doi.org/10.1016/j.jpsychores.2016.06.001>
- Perkins, S., Keville, S., Schmidt, U., & Chalder, T. (2005). Eating disorders and irritable bowel syndrome: is there a link? *Journal of Psychosomatic Research*, 59, 57–64.
- Quick, V. M., Byrd-Bredbenner, C., & Neumark-Sztainer, D. (2013). Chronic illness and disordered eating: A discussion of the literature. *Advances in Nutrition: An International Review Journal*, 4(3), 277–286. <https://doi.org/10.3945/an.112.003608>

- Quick, V. M., McWilliams, R., & Byrd-Bredbenner, C. (2012). Case-control study of disturbed eating behaviors and related psychographic characteristics in young adults with and without diet-related chronic health conditions. *Eating Behaviors, 13*(3), 207–213.
- Rosen, D. (2010). Clinical report-identification and management of eating disorders in children and adolescents. *Paediatrics, 126*, 1240-1253.
- Smith, J. A., & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods* (pp. 53-80). Sage.
- Volpe, U., Tortorella, A., Manchia, M., Monteleone, A.M., Albert, U., & Monteleone, P. (2016). Eating disorders: What age at onset? *Psychiatry Research, 238*, 225-227.

Appendix 4-C

Participant Information Sheet

Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.

My name is Emma Mellor and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University.

What is the study about?

We would like to hear about your experiences of having IBD and how this has impacted upon your relationship with eating, for instance any psychological difficulties with eating which you may now face.

Why have I been approached?

You have been approached because you have identified that you are interested in taking part in a piece of research looking at the experiences of individuals with IBD and the consequent relationship with eating on a social media page. It is hoped that this research will support future developments in practice for staff working in these areas.

Do I have to take part?

No. Taking part is completely optional you can decide to take part and then change your mind.

What will I be asked to do if I take part?

If you agree to take part you will be asked to do an interview where you will answer some questions and talk about your experiences of IBD and difficulties with eating. The interview will last for approximately 1 hour and would take place either face to face in a place convenient to yourself, by telephone or using an application such as skype. You can stop the interview at any time and it can be done in two parts if required. The interviews will be audio recorded and then written up.

Will my information be confidential?

The information you provide will be kept confidential and stored safely. Your personal information will be kept securely and will be destroyed at the end of the project.

Only the researchers conducting this study will be able to access the data.

Audio recordings from the interviews will be written up and then the recording will be destroyed securely at the end of the project.

- Lancaster University will keep copies of the anonymised transcripts for 10 years after the study has finished or after it is published, whichever is longer. At the end of this time, they will be destroyed securely.
- Files held on computer will be password protected.
- The transcript of your interview will not have any personal information like your name. Anonymised quotes from your interview may be used in the report or in publications of the study, but your name will not be used with them.
- Personal data will be confidential and will be kept separately from your interview.

If it is felt that there is a risk of harm to yourself or someone else or if there are concerns about your wellbeing, confidentiality would have to be broken. This would most likely be my supervisor in the first instance and would then be followed up through whatever channel is appropriate. If it is possible, I would speak to you and agree a plan together before doing this.

Another possible limit of confidentiality is that it might be difficult to make quotes fully anonymous in the report. Your personal details such as your name will not be used but there is a chance that people who know you and work with you might be able to identify you from the quotes.

Participants using Skype should be aware that the internet cannot be guaranteed to be a completely secure means of communication.

What will happen if I decide to leave part way through?

You can choose to leave the study at any time. You can also ask for your data to be taken out, up to a period of two weeks after the interview.

What will happen after I take part?

The results will be written up in a research report and may be published in an academic journal and may be presented at conferences. If you would like a copy of the results, please ask the researchers.

Are there any risks?

We expect there to be minimal risks associated with taking part in this study. If you experience any distress during or after the interview, please discuss it with Emma (the interviewer), or using the resources provided at the bottom of this sheet.

Are there any benefits to taking part?

Taking part may give you the opportunity for your opinions and experiences to be heard and this could provide valuable information about how services can better support individuals with these experiences. If travel is necessary, you will be reimbursed for your expenses, up to a maximum of £20.

Who has reviewed the project?

This study has been reviewed and given approval by the Lancaster University Faculty of Health and Medicine Research Ethics Committee.

Who is organising and funding this study?

The project is being completed in partial completion of a Doctorate in Clinical Psychology at Lancaster University.

How do I take part?

If you are interested in taking part then you can contact myself at e.mellor@lancaster.ac.uk or on 07908613796. I am a Trainee Clinical Psychologist and a member of the project research team. I will be able to give you more information about taking part.

Research team

Members of the research team are:

Emma Mellor (Trainee Clinical Psychologist, Lancaster University)

Dr Craig Murray (Senior Lecturer in Health Research, Lancaster University)

Dr Georgina Rowse (Senior Clinical Psychologist, Doctorate in Clinical Psychology Programme at the University of Sheffield)

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood, Programme Director of the Doctorate in Clinical Psychology

Faculty of Health and Medicine

Lancaster University

Tel: +44 (0)1524 593998

Email: b.sellwood@lancaster.ac.uk

or

Professor Roger Pickup Associate Dean for Research

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YG

Tel: +44 (0)1524 593746

Email: r.pickup@lancaster.ac.uk

GDPR

“Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection”

Resources

It is not anticipated that taking part in this research will cause distress. However, should you feel distressed as a result of taking part you can contact:

- The Samaritans if you feel you need to talk to someone using their local helpline: 01524 61666 or website www.samaritans.org
- You can contact Mind on the following number: 0300 123 3393, or by email on: info@mind.org.uk or by text message on: 86463

Thank you for taking the time to read this information sheet.

Appendix 4-D**Consent Form****Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel****Disease (IBD) and how this has impacted upon their relationship with eating.**

We are asking you to participate in a study which investigates experiences of individuals with a diagnosis of IBD and their relationship with eating. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with a tick if you agree. If you have any questions or queries before signing the consent form please speak to a member of the research team.

	Please initial box
1. I confirm that I have read the participant information sheet and understand what is expected of me in this study	
2. I confirm that I have had the chance to ask any questions and to have them answered.	
3. I understand that my involvement is voluntary and I can withdraw at any time.	
4. I understand that if I wish to withdraw my data, I can do so up to 2 weeks after the interview without giving a reason.	
5. I understand that my interviews will be audio recorded and then made into an anonymised written transcript.	
6. I understand that the information from my interviews will be anonymised along with information from others and may be published.	

7. I consent to information from the study including quotations from my interviews being used in reports and conferences.	
8. I understand that any information I give will remain confidential unless there may be a risk of harm to myself or others. In these circumstances, information may need to be shared with appropriate people.	
9. I consent to Lancaster University keeping the anonymised data from the study for up to 10 years after the study has finished or after publication.	
10. I consent to take part in the study.	

Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Appendix 4-E

Interview Schedule

Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.

This interview schedule outlines areas to be discussed in the interview with some example questions. The interview will use a narrative approach based on that set out by Anderson and Kirkpatrick (2016) and will therefore prioritise the participant's experiences. The interview will therefore start broad to try to gain the participant's story. Exact questions will depend on participants' responses and content that the individual being interviewed finds important and discusses. Below are some examples of possible questions and prompts if required. The interview schedule may be revised following the first interview if it is found that the required data is not being obtained.

Introduction

Introduce self. Cover participant information sheet, consent and purpose of interview. Check any necessary demographic information not already collected at point of consent and any changes in circumstances. Orientate participants to think about experiences IBD and ED. The interview will then begin with open questions asking the participants for their story. Following this, follow up questions will be used based on the content described by the participant. This may include questions about before, during and after the identification of an ED; some examples are outlined below.

Before identification

Example questions:

Thinking back to the time you were diagnosed with IBD, what was your relationship like with eating at this point?

What changes did you notice with your relationship with eating over time? How did this change?

What other changes did you notice aside from your relationship with eating?

During identification

Example questions:

How did the identification of difficulties with eating/ ED come about?

What differences did you first notice?

How did your experiences develop over time?

Were you able to talk to anyone about this? E.g. peers, family

In what way did/does your experience of difficulties with eating impact on your IBD?

Did you attend services? Which services? What was your experience of the meeting? Did you feel understood/ heard? Was the focus on your existing IBD or difficulties with eating? How did the service make sense of things?

After identification

Example questions:

Have you noticed any changes in your relationship with eating since this identification?

Have you noticed any changes in any other experiences since this identification?

Have you noticed any changes in the care you've received from services? And additional involvement from other services?

Conclusion

In this part of the interview the participant will be thanked for taking part. The interviewer will ensure the participant has not been distressed by the interview by asking how the participant feels. If necessary, participants will be directed to sources of support on the participant information sheet.

Appendix 4-F**Email for field supervisor to distribute to individuals with registered interest of participating in future research**

*Email Subject: Research conducted at Lancaster University - **Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating.**

Dear X

RE: Participation in research study

We would like to invite you to participate in a research study about experiences of living with a diagnosis of Inflammatory Bowel Disease and your relationship with eating following the onset of IBD. If this is something you feel you could contribute to and would like to participate, you would be asked to attend a one-off interview in which you would talk about your experiences and it would last approximately 30 minutes to 1 hour. The interview would be at a place convenient to you or by telephone/skype. If travel is necessary, you will be reimbursed for your expenses, up to a maximum of £20.

More details are available in the attachments. If you have any queries or you are interested in taking part, please contact Emma Mellor (Trainee Clinical Psychologist) on e.mellor@lancaster.ac.uk or XXXXX, or Georgina Rowse (Clinical Psychologist) on g.rowse@sheffield.ac.uk.

Yours sincerely,

Emma Mellor.

Trainee Clinical Psychologist

Lancaster University

e.mellor@lancaster.ac.uk

Appendix 4-G

Email to Charity Organisations

Dear [Recipient Name]:

I am writing to ask you to advertise the following study [on your website AND/OR on your social media pages] [Crohn's and Colitis UK website AND/OR Facebook, Twitter, Instagram; Beat Eating Disorders website AND/OR Facebook, Twitter, Instagram; and others].

I would like to recruit people aged 18 years or over who have been diagnosed with Inflammatory Bowel Disease (IBD) and who experience difficulties with their relationship with eating following the onset of IBD.

This research is part of my educational studies and I intend to submit the findings for publication once the study is complete.

Participants are asked to complete an interview which should last approximately 1 hour and includes questions relating to their individual experience of having IBD and difficulties with eating.

The findings of this study are intended to provide information about how health professionals can better support people who live with both of these conditions.

The study has been screened and approved by the Faculty of Health/Faculty of Sciences Ethics Committee at Lancaster University, UK.

If you would like to discuss any aspect of the study prior to deciding whether to advertise the study to your members then please make contact with me via the following email address:

e.mellor@lancs.ac.uk.

Thank you for reading this message.

Appendix 4-H**Social Media/Website Handle**

Would you like to take part in a study about your experience of IBD and your relationship with eating? Your experiences are valuable to help improve care provided by services. For more information and how you can support [#IBD](#) [#research](#) [@CrohnsColitisFn](#):

[LINK](#)

Appendix 4-I**Expression of interest/ Opt-In Form****Participant Opt-In Form**

Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel

Disease (IBD) and how this has impacted upon their relationship with eating.

I would like to be contacted further about this research project:

Name	Signature	Email/Contact number

You can return this form by posting it to me in the envelope provided or you can contact me using the details below:

Emma Mellor
Trainee Clinical Psychologist
Lancaster University

Email: e.mellor@lancaster.ac.uk
Mobile:

Thank you.

Appendix 4-J

Demographic Data Collection Sheet

Age:

Gender:

IBD:

Diagnosis:

Age at time of diagnosis:

Difficulties with eating:

Eating Disorder Diagnosis/diagnosis which you identify with:

Age at time of diagnosis/ diagnosis which you identify with:

Are the difficulties with eating current?

Appendix 4-K
FHMREC Approval Letter



Applicant: Emma Mellor
Supervisor: Dr. Craig Murray
Department: DHR
FHMREC Reference: FHMREC19110 (amendment to FHMREC19027)

11 June 2020

Re: FHMREC19110 (amendment to FHMREC19027)
Understanding the experiences of individuals with a diagnosis of Inflammatory Bowel Disease (IBD) and how this has impacted upon their relationship with eating

Dear Emma Mellor,

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in blue ink that reads "E. Suri-Payer".

Dr. Elisabeth Suri-Payer,
Interim Research Ethics Officer, Secretary to FHMREC.