Emma Harriman BSc Hons MSc

SELF-DISCLOSURE AND DISORDERED EATING IN INFLAMMATORY BOWEL DISEASE (IBD)

Section A: Disclosing Inflammatory Bowel Disease: A meta-synthesis exploring the experiences, barriers, and facilitators of self-disclosure

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Section B: Prevalence and predictors of developing Avoidant Restrictive Food Intake Disorder in Inflammatory Bowel Disease

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A thesis submitted in partial fulfilment of the requirements of
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Acknowledgements

I would like to thank my partner, Matthew, for all his time, effort, support, and encouragement. Thank you for always believing in me and being there to help me manage my stress and panic. I would also like to thank my family for all their encouragement, support and sacrifice to get me to where I am.

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Summary of Major Research Project

Section A: This review aimed to collate individuals' experiences of disclosing Inflammatory Bowel Disease (IBD), focusing specifically on the factors facilitating or preventing these decisions. A systematic review of five databases identified 34 studies eligible for inclusion in this review. Studies showed that the disclosure decisions for individuals with IBD are complex and influenced by several personal and social contexts, including the visibility of the illness, perceived stigma, and necessity of disclosure. Individuals' experiences of talking to others about their IBD varied, with some experiencing strengthened relationships, while others were met with negative responses.

Section B: The perceived association between gastrointestinal symptoms and diet, may increase the risk of Avoidant Restrictive Intake Disorder (ARFID) for individuals with Inflammatory Bowel Disease (IBD). This study aimed to estimate the prevalence, and identify biopsychosocial predictors, for ARFID in the UK IBD population. The results from this study indicated that ARFID symptoms were present in a high proportion of the sample, with biopsychosocial factors appearing to predict this. Particularly, it was found that gastrointestinal-specific anxiety predicted ARFID symptoms over and above IBD-related factors. These findings suggest that healthcare services offering interventions around gastrointestinal-specific anxiety may be important in reducing ARFID for this population.

Context of Major Research Project

Section A and B of this Major Research Project both explore psychological phenomena within the context of individuals living with Inflammatory Bowel Disease (IBD). However, the psychological phenomena which the papers focus on vary between Sections A and B. This is due to recent review papers relating to disordered eating, including avoidant and restrictive eating patterns, in IBD already existing (example references in Appendix A). Adaptations of these were considered, however, the literature search did not provide any new papers, or any new information, which would justify Section A. Therefore, the search was expanded to consider Avoidant Restrictive Intake Disorder more specifically. However, the existing literature for this, especially in relation to an IBD population, was sparce and was not enough for a comprehensive review. Therefore, the decision was made to expand the scope of Section A and consider other psychological aspects, while keeping the focus of the research within the context of IBD.

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SELF-DISCLOSURE AND DISORDERED EATING IN INFLAMMATORY BOWEL DISEASE (IBD)

SECTION A:

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Abstract

Introduction: As Inflammatory Bowel Disease (IBD) is an invisible illness, individuals must make decisions around self-disclosure. Existing reviews have identified stigma as a barrier to disclosing IBD, however, other factors potentially affecting disclosure decisions have not been reviewed. The current review sought to synthesise qualitative papers exploring the experiences of disclosure, and identify facilitators and barriers to disclosure, within IBD. **Methods:** A systematic review across five databases was completed. In total 1487 papers were identified, with 34 (comprising 1004 participants) being included in analysis. Following critical appraisal, a thematic meta-synthesis was completed. This review was registered with The International Prospective Register of Systematic Reviews (PROSPERO; registration ID CRD42023481441). **Results:** A total of five main themes were identified: It's an invisible, stigmatized illness; Reluctance to disclose; A need to disclose; Balancing the need to disclose and the reluctance to disclose; and Varied consequences to disclosure. **Conclusions:** This review synthesised the varying experiences of disclosures for individuals with IBD and highlighted the complexity of disclosure decisions, with these decisions being influenced by personal beliefs, social contexts, and previous experiences. In support of previous reviews, individuals identified the role of stigma in preventing self-disclosures. Potential clinical implications, the impact for public health services, and the need for future research is discussed.

Key words: Inflammatory Bowel disease (IBD), Crohn's Disease, Ulcerative Colitis, Self-disclosure, Stigma.

Introduction

Inflammatory bowel disease

Inflammatory Bowel Disease (IBD), including Crohn's disease (CD) and Ulcerative Colitis (UC), is a progressive autoimmune illness affecting the gastrointestinal tract (Kalla et al., 2014; Ungaro et al., 2017). This lifelong condition is estimated to effect 0.81% of the UK population, with 1 in 123 people being diagnosed a year (Crohn's & Colitis UK, 2022). IBD presents as a relapsing-remitting disease (Liverani et al., 2016) causing periods of unpleasant symptoms, including abdominal pain, difficulties with bowel movements (frequent diarrhoea, constipation, or blood), vomiting, fatigue, weight loss and growth difficulties (Farrell et al., 2016), which can be challenging for individuals living with the disease.

Visibility of illnesses

Chronic illnesses can be categorised as "visible", where symptoms are externally observable by others, or "invisible" where symptoms are less outwardly detectable (Donoghue & Siegel, 2000; Joachim & Acorn, 2000; Stone, 2005). Although there are some aspects of IBD, such as changes in appearance, uncontrollable odour and frequent bathroom use which make it visible, especially during flare-ups (Guo et al., 2020), it is generally considered "invisible", as individuals can appear "healthy" to others (Micallef-Konewko, 2013; Vickers, 1997) despite the ongoing internal symptoms, such as pain and fatigue (Crohn's & Colitis Foundation, 2023; Micallef-Konewko, 2013). This internal struggle creates further challenges for those living with IBD as their illness is misunderstood by others and can go unnoticed (Kouveli, 2022; Micallef-Konewko, 2013; Plant & Brody, 2023).

Disclosure decisions

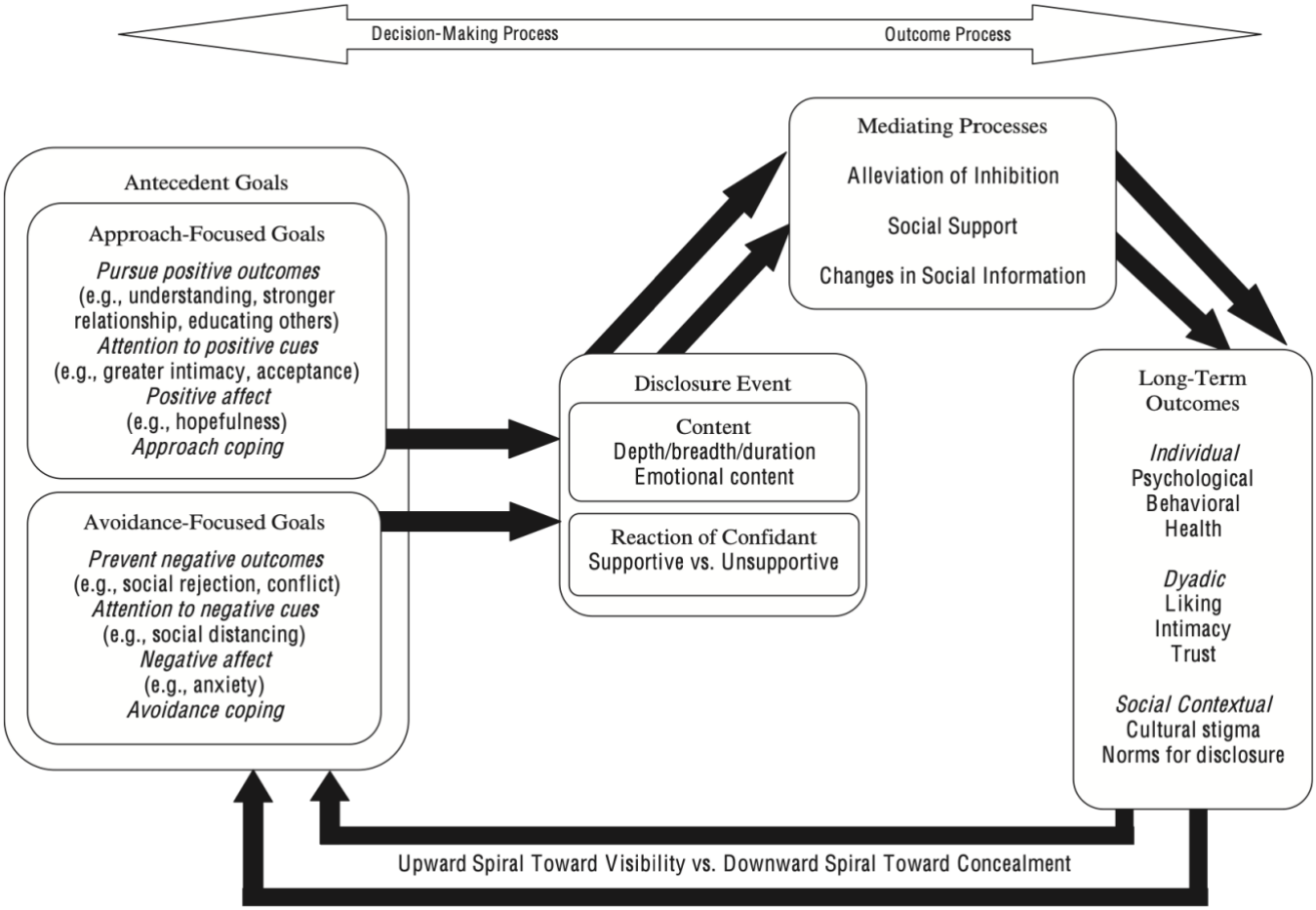
Self-disclosure and disclosure are terms used interchangeably to describe the sharing of personal information with another person (Chelune, 1979; Omarzu, 2000). Although sharing general information about oneself with others has been demonstrated to positively impact

physical health, mental health, and social relationships within general social settings (Omarzu, 2000), the choice of what information, when, and how much, to share with others is a personal choice. As with other invisible illnesses, individuals with IBD are left with the decision of whether to disclose their diagnosis and what information regarding their illness to share.

Disclosure processes and outcomes for concealable illnesses, such as IBD, can be understood theoretically by the Disclosure Processes Model (DPM, Chaudoir & Fisher, 2010). The DPM, as outlined in Figure 1, proposes the interaction of five main components on the decision-making process - antecedent goals, the disclosure event itself, mediating processes, outcomes, and a feedback loop. The DPM understands disclosure decisions as a complex interaction of personal and societal factors, which are used to determine the answer to *when* and *why* the disclosure would be beneficial. In support of the DPM, the literature highlights that the choice to disclose a chronic illness is complex and influenced by a host of factors including the type and severity of illness, and access to support (Benson et al., 2015; Chaudoir et al., 2011; Greene, 2000; Vickers, 1997).

Figure 1

The Disclosure Processes Model of disclosing concealable stigmatized identities (Chaudoir & Fisher, 2010)



Disclosing a stigmatised illness

One factor identified by the DPM to impact disclosure decisions is the perceived stigmatization of the illness (Benson et al., 2015; Chaudoir & Fisher, 2010; Chaudoir et al., 2011; Frank et al., 2006; Joachim & Acorn, 2000). Stigma is a social construct which Goffman (1963) describes as any attribute of an identity that is discredited or seen as "tainted" within a society, which leads individuals to be viewed as "different", devalued, or discriminated against (Major & O'Brien, 2005; Sheehan et al., 2022). Theoretically, it has been understood that illness stigmatization results from perceived or enacted public stigma

and internalised stigma (Green, 2009; Sheehan et al., 2022; Stangl et al., 2019), and is considered the interaction between dimensions of visibility, controllability, course, and perceived danger (Engebretson, 2013; Green, 2009).

The experience of stigma, or the perceived risk of stigmatization, has been identified to prevent self-disclosures in invisible illnesses including HIV, epilepsy, and cancer (Catona et al., 2016; Clifford et al., 2023; Gray et al., 2000; Macleod & Austin, 2003; Wanjala et al., 2023). For IBD specifically, the experience of perceived stigma is commonly reported due to concerns around physical symptoms (Daniel, 2002; Taft et al., 2009) and has been associated with psychological distress, reduced health-related quality of life, reduced adherence with medication and decreased self-esteem (Taft & Keefer, 2016). It has been reported that individuals with IBD may attempt to conceal their illness in attempt to "pass" as someone without a chronic illness, and therefore, avoid the perceived stigmatization (Taft & Keefer, 2016).

In a recent review, Muse et al. (2021) synthesised the qualitative literature exploring the experiences of stigma in individuals with IBD. The themes they identified highlighted common experiences of stigma for people with IBD, with stigma contributing to individuals feeling "labelled" by the disease and a "loss of self" following the diagnosis. In this review, the authors refer to the impact the stigmatization of IBD has on disclosure decisions, with participants wanting to be understood, but feeling the need to conceal their illness identity. Despite the potential benefits from disclosing their IBD, it was found that the fear of stigmatization and shame prevented individuals feeling safe to talk about their illness.

Another recent review by Guo et al. (2020) explores the experience of stigma in IBD, with a more direct consideration of the impact this has on self-disclosure. This paper distinguishes between voluntary and involuntary disclosures and discusses the differing experiences individuals' have when talking about their diagnosis. This review highlights

participants experiences of, and the reasons for, disclosure across different social contexts, such as young people feeling forced to disclose to "explain" their behaviours and individuals disclosing in the workplace to access more appropriate "sick leave" entitlement. However, this review does not detail a systematic approach to their literature search, making it possible that some literature has not been included.

To date, the existing reviews provide an understanding of how stigma impacts self-disclosure for individuals with IBD. However, these reviews have focused on stigma and assumed its importance as a factor influencing self-disclosure without consideration of what other factors may be contributing to these decisions. A review conducted by Micallef-Konewko (2013) aimed to review experiences of disclosing an IBD diagnosis for young people. However, due to the sparsity of literature on this topic, their search also included papers exploring disclosure in other invisible chronic conditions, which was then applied to IBD for young people. This review identifies factors preventing disclosure, such as the risk of bullying, uncertainty around the diagnosis and a desire to live a normal life, as well as reasons why people choose to disclose.

However, due to limited literature at the time it was written, this paper predominantly drew from other chronic illness literature, including HIV, sickle cell disorder and cancer diagnoses, and applied it to IBD, rather than identifying the experiences of IBD directly. As the literature has not been sufficiently reviewed, the understanding of IBD disclosure experiences and factors facilitating/preventing these decisions remains limited.

Current Review

Disclosing physical health conditions involves complex interpersonal and intrapersonal processes (Woodgate et al., 2022), which can have both positive and negative effects on the individual. To date, however, the experiences of disclosing IBD across the life span and/or

the barriers/facilitators associated with disclosure for this population have not been adequately reviewed.

Understanding people's experiences of disclosure decisions in IBD is important for health care staff, as it may identify areas that could be incorporated into patient care. Knowledge of disclosure decisions is important for the psychological care of individuals living with IBD and has the potential to identify areas and resources required to empower individuals to make disclosure decisions (Pathmalingam et al., 2023).

Therefore, this review aims to synthesis the existing literature regarding disclosure within IBD, particularly focusing on how individuals experience disclosures and how they make decisions around choosing to/choosing not to disclose. The main objectives of this review were to:

- Understand the experiences of disclosing and disclosure decisions for individuals living with IBD.
- Identify the barriers preventing people from disclosing information about their IBD or their diagnosis to others.
- Explore the facilitators which have supported individual self-disclosures and the benefits that arise from disclosing.

Method

Review Design

This review was conducted using a meta-synthesis, a broad term used to describe a systematic approach to reviewing qualitative research (Dixon-Woods et al., 2006). Although there are different approaches to meta-synthesis, this review chose thematic synthesis due to its appropriateness in analysing experiences, facilitators, and barriers within healthcare literature (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). A critical realist epistemology was taken, which assumes that although an objective reality exists, our

understanding of this is influenced by our experiences and beliefs (Barnett-Page & Thomas, 2009). This review was registered with The International Prospective Register of Systematic Reviews (PROSPERO, registration ID CRD42023481441, Appendix B).

Search strategy

A search for literature was conducted in October 2023 using five databases: PsychInfo; Medline (Ovid); Scorpus; ASSIA; and CINAHL Complete (EBSCO). Due to the introduction of in Infliximab in 1999, which changed the outcomes and experiences for people living with IBD (Feagan et al., 2007), this review focussed on studies published from 2000 onwards.

The search terms used are displayed in Table 1, with existing research in mental and physical health being consulted to support development of search terms (Adeoye-Agboola et al., 2016; Gonsalve et al., 2023). Forward and backward searching was also used to search the references lists and citations of included studies.

Table 1

Search terms used for this meta-synthesis

Search Area		**Terms used**
Inflammatory Bowel Disease		(“Inflammatory Bowel Disease*” OR IBD OR Crohn* OR Colitis)
	AND	
Disclosure		(disclos* OR self-disclos* OR shar* OR tell* OR conceal* OR talk* OR experience* OR expos*)
Qualitative literature	*AND*	(qualitative OR interview* OR IPA OR “interpretive phenomenological analysis” OR narrative* OR “focus group*” OR “thematic analysis” OR “grounded theory” OR “discourse” OR “ethnography”)

Eligibility criteria

Studies were eligible for inclusion in this review if they met the inclusion criteria and did not violate the exclusion criteria, as detailed in Table 2:

Table 2

Inclusion and exclusion criteria for papers

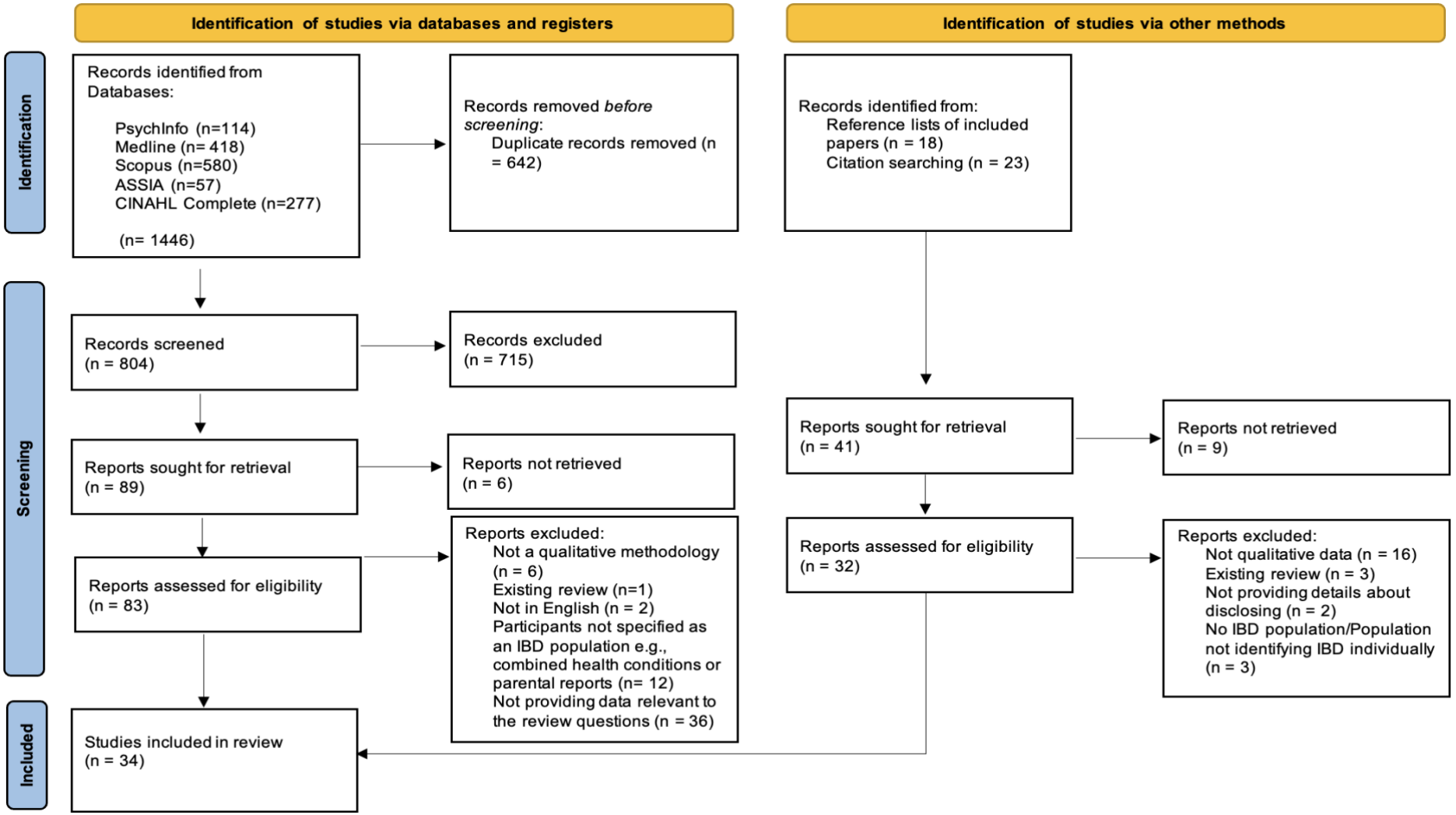
	Criteria
Inclusion	- Studies written in English language. - Studies with participants who had a diagnosis of IBD (Crohn's disease or ulcerative colitis). - Studies using a qualitative approach to methodology and data analysis. Papers using a mixed methodology were also included if the qualitative results provided information which contributed to the review questions. - Studies which explored experiences of disclosing/sharing/discussing/talking about an IBD diagnosis or living with the disease (papers were not required to have explored disclosure as the focus of the research but were included if their qualitative data provided information relevant to any of the research questions). - Peer reviewed journal article or published theses/dissertations.
Exclusion	- Studies reporting the experiences of friends, parents, or family members of people with IBD. - Studies containing participants with different physical health conditions (including other gastrointestinal disorders), where the results were not presented independently for those with IBD. This decision was made as it would not be possible to determine whether quotes were given by an individual with IBD or someone with a different diagnosis.

Screening and selection

This review followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses – PRISMA (Moher et al., 2009) which is summarised in Figure 2. The initial search identified 1446 studies; 642 duplicates were removed. The title and abstracts of the remaining studies were screened, with a further 58 being excluded at this stage for not meeting the eligibility criteria. Reference lists and citations of included studies were screened, identifying 41 that may have been relevant for inclusion. An independent reviewer screened 20% of the included studies against the eligibility criteria. The inter-reliability for screening was 85.7%, with disagreement occurring for one study. Following discussion, the decision was made to include this paper.

Figure 2

PRISMA flow chart for study select



Quality appraisal

The Critical Appraisal Skills Programme framework for qualitative studies (CASP, 2018, Appendix C) provides a 10-item checklist for appraising the aims, methodological design, and outcomes of studies, which is frequently used in syntheses of health-care literature (Long et al., 2020; Majid & Vanstone, 2018). An independent reviewer appraised 50% of the studies which were selected using an online random number generator. The inter-rater quality agreement was 85%. Most of the disagreement occurred between ratings of "can't tell" and "no". Any disagreements were discussed, and an outcome for the final rating was agreed.

Approach to synthesis

All qualitative data and quotations in the results sections of included studies that provided information relevant to the research questions were extracted and inputted into NVIVO 12 software. This software allows data to be highlighted, coded, and arranged into hierarchical themes which supported with the analysis process.

The data was analysed through an inductive thematic analysis which followed the three steps outlined by Thomas and Harden (2008): developing "free codes", organising codes into descriptive categories, and developing analytic themes. The author initially developed free-codes through line-by-line coding which summarised the data by content and meaning. This bank of codes was organised and grouped based on similarities and differences. The final stage of synthesis involved applying meaning to develop analytical themes. Theme construction was discussed and agreed by the author and supervisors.

Reflexivity

Although the steps outlined by Thomas and Harden (2008) do not comment on the researchers positioning, Braun and Clarke (2019) highlight the subjectivity of thematic analysis, with researchers' assumptions influencing the analytic process. Due to this,

reflexivity was held in mind throughout this stage. A reflexive account detailing the author's positioning is provided in Appendix D.

Results

Overview of Included Studies

There were 34 studies included for analysis in this review, 26 identified from the initial database search and eight identified via forward/backwards searches. Table 3 summarises the included studies.

In total, there were 1004 participants contributing to the included studies. Studies varied in their number of participants, with this ranging from six participants (Gelech et al., 2021; Savard & Woodgate, 2009) to 134 (Peters & Brown, 2022), with 29.5 being the average number of participants. The studies included participants from across the lifespan, including nine exploring children and young people up to the age of 25, and 20 had an adult population (aged 18+). Five studies did not include information on the ages of their participants. Most studies included a sample of participants with different types of IBD, however four looked independently at CD (Kitchen et al., 2020; Ruan & Zhou, 2019; Wåhlin et a., 2019; Wang et al., 2017), one looked at UC (Colmer, 2021) and two looked at experiences of individuals either with, or who had previously had, a stoma (Sammut et al., 2017; Savard & Woodgate, 2009). There were two studies which had a sample consisting only of female participants (Lolli, 2022; Murphy et al., 2022), whereas all other papers consisted of both males and females. Although most papers did not include details on ethnicity (n = 24), those that did, reported Caucasian participants as the majority.

Most studies used interviews as their data collection method. Some studies supplemented interview data with participant observations (Salazar & Heyman, 2014), fieldnotes (Salazar & Heyman, 2014), focus groups (Devlen et al., 2014; Hall et al., 2005; Woodward et al., 2016), friendship maps and photographs (Carter et al., 2020; Rouncefield-

Swales et al., 2020). Studies used a range of qualitative analysis. The most common forms of analysis were thematic analysis (n= 13) and phenomenological approaches (n = 7).

Only six studies aimed to explore disclosure directly as part of their research (Barned et al., 2016; Carter et al., 2020; Colmer, 2021; Micallef-Konewko, 2013; Murphy et al., 2022; Saunders, 2014). Most studies aimed to explore individuals' experiences of living with IBD within their wider contexts.

Table 3

Overview of included studies

Study Number	Author (year)	Country	Aims	Participants	Data collection	Qualitative analysis	Key Findings relating to Disclosure
1.	Barned et al., (2016)	Canada	To understand how children and adolescents decide whether to conceal or disclose their illness and how they decide when the appropriate time is to tell others. To understand the main challenges faced when disclosing their illness to others.	25 participants (13 boys, 12 Girls) aged between 10 and 17.	Semi-structured interviews	Thematic analysis	Disclosure decisions were a key part of a young person's experience of IBD. Several factors including severity of illness, knowledge of IBD and others asking influenced these decisions.
2.	Carter et al., (2020)	UK	To explore experiences of disclosing an IBD disclosure, in the context of friendships and social connectedness among young people with IBD.	31 participants (16 male, 15 female) aged between 14-25 (mean age18.7 years). Age at diagnosis ranged from 8 to 23.	Conversational interviews, friendship maps and photographs (photo elicitation technique)	Interpretive Description	Decisions about telling friends about having IBD are challenging for many young people. Having control over disclosure is not always possible, and the potential consequences can feel risky. However, most young people had positive experiences of disclosure and gained

							support from friends and romantic partners.
3.	Colmer, (2021)	Holland	To explore what costs and benefits employees with IBD experience because of their disclosure decision.	93 participants (23 male, 70 female) with an average age of 34.18 years.	Open-ended survey questions	Cutting and sorting technique	Disclosure was associated with little cost and the psychological benefits of transparency and understanding were stated by the participants.
4.	Devlen et al., (2014)	USA	To understand IBD and its treatment from the patient perspective.	27 participants (14 male, 13 female) aged between 20 and 59 (Mean age = 31.5). There were 21 participants with UC and 6 with CD.	Focus groups and one-on-one interviews.	Grounded theory	Disclosure was a major hurdle to overcome, with it being difficult to tell new friends and potential partners about an IBD diagnosis.
5.	Dibley et al., (2017)	UK	To explore stigma experiences in people with IBD.	40 participants aged 23-78 (65% female) and 22 (55%) had CD.	Unstructured interviews	Interpretative Phenomenological Analysis	Feeling stigmatised was a common experience for participants. However, emotional control, social support and mastery over disease can support stigma reduction. Although

							some individuals attempt to conceal their disease due to the risk of others not understanding, self-disclosure had been successful and enabled individuals to receive support and obtain control over their disease.
6.	Dibley et al., (2020)	UK	To explore the experience and meaning of kinship stigma in people with IBD.	18 participants (77% female) aged 21 to 64.	Unstructured interviews	Iterative Hermeneutic Phenomenology	The response from some family members made individuals feel that they could not talk about their IBD and that attempting to disclose often made them feel misunderstood or dismissed.
7.	Frohlich, (2014)	USA	To explore how people with IBD experience stigma because of their disease.	14 participants (7 male, 7 female), aged between 20 to 56 years (mean = 23.6). Average age of disease diagnosis was	Interviews	Phenomenological approach	Most participants perceived their disease to be stigmatizing at one point. However, their experiences of disclosing were generally positive.

				22.1 (ranging 5-45 years).			
8.	Gelech et al., (2021)	Canada	To explore how individuals living with IBD make sense of changes in their approach to coping over time.	6 young adults (3 female, 3 male) aged 21-28. All diagnosed with IBD between 3 and 10 years prior to study.	Semi-structured Interview	Syntactic and thematic analysis	Being more open to friends about their diagnosis and illness was important in participants ability to cope, as it allowed participants to develop and keep important relationships.
9.	Hall et al., (2005)	UK	To gain an understanding of the perspectives and experiences of individuals with IBD and a poor quality of life.	31 participants (19 female and 12 male). There were 17 participants with UC and 14 with CD.	Individual interviews and 3 Focus groups (male group, female group and a mixed group).	Grounded theory	IBD diagnosis and symptoms were often kept private due to fears of not being understood, embarrassment, fear of being labelled or a burden. This also maintained a sense of "normality" for those living with IBD. However, it was identified that disclosure to others also living with IBD was a positive experience.

10.	Kitchen et al., (2020)	USA	To understand adult and adolescent patients' experiences of CD, including CD-related symptoms, the burden of living with CD, as well as the symptoms that drive patients to seek medical treatment.	Round 1: 24 participants (12 male, 12 female) aged 14 to 75. Round 2: 6 adults (2 male, 4 female) aged 41-74.	Interviews	Thematic analysis	Due to the embarrassment around bathroom use, participants avoided telling people, unless an emergency meant that they had to.
11.	Kluthe et al., (2018)	Canada	To elicit perspectives following a diagnosis of Inflammatory Bowel Disease (IBD).	18 participants (7 female, 11 male) aged between 6-17. There were 12 diagnosed with CD, 5 with UC and 1 with IBD unclassified.	Interviews	Qualitative content analysis	Children varied widely in who they told about the disease. For some, it was inevitable that they would have to tell people. However, others feared sharing the diagnosis because of the threat of teasing. Children experienced a range of responses when they did disclose, including curiosity, understanding, and teasing.
12.	Lolli, (2022)	USA	To explore how patients make sense of and communicate their changed	15 female participants aged between 18 and 40. Time since	Compassionate interviewing	Thematic analysis	Social situations involving food often led to people feeling pressured into

			relationships to food following an IBD diagnosis.	diagnosis ranged from 1.5 years to 28 years.			disclosing in attempt to avoid or lessen disapproval from others around their food choices.
13.	Matini & Ogden, (2016)	UK	To explore the notion of adaptation in patients with IBD, particularly focusing on lived experiences from diagnosis to the present.	22 participants (14 females, 8 male) aged 19-60 years. There were 10 individuals with CD and 12 with UC.	Semi-structured Interview	Thematic analysis	Self-disclosure can have a positive impact on relationships for those with IBD because it makes people feel closer and more open with others. Additionally, the misconceptions around IBD as an "invisible" disease makes disclosures more necessary.
14.	Micallef-Konewko, (2013)	UK	To gain an understanding of what it is like to disclose and talk about IBD as a young person following the transition to secondary school.	7 participants (4 males, 3 female) aged 12-13.	Semi-structured Interview	Interpretative Phenomenological Analysis	Disclosure was experienced as a risky but potentially rewarding experience, with participants weighing-up potential rewards against anticipated costs. Disclosure was viewed to influence how young people accepted their IBD diagnosis.

15.	Murphy et al., (2022)	United Kingdom	To explore the link between IBD and psychologically difficult emotions and their impact on illness disclosure decisions.	16 Females	Interviews	Interpretative Phenomenological Analysis	Women identify that shame is a key emotion linked to their IBD due to it being an "invisible" illness, which can make it difficult to disclose. Women identified finding it more difficult to disclose depending on the person they were telling and identified the difference between voluntary disclosure and times where it felt more of a necessity.
16.	Nehasil, (2014)	USA	To discover how individuals participating in a Montana-specific, online support community for those with IBD describe their experiences within the community, and how these experiences have affected their health-related quality	10 participants (8 females, 2 male) aged between 20 to 66. There were 7 participants with CD and 3 with UC.	|Interviews	Thematic analysis	An online community made it easier for individuals to talk about their illness and feel listened to.

			of life (HRQOL) in the areas of social support and illness knowledge.				
17.	Nicholas et al., (2007)	Canada	To understand the lived experience of/and elements of quality of life as depicted by children and adolescents with IBD.	80 young people (44 male, 36 female) aged 7 to 19 years of age (mean age of 13.3 years). The majority had CD (n=61).	Semi-structured Interview	content analysis	Participants reported withdrawing from others to avoid negative judgements and feeling different to them. Fear around other's reactions and perceptions towards the disease prevent people disclosing about their illness.
18.	O'Leary et al., (2020)	UK	To understand how therapeutic outcomes are realised through the technological features offered by social media platforms.	38 participants (20 female, 18 male). There were 25 participants with CD, 13 with UC.	Interviews	Deductive thematic analysis	The availability of closed groups contributed to a "safe" space that enabled users to talk openly about their illness and experiences away from their family members. The ability to post anonymously encourages self-disclosures by reducing the risk of stigma.

19.	Palant & Himmel, (2019)	Germany	To determine whether patients with IBD experienced negative effects from social support and if so, how these experiences can be categorised and what role different sources of social support play.	42 participants (54% female) aged between 18 and 76 (mean age = 42). Duration of illness ranged from 5 to 40 years.	Narrative interviews	Grounded theory	There were several negative effects from social support identified, including unwanted confrontation and undesirable reactions. This included participants experiencing pity from those that they are close with when choosing to disclose their diagnosis.
20.	Peters & Brown, (2022)	UK	To examine the relationship between illness identity and self-management of IBD.	134 participants (102 females, 31 males, and 1 other gender) aged 19-75.	Two open-ended questions	Thematic analysis	Disclosing information about IBD was viewed positively, with it being used as a method of support and to meet other people experiencing similar difficulties.
21.	Restall et al., (2016)	Canada	To illuminate the commonalities of experience, identify variations, and highlight implications for practice, research, and policy, to inform a broader goal of	45 participants (23 women, 22 male) aged 21 to 73. Mean disease duration was 10.9 years.	Interviews	Thematic analysis	The decision about whether to disclose to an employer or college at work is conflicted, with it being viewed as both potentially helpful and a show of weakness which may

			minimizing work disability for people living with IBD.				result in negative consequences.
22.	Robertson et al., (2022)	UK	To explore the experience of self-conscious emotions in people with IBD and understand the psychological and social impact of self-conscious emotions on individual's lives.	15 participants (4 male, 11 female) aged 25-75. Time since diagnosis ranged from 4-20 years.	Interviews	Thematic analysis	Talking about IBD as a disease and its accompanying symptoms was viewed as socially unacceptable and something that should be avoided due to other people not being able to tolerate it.
23.	Rouncefield-Swales et al., (2020)	UK	To explore young people with IBD's friendships and their friendship networks.	31 participants (15 female, 16 male) aged between 14 and 25.	Interviews, friendship maps and photographs	Interpretive Description	Some young people in the current study concealed their IBD from friends, while others downplayed the seriousness of their condition. Limiting disclosure and explanations about the "gory detail" are aimed at both protecting their friends and minimising the risk of rejection. For young people, some friendships were

							improved because of disclosure.
24.	Ruan & Zhou., (2019)	China	To explore the illness experiences of patients with Crohn's disease in China and construct an interpretative understanding of these experiences.	31 participants (17 males, 14 females) aged 19-68.	Interviews	Grounded theory	There were several advantages and disadvantages to disclosing identified by participants. When advantages outweighed the disadvantages or vice versa, the decision to disclose became easier. However, participants still had choices to make regarding the disclosure strategy, including how much to tell and when.
25.	Salazar & Heyman, (2014)	USA	To examine the benefits of attending an IBD specific camp.	A total of 25 participants (16 girls and 9 boys) aged between 8 and 17.	Interviews, participant observations and fieldnotes	Thematic analysis	Attending the summer camp offered people the opportunity to be around people that were like them and who understood what they were trying to talk about in relation to their disease.

26.	Sammut et al., (2017)	Malta	To explore the experiences of individuals living with an ileoanal pouch.	10 participants (6 female, 4 male) aged 25-65. The mean time since formation of the ileoanal pouch was 5.4 years.	Semi-structured interviews	Interpretative Phenomenological Analysis	Participants were afraid of how others would react to their experiences, if they found out about them.
27.	Saunders, (2014)	UK	To investigate young adults' representations of IBD-related stigma and explore how this influences their self-disclosure.	16 participants (10 female and 6 male) all aged 18–29 years.	Interviews	Rhetorical discourse analysis	Participants identify that the stigma associated with IBD, and the taboo nature of symptoms, contributes to concealing their illness from others. However, these accounts identified that some people feel safe talking to those they trust.
28.	Savard & Woodgate, (2009)	Canada	To understand the lived experience of young people living with IBD and an ostomy.	6 participants (5 women, 1 male), aged between 19 to 24. Time since diagnosis ranged from 3 to 13 years and time since having ostomy ranged from 1 to 8	Interviews	Hermeneutic Phenomenology	The symptoms and bodily changes experienced from treatment and ostomy impacted how much participants felt comfortable disclosing. IBD and treatment was viewed as an illness that is not

				years. All participants were Caucasian.			talked about and an embarrassing thing to discuss.
29.	Schwenk et al., (2014)	USA	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.	15 participants (7 male, 8 female) aged 19-21. There were 6 with UC and 9 with CD.	Interview	Thematic analysis	Participants were guarded about discussing their IBD with other students. Disclosure was often prompted by others being curious about their behaviours. Despite participants being cautious, no negative consequences were reported, rather it allowed developments in social connections.
30.	Vaughan & Jolliffe, (2023)	UK	To explore the working lives of those living with the condition IBD.	7 participants (4 UC, 3 CD).	Semi-structured interviews	Content analysis	Disclosing within the workplace was positive for some individuals who felt it allowed adaptations and their needs to be met. However, for others, disclosing their illness led to feelings of resentment, especially when employers had a poor attitude or lack of

							understanding towards the illness.
31.	Wåhlin et al., (2019)	Sweden	To explore disease-related worries in persons with Crohn's disease.	12 participants aged 20-60+ (4 male, 8 female).	Interviews	Qualitative content analysis	Participants felt a need to talk about their IBD and the worry associated with it. They wanted to talk to someone in a similar situation to themselves.
32.	Wang et al., (2023)	China	To explore the psychosocial process of posttraumatic growth in Chinese patients with CD.	19 participants with CD (8 female, 11 male).	Interviews	Constructivist grounded theory	People's perceptions of how the diagnosis of IBD made them look prevented people from disclosing their disease. This was particularly present in environments where "looking weak" put you at a disadvantage.
33.	Woodward et al., (2016)	UK	The aim of this study was to detect IBD-specific distress and to generate items for a new IBD-distress scale.	52 adult participants aged 17+.	Secondary interview transcripts and an IBD focus group	Thematic analysis	Most participants agreed that discussing their diagnosis was a taboo subject and that the stigma associated with it made it difficult for them to talk about their experiences.

34.	Zigron & Bronstein, (2018)	Israel	To examine the activity of virtual health communities for users with IBD by understanding the role that these online spaces play as sources for information and social support.	23 participants (15 female and 8 male) aged between 20 and 40.	Interviews	Content analysis	The virtual community allows people to disclose personal information about their disease as it is viewed as “low risk” compared to disclosure in other situations. The use of disclosure in these communities was viewed positively by people wanting to seek or share information about IBD.

Quality Appraisal

The quality of included studies was assessed by the author and an independent reviewer using the CASP qualitative assessment. A summary of the quality appraisals is shown in Table 4 and in full in Appendix E.

Aims and Design

All studies provided a clear statement of their aims, objectives, or research question/s. Whilst the aims and objectives of each study varied, all aimed to understand or describe complex phenomena, predominantly the experiences of IBD, thus qualitative methods were deemed appropriate. There were several studies (n=9) who did not provide details regarding the research design. However, the design was identifiable from other sections of the paper despite it not being explicit.

Participants and Sampling

Most studies provided clear and appropriate information on how participants were recruited, including the methods or organisations used to support this, an in-depth inclusion/exclusion criterion for participants and information about the demographics of their sample. However, it was acknowledged that very few studies provided details on why their sample was chosen and what knowledge this offered. Although not directly measured by the CASP, it was identified that ethnicity was not reported in 24 papers, raising caution regarding the studies' transferability.

Ethical Considerations and reflexivity

Ethical considerations were a strength across the studies as all stated having obtained ethical approval from appropriate panels/organisations. However, it is acknowledged that the level of detail provided around ethical considerations varied across studies. Most studies provided details on obtaining informed consent from participants (n=26) and several provided details around confidentiality (n=9).

Although the consideration of researcher positioning and bias varied across studies, it was generally assessed as the weakest domain with only nine papers providing detailed consideration of their role and position, including personal diagnoses of IBD or gender, and its influence on the qualitative approach used. Therefore, caution should be taken in interpreting the studies, as it is uncertain how the researchers positioning may have influenced their data collection and/or findings.

Data Collection and analysis

Details regarding data collection varied but was assessed to be adequate across all studies. Most studies used a form of interview, however, only 5 papers provided full interview schedules.

Information related to data analysis varied, but methods were assessed as appropriate across studies. A high proportion of studies reported the process of coding, theme development and/or consideration of rigor in data analysis. However, a few studies reported themes without detailing the development of these. Some papers (n=15) referred to saturation, with two justifying saturation to be impossible within their chosen theoretical framework (Dibley et al., 2017; Dibley et al., 2020).

Findings and Value

Although the findings varied in the level of detail provided, all studies presented clear information about their themes with supporting quotes. However, it was recognised that the discussion around conflicting findings was limited across all studies. Therefore, there should be caution in interpreting these results, as it is unclear what additional findings may have emerged and the impact this may have had on the findings. There was variation in the amount of information provided regarding the value of the research, however most studies met at least one criterion. Most studies discussed the implications of their research, including how findings could be applied to healthcare and made recommendations for future research.

Summary of quality appraisal

Overall, study quality was considered moderate to high, with all papers explicitly stating their aims and using appropriate qualitative methodology. However, it was recognised that reflexivity was a weakness across most studies. It was also identified that descriptions of data analysis were not fully detailed for some papers. The quality of these papers was considered throughout the thematic analysis and as seen in Table 5, none of the themes relied solely on lower quality papers.

Table 4

CASP Summary by Criterion

Criteria	Example	Quality assessment of studies
		Met Criterion (N Papers) Cannot tell if Criterion met Did not meet Criterion
Aims	Aims/objectives explicitly stated	(34)
Method	Appropriate use of qualitative methods	(34)
Research Design	Research design was justified	(26) (7) (1)
Sampling	Recruitment strategy and participant selection was appropriate	(26) (8)
Data collection	Appropriate data collection methods	(34)
Reflexivity	Critical examination of researcher biases and influence	(11) (8) (15)
Ethical Issues	Sufficient evidence of maintaining ethical standards	(33) (1)
Data Analysis	Adequate and in-depth description of analysis process	(28) (6)
Findings	An explicit statement of findings and discussion of their credibility and validation.	
Value of Research	Discussion of contribution of findings in relation to new and existing research areas.	(26) (8)

Thematic synthesis

In total, the thematic synthesis generated five themes and 18 subthemes to describe the experiences of disclosing IBD, which are summarised in Figure 3. The studies and example quotes contributing to each theme/subtheme are presented in Table 5 (Appendix F displays more quotes contributing to the themes).

Figure 3

Themes and subthemes identified during the thematic synthesis

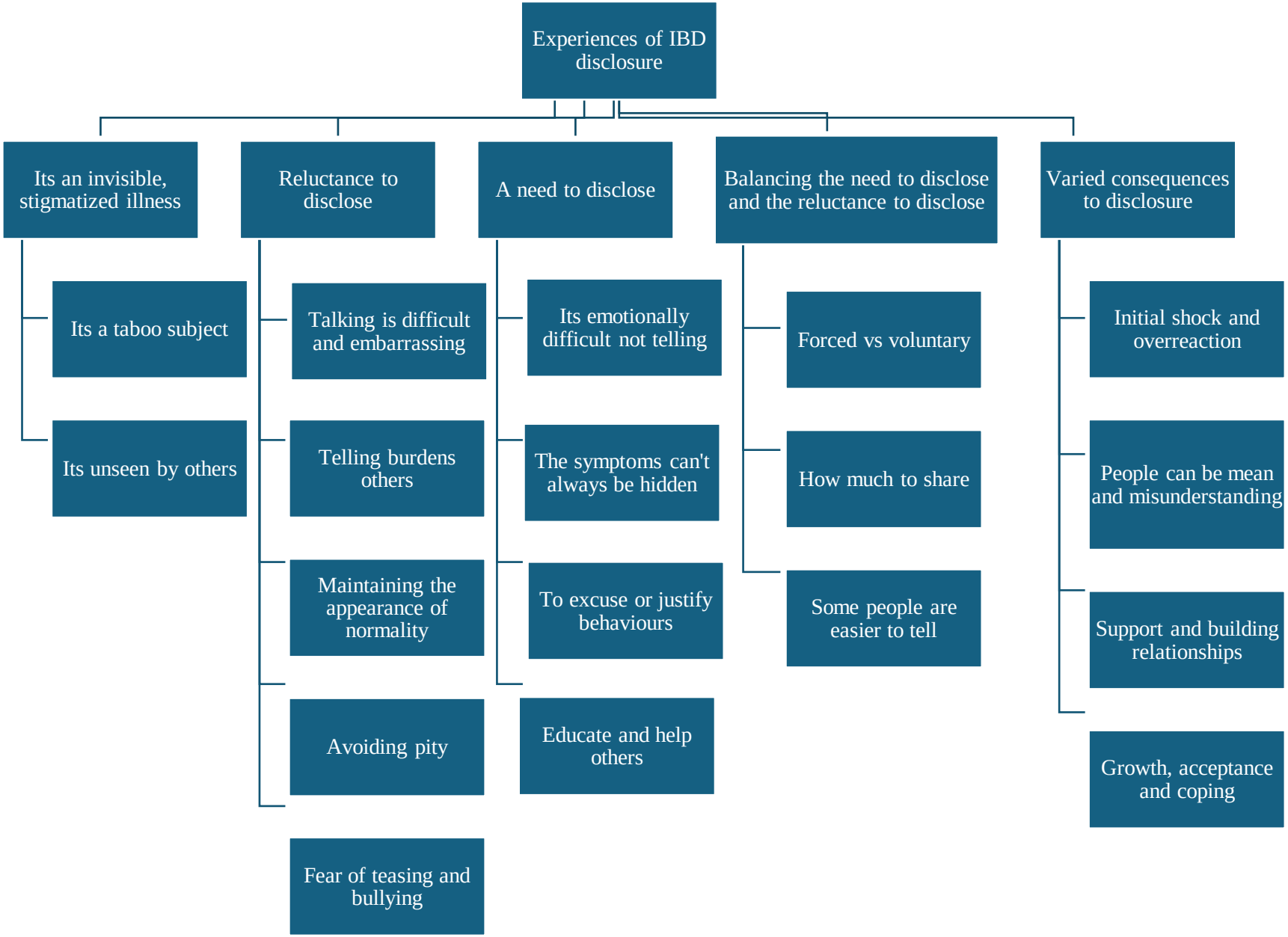


Table 5

Studies and quotes contributing the theme and subthemes

Theme	Subtheme	Example Quotes	Papers contributing to this theme
It's an invisible, stigmatized illness	It's a taboo subject	"*They can be such disgusting aspects, having diarrhoea and the other things, I just think, do people really want to hear about that, about someone else?"* *"Everyone gets a little squeamish when you start talking about your bowel habits."*	2; 5; 8; 9; 14; 15; 17; 22; 23; 27; 28; 33; 34
	Its unseen by others	*"...relative invisibility of IBD allowed participants to keep their condition successfully concealed much of the time."* *"it's something for me that's private."*	2; 6; 8; 12; 13; 14; 15; 27; 29; 33
Reluctance to disclose	Talking is difficult and Embarrassing	*"It was very difficult for me to explain, to cross this line and say that I've got this condition, and how I feel and everything. It took me a lot of time because it was not easy to explain how it is."* *"I find it's, I don't know, may be a bit embarrassing sometimes."*	1; 2; 5; 7; 8; 10; 11; 12; 14; 15; 21; 22; 25; 27; 28; 33
	Telling burdens others	*"I don't want to make a lot of noise... (because) I'm a burden on my family."*	2; 3; 7; 14; 15; 17; 22; 30; 34

		" I always felt like it was going to fail, that it was going to be something. I say too much, and he would just leave."	
	Maintaining the appearance of normality	*"They might not know the illness very well, and I didn't want to make myself seem particularly different because of the illness."*	1; 2; 3; 5; 6; 8; 14; 19; 22; 23; 28; 32; 33
		"I don't want things to really change, where my friends think […] that all I like to talk about is my illness, because that's all I can talk about."	
	Avoiding Pity	*"Sometimes I don't want people to know I've got an illness. I don't want people to start the whole pity party, you know, 'Oh, you poor thing! I feel really sorry for you.'"*	2; 3; 14; 23; 30
		"Sometimes it feels like I'm being handled with kid gloves."	
	Fear of teasing and bullying	*"I'm afraid to tell my friends about the disease. I'm afraid they will laugh."*	1; 14; 17; 26; 27
		"I didn't want them [peers] to hear […] because some stupid stuff might happen […] like making nasty remarks about it."	
A need to disclose	Its emotionally difficult not telling	*"I didn't tell anyone. I hid that for years, believe it or not. And that was agony."*	2; 7; 9; 14; 24; 25; 32; 33

		"I think if I had tried to hide all the time, the stress levels would just make it so much worse."	
	The symptoms can't always be hidden	*"I talk about it less now, because in primary school, I couldn't really hide it, because I couldn't eat."* *"They would clearly know that something was wrong, and I couldn't keep that from them anymore."*	1; 2; 7; 8; 13; 14
	To excuse or justify behaviours	*"I would have told him [referring to her husband] because he was thinking that I was making up excuses."* *"I fear the regular days off I need for treatment or sudden emergency flares may be misconstrued as skipping work without reason. And this could be another reason for my employer to fire me."*	1; 3; 8; 12; 26; 29; 30
	Educate and help others	*"I can help somebody else with questions. Somebody needing help in something I had trouble with and found a way to help to make it work. I love sharing any of that if someone asks."* *"Telling people] was definitely a challenge. I think it's better when you explain it to people, because then they understand."*	1; 2; 5; 8; 16; 18; 29; 30; 34
Balancing the need to disclose and the reluctance to disclose	Forced vs voluntary	*"I talk about it less now, because in primary school, I couldn't really hide it, because I couldn't eat."* *"Some people might come up to me after class and go, 'Oh Will, why are you allowed to go to the toilet?', and then I'd*	1; 2; 5; 8; 11; 12; 14; 29; 34

		have to tell them. Well, I wouldn't have to tell them, but I'd feel like, I was lying to them."	
	How much to share	*"because it's just telling someone about […] a part of you […], it's easier telling people like what I have to have done."*	1; 2; 11; 14; 15; 27
		"…just like because I wasn't sure if if I'd like said something that wasn't actually how like if I said it was bad when it wasn't actually so bad or something."	
	Some people are easier to tell	*"like an actual friend that I know that won't tease me about it or something like that so umm yeah I have really good friends that they all know that I have Crohn's."*	1; 2; 4; 7; 11; 14; 17; 18; 21; 23; 24; 27; 31; 34
		"So, uh, I couldn't trust him; so I didn't share anything with him."	
Varied Consequences of disclosure	Initial Shock and overreaction	*"When it's explained to them, they either don't take it seriously at all or they are profoundly shocked."*	1; 2; 3; 7; 8; 11; 14; 17; 19; 21; 26; 27
		"new people's reactions that are the weirdest (.) it's like oh my god (.) at work and stuff they just don't get it the comment I had yesterday was 'isn't it really sad you're so young' and it's like 'so young what?' and they're like 'so young to be like this' and I don't think like that."	
	People can be mean and misunderstanding	*"They [peers] would say things like, "You're a bit like a cripple really, aren't you?" and […] then, they would start talking about bowel movements. I could take all of the other things but, for some reason, them [sic] making comments*	1; 2; 3; 5; 6; 7; 11; 14; 17; 19; 21; 25; 26; 27; 29

	associated with bowel movements, that really upsets me. That's too much for me to deal with." *"some people think that because it's a disease, Crohn's - they say 'Oh my God can I catch it off you?"*	
Support and building relationships	*"It [talking to friends] feels good because […] I know that they would listen to me and I know I can speak to someone about it and they won't go telling other people that I don't want to know."* *"it helps a lot to talk about (IBD) with someone who has it".*	1; 2; 4; 5; 7; 8; 11; 13; 14; 16; 17; 18; 19; 20; 24; 29; 31; 32; 33; 34
Growth, Acceptance and coping	*"You kind of have that freedom once you tell people. You don't have to hide it anymore".* *"Because my parents and I talk things through about my IBD, I can deal with it".*	1; 2; 3; 7; 8; 14; 15; 17; 22; 28; 30; 34

Theme 1: It's an invisible, stigmatized illness

This theme described how participants perceived their diagnosis within the context of society and the impact this had on whether they disclosed their diagnosis. Two subthemes emerged within this theme.

It's a taboo topic. Participants in the studies highlighted that, due to societies construction around the privacy of bowel habits, IBD was experienced as a "taboo" subject and an "unacceptable" conversation (Zigron & Bronstein, 2018). Participants disclosure decisions were influenced by the perception that others are "squeamish" or "disgusted" (Dibley et al., 2020; Hall et al., 2005; Nicholas et al., 2007; Robertson et al., 2022; Saunders, 2014) by the topic of conversation. Even within the home, participants reported an absence of conversation around bowel habits, making individuals feel that IBD was "not allowed" to be talked about (Dibley et al., 2020; Gelech et al., 2021). The role of stigma in the experience of disclosure aligned with the authors prior expectations, despite the "taboo" symptoms of IBD being different to their own invisible illness.

It's unseen by others. Participants referred to the "invisibility" of IBD, with it being a disease that is already concealed, and therefore something that should be kept hidden (Gelech et al., 2021). Participants referred to the perceived stigma and taboo nature of IBD as a barrier to disclosure, with their disease being described as a "private" illness which is "no one's business" (Carter et al., 2020; Lolli, 2022; Micallef-Konewko, 2013; Savard & Woodgate, 2009; Woodward et al., 2016). Some participants spoke of respecting their own privacy, with the socially constructed privacy around bowel habits further confirming that their IBD should be kept hidden (Schwenk et al., 2014; Woodward et al., 2016).

In contrast, one study (Matini & Ogden, 2016) highlighted that due to its invisibility, disclosure is necessary to raise awareness of the condition or someone's experience of this, which would otherwise remain unseen and ignored.

Theme 2: Reluctance to disclose

Following on from Theme 1, which captured how the perception of IBD within society influenced disclosure decisions, Theme 2, *Reluctance to disclose,* described personal feelings and contexts influencing individuals' decisions around not wanting to disclose or avoiding disclosure. It comprised the following five sub-themes.

Talking is difficult and embarrassing. Participants reported personally trying to avoid disclosure due to it being a challenging thing to talk about. It was hard for individuals to know how to initiate conversations (Kluthe et al., 2018; Woodward et al., 2016), articulate information, or "find the right words" (Restall et al., 2016), to try and explain their diagnosis.

Talking about IBD was also identified as an "emotionally taxing" (Barned et al., 2016) experience for people, especially when feeling the need to justify their experiences and explain that these vary between individuals. When considering disclosure, participants described feelings of embarrassment (Gelech et al., 2021) and anxiety (Carter et al., 2020), with it appearing easier to avoid having these conversations than to have to endure the uncomfortable emotions, and the emotional efforts, caused by disclosure.

Telling burdens others. It was often perceived that hearing about IBD was a burden or would result in pushing people away (Murphy et al., 2022). Participants spoke about not talking about their IBD openly or "downplaying its seriousness" (Carter et al., 2020) to protect others and prevent them from having to worry, while also reducing the guilt experienced by the person with IBD (Nicholas et al., 2007; Robertson et al., 2022). However, in one study (Micallef-Konewko, 2013), it was recognised that disclosure may reduce worry, as it enables people to know the truth and prevents them thinking it's something more sinister.

Maintaining the appearance of normality. When considering diagnosis disclosure, participants referred to the impact this has on how they are seen by others. Participants

described not talking about IBD as they did not want to be viewed or treated differently by others (Dibley et al., 2017; Micallef-Konewko, 2013; Savard & Woodgate, 2009; Wang et al., 2023; Woodward et al., 2016) and wanted to be seen as "normal" (Gelech et al., 2021; Micallef-Konewko, 2013; Rouncefield-Swales et al., 2020). For several participants, disclosure was viewed as a challenge to their identity, with them fearing that they would "become their disease" if others found out about it (Barned et al., 2016; Micallef-Konewko, 2013; Rouncefield-Swales et al., 2020).

In addition to appearing different, participants reported not wanting to be viewed negatively by others (Colmer, 2021), such as being "boring or depressing" in social situations (Micallef-Konewko, 2013). Participants also assigned feelings of "weakness" to both their ill-health and talking about these difficulties (Micallef-Konewko, 2013; Robertson et al., 2022; Wang et al., 2023). To avoid being viewed by others in this way, and to avoid internal feelings of powerlessness (Micallef-Konewko, 2013), participants were reluctant to disclose their IBD.

Avoiding pity. Participants spoke about avoiding disclosure due to worries that others will "make a fuss" (Carter et al., 2020) or feel sorry for them (Micallef-Konewko, 2013; Rouncefiled-Swales et al., 2020). For others, direct experiences of having been made to feel "handled with kid gloves" (Colmer, 2021) or "made to feel like a child" (Micallef-Konewko, 2013), reinforced that they would receive pity and be made to feel less able.

Fear of teasing and bullying. Prior to analysis, the author had the assumption that, as "bowel habits" are often used as humour, individuals would perceive their symptoms to be met negatively. This expectation was supported by the data which highlighted that, due to the nature of their symptoms and the stigma associated with bowel habits within society, participants spoke of feeling worried about receiving nasty comments, being laughed at, or being bullied because of their disclosure (Kluthe et al., 2018; Micallef-Konewko, 2013;

Nicholas et al., 2007; Saunders, 2014). Although participants did not speak about directly experiencing bullying or teasing, it was the perception of this threat that prevented disclosure. The fear of bullying was more present for young people and adolescents due to the perception of other young people being "childish and immature" (Saunders, 2014).

Theme 3: A need to disclose

Despite the reluctance to disclose, it was recognised that concealing IBD is not always possible. The theme *A need to disclose* described participants experiences of when disclosure occurred or when/why individuals felt obliged to tell others about their diagnosis. This theme comprised four sub-themes.

Its emotionally difficult not telling. When choosing not to disclose, individuals continued to experience the symptoms and challenges associated with their IBD. Participants in spoke about how attempting to hide or "bottle up" their diagnosis was an additional challenge which caused stress, anxiety, and social isolation (Gelech et al., 2021). In one study, participants identified that non-disclosure at work meant that there was extra stress and difficulties as no allowances or adjustments were made (Ruan & Zhou, 2019). Trying to hide a part of your identity was deemed stressful, with disclosure providing a sense of relief (Frohlich, 2014).

The symptoms can't always be hidden. Despite the "invisibility" of IBD, it can become observable in an individual's appearance and behaviours, such as more frequent bathroom trips, weight and skin changes, and withdrawal from work, education, or social events, especially during flare ups (Carter et al., 2020; Gelech et al., 2021; Frohlich, 2014). Participants spoke of feeling their diagnosis "can't be kept a secret" (Gelech et al., 2021). At these times, disclosure was deemed more of a necessity due to its "visibility" and enabled others to understand the reason for these observed changes (Frohlich, 2014).

To excuse or justify behaviours. IBD impacts multiple areas of an individual's life, despite some of the symptoms not being physically visible to others. Participants in seven studies spoke of disclosing to justify themselves and avoid judgements from others. In one paper (Barned et al., 2016), a young person reported disclosure as a "safer option", otherwise peers may believe the symptoms and school absences are for something else, such as self-injurious behaviours, which may be viewed more negatively than IBD itself.

From the authors experiences, it was expected that disclosure decisions would be motivated by avoiding judgements for things such as work absences. The data supported this, with disclosure providing excuses for "sick days" (Colmer, 2021; Vaughan & Jolliffe, 2023) or justify eating habits, as participants choices received judgements for not being "healthy" or "appropriate" within a social context (Lolli, 2022). The need for disclosures in these cases was described as more necessary due to the "invisibility" of the disease, as people jump to conclusions due to the individual generally "looking okay" (Gelech et al., 2021; Matini & Ogden, 2016; Schwenk et al., 2014).

Educate and help others. There were several studies where participants spoke about disclosure being important for providing education around the disease. It was recognised that the stigma associated with the disease meant that there were often misconceptions held by the public (Dibley et al., 2017). Participants felt that, as someone experiencing IBD, they had an obligation to inform others about the disease and help increase the understanding (Carter et al., 2020; Schwenk et al., 2014), especially for those that had not heard of IBD or confused it with irritable bowel syndrome (Vaughan & Jolliffe, 2023).

Participants also spoke of disclosing to help others experiencing similar challenges, including those recently diagnosed with IBD (Nehasil, 2014). It was acknowledged that disclosing IBD became easier for participants as they gained more information and understanding about the disease (Carter et al., 2020). For individuals who had come to know

about the illness, disclosure was seen as a useful way to pass on this information and help those that were still trying to acquire an understanding for themselves. The role of educating others and supporting others was not something that was expected by the author prior to analysis, especially due to the experiences of living with IBD being different among individuals.

Theme 4: Balancing the need to disclose and the reluctance to disclose

Individuals were faced with conflicting perceptions of whether their IBD should be talked about or concealed. Theme 4 encompassed three sub-themes focussed on the experiences individuals encountered when making disclosure decisions and the contextual factors influencing these processes.

Forced vs voluntary disclosures. Participants described the level of choice they experienced around making their disclosures. Several participants spoke about feeling open and happy to initiate conversations related to their IBD (Carter et al., 2020; Micallef-Konewko, 2013). Voluntary disclosures were more likely when symptoms became "visible" or when individuals felt others "need to know" to ensure support is available (Barned et al., 2016; Carter et al., 2020; Micallef-Konewko, 2013). One participant described the timing of disclosure to be important, with this being easier after the "bad symptoms" had passed (Carter et al., 2020). Additionally, participants described voluntary disclosure being more likely when they felt they had control and understanding of their disease (Carter et al., 2020; Dibley et al., 2017; Micallef-Konewko, 2013).

In line with the authors prior expectations, some participants spoke of circumstances where they felt disclosure was more forced. This occurred when other people directly ask questions or showed curiosity around their behaviour, such as why they have been absent from work or college (Lolli, 2022; Schwenk et al., 2014). These questions appeared to provide an opening for a disclosure, where participants were left with a conscious choice as

to whether to commit to disclosing or withhold this truth (Barned et al., 2016). Even when disclosure was initially voluntary, this may be followed by more questions or others bringing it up in other contexts, making it feel more forced (Colmer, 2021; Lolli, 2022).

What and how much to share. Participants described making choices about what information to share and whether they provided a "complete disclosure" or "selective disclosure" (Carter et al., 2020; Ruan & Zhou, 2019). Some participants spoke about "not holding back" and sharing all information (Frohlich, 2014), whereas others found it easier to talk about certain aspects of their experience, such as disclosing treatments rather than symptoms or coping (Micallef-Konewko, 2013). For others, the amount of information they disclosed was dependent on what other people wanted to know and what questions were being asked, with participants disclosing to "satisfy curiosity" (Micallef-Konewko, 2013). Deciding the amount of information to share influenced people's experience of how successful their disclosure was, with some participants feeling regret around withholding information which they later felt they should have shared (Micallef-Konewko, 2013).

Some people are easier to tell. Whether to conceal or disclose also involved decisions regarding who to tell. Participants in several papers referred to the importance of "trust" in this decision. It was important that participants trusted the individual to both keep their disease private (Carter et al., 2020) and be able to tolerate and respond positively to the information (Barned et al., 2016; Restall et al., 2016; Rouncefield-Swales et al., 2020). People often felt open to telling family members, close friends, and romantic partners (Frohlich, 2014; Ruan & Zhou, 2019). It was noted that younger participants were more selective about who to tell (Carter et al., 2020), with some being concerned that disclosure to one person, may lead to this information being spread to people that they did not want to share the diagnosis with (Micallef-Konewko, 2013; Restall et al., 2016).

Participants also spoke about feeling more open to sharing information with those also living with IBD or family members with a similar condition. This decision was easier due to a shared understanding of the challenges and the expectation of receiving support (Carter et al., 2020; Micallef-Konewko, 2013; Nicholas et al., 2007; Zigron & Bronstein, 2018). Disclosure was also viewed as easier on online forums and on social media, as opportunities to limit what is said and having a level of anonymity provided safety (O'Leary et al., 2020; Zigron & Bronstein, 2018).

Theme 5: The varied consequences of disclosure

Across the studies, participants described varying perceptions towards the appropriateness of disclosure and various experiences in making disclosure decisions. Theme 5 described the direct experiences participants encountered when the decision to disclose was made. This comprised of four subthemes.

Initial shock and overreaction. Multiple participants said that their disclosure was met with "shock" from other people. Initial shock was described as the general reaction when people first learnt of an IBD diagnosis and that this was often accompanied with sympathy, pity or extreme worry and negativity (Micallef-Konewko, 2013; Palant & Himmel, 2019; Saunders, 2014). This reaction gave participants the impression that others can't "handle" learning about the diagnosis (Saunders, 2014), supporting why participants may be reluctant to disclose, as discussed in theme 2. However, despite people's initial shock, some experienced this to be temporary and followed by acceptance and support, becoming a more positive experience (Saunders, 2014).

People can be mean and misunderstanding. Over half of the studies highlighted negative experiences of IBD disclosure. When talking about IBD, participants experienced that their disclosure was met with misunderstanding and disbelief around the condition due it's "invisibility". Participants spoke about physically "looking fine", which resulted in the

seriousness of their illness not being fully appreciated (Colmer, 2021; Micallef-Konewko, 2013). Participants identified being made to feel ignored, not listened to and not cared about due to others not registering or understanding the information provided from their disclosure (Dibley et al., 2020; Schwenk et al., 2014).

Several participants described negative disclosure experiences as they were met with comparisons to others with IBD and made to feel that they should be coping better based on what people had heard from others (Barned et al., 2016; Vaughan & Jolliffe, 2023). Additionally, one participant felt that their disclosure was a "waste of time" as it was met with the misunderstanding that they had IBS which could be easily managed (Micallef-Konewko, 2013). Furthermore, the lack of understanding, and the term "disease" in IBD, resulted in participants receiving comments and teasing about being "contagious" (Carter et al., 2020). Although several studies identified negative responses from others, there were no direct reports of experiencing bullying due to IBD. This finding contrasted with the authors prior assumptions/expectations, especially following reading articles that identified the "risk" of bullying as a potential barrier to disclosure.

Support and building relationships. Although some individuals experienced negative outcomes, participants in eighteen studies spoke about positive disclosure outcomes. When talking about their disease, participants generally found others to be understanding, supportive and wanting to help (Carter et al., 2020; Frohlich, 2014; Micallef-Konewko, 2013; Wang et al., 2023). Disclosing IBD was viewed as helpful as it enabled people to know about the disease and understand its challenges, which meant they could help accommodate for these (Barned et al., 2016; Frohlich, 2014; Micallef-Konewko, 2013).

Being open about and talking about their illness and difficulties also contributed to participants developing closer relationships with others, as people appreciated the openness and honesty from them (Carter et al., 2020; Matini & Ogden, 2016). Disclosure also enabled

participants to connect and develop new friendships with other people with IBD who understand their experiences (Schwenk et al., 2014). Meeting others with IBD also provided the opportunity for people to ask questions and learn more about their illness (Nehasil, 2014), which was empowering and encouraged further disclosures.

Growth, acceptance, and coping. Participants described experiencing positive outcomes in themselves and their perception of coping because of disclosure. Some participants described how disclosing enabled them to feel more honest and over time, less embarrassed about the illness (Frohlich, 2014; Murphy et al., 2022). Through disclosure, participants were able to develop a more positive view of themselves and became more accepting of their diagnosis, which was reported to make disclosure easier and more frequent (Micallef-Konewko, 2013; Savard & Woodgate, 2009).

It was also highlighted that talking about IBD enabled participants to feel more able to manage their IBD, with participants feeling relieved, free, and happier after disclosure (Vaughan & Jolliffe, 2023). Within employment settings disclosure allowed people to feel able to take the time off "sick" when needed without the risk of negative consequences that may have come from non-disclosure (Colmer, 2021). This benefit was also identified by a younger participant, who described open conversations with parents as important for their perception of how they can "deal" with the disease (Nicholas et al., 2007).

Discussion

This review set out to synthesise the existing qualitative literature exploring experiences of disclosing IBD, aiming to identify barriers and facilitators influencing these decisions. A total of 34 studies contributed to the development of five themes which identified some of the process's individuals experience in relation to disclosing their IBD. To the authors knowledge, this is the first review to systematically synthesise data related to self-disclosure within this population. Throughout this review, the author remained reflexive and

considered their own position and biases. This allowed them to identify themes that met as well as considering the data which contradicted their prior assumptions/expectations.

Summary of findings

As proposed by the DPM (Chaudoir & Fisher, 2010), this review highlights the complex processes individuals with IBD encounter in relation to self-disclosure. Participants in this review identify an integration of factors, both on a personal and societal level, which contribute to their feelings towards disclosure and whether they take this step. The themes emerging in this review highlighted that there were different motivators for disclosure amongst participants, which corresponded with the "approach-goals" and "avoidance-goals" as theorised by the DPM (Chaudoir & Fisher, 2010). In the theme, *a need to disclose*, participants described experiencing disclosure as an opportunity to educate others (Carter et al., 2020; Schwenk et al., 2014; Vaughan & Jolliffe, 2023) and provide support to others (Carter et al., 2020; Nehasil, 2014). These "approach-goals" acted to facilitate individuals' disclosure due to the perceived benefits that it would have on other people, resulting in generally positive experiences towards disclosure.

It was also identified that for some participants "avoidance-goals", particularly to avoid negative judgements from others and justify their behaviours around food, absences, and toilet use (Colmer, 2021; Lolli, 2022; Vaughan & Jolliffe, 2023) facilitated disclosure. However, this avoidance approach, particularly experiences of wanting to avoid teasing, appearing different and pity from others, also acted as a barrier to disclosure for individuals with IBD, which supports findings within the DPM literature and its application to other physical health conditions, including HIV (Chaudoir, 2009; Chaudoir & Fisher, 2010; Chaudoir et al., 2011; Krsmanovic & Dean, 2022).

In line with the findings from other chronic illnesses (Benson et al., 2015; Chaudoir et al., 2011; Frank et al., 2006; Joachim & Acorn, 2000), the previous reviews in IBD (Guo et

al., 2020; Micallef-Konewko, 2013; Muse et al., 2021; Taft & Keefer, 2016), and the authors assumptions of the experiences of living with IBD, the current review highlighted that stigma, or perceived stigmatization, was a common barrier which prevented individuals disclosing their diagnosis. Consistent with the findings from other gastrointestinal research (Taft et al., 2017; Vidali, 2010), the theme *it's an invisible, stigmatized illness* describes how participants perceive their disease to be viewed in society, with "bathroom talk" and "bowel habits" being viewed as a taboo and inappropriate topic of conversation. Additionally, internalised stigma also contributes to individuals' self-perceptions and their beliefs of how their disease is perceived by others (Corrigan et al., 2006; Park et al., 2013; Taft & Keefer, 2016). It emerged that maintaining a "normal" appearance motivated their disclosure decision, with individuals perceiving disclosure to be a gateway to being consumed by an illness identity (Taft & Keefer, 2016). However, it is important to acknowledge that most studies included in the current review did not report the ethnicity of their participants, and of those that did, the majority were Caucasian. Therefore, the finding may not be transferrable to all populations living with IBD, especially as perceptions of "normality" and perceived/internalised stigma may vary cross-culturally (Burns, 2003; Franz et al., 2013; Wong et al., 2017).

In their review, Micallef-Konewko (2013) identify that disclosure decisions are influenced by more than just stigma, including the desire to live a normal life and uncertainty around their diagnosis. The current review identified similar influences on participants disclosure decisions, with knowledge of IBD, visibility, and personal emotions impacting on whether disclosure took place. In addition, the current review considers both paediatric and adult literature, offering a broader understanding of disclosure experiences in this population and identifying factors perceived to be influencing these decisions, including protection or

self-identity and workplace security. Factors aligning with this have previously been identified in other chronic illnesses, including diabetes (Ledford et al., 2022).

As well as identifying experiences of disclosure decisions, the current review highlights variations in experiences encountered when the action of disclosing is taken, which based on the authors experiences and assumptions, was not surprising. In this review, disclosure was identified as a potentially harmful action, with some participants being met with hurtful comments or continued misunderstandings (Dibley et al., 2020; Micallef-Konewko, 2013; Schwenk et al., 2014). However, multiple studies reported a positive outcome, with disclosure being important for connecting with others, building stronger relationships and for accessing support, help and developing coping (Carter et al., 2020; Frohlich, 2014; Micallef-Konewko, 2013). Disclosure was also identified as an important step in individuals IBD journey, with disclosure facilitating general acceptance of oneself and their disease. This highlights the important role that disclosure can have on self-acceptance, which can contribute to increased quality of life (Lewko et al., 2007; Potocka et al., 2009). The current review supports the existing literature identifying that disclosing chronic illnesses can be both a positive and a negative experience (Pathmalingam et al., 2023; Sheridan et al., 2016; Venema et al., 2023). Additionally, the DPM's concept of a feedback loop is supported, with the outcome of a direct disclosure experiences, and whether this was deemed positive or negative, influencing individuals' decisions to make their IBD visible, or concealed, through future disclosures (Chaudoir & Fisher, 2010).

Implications of findings

Clinical Implications

The current review highlights the factors that influence individuals' decisions to disclose or not disclose their IBD. It was identified that knowledge and understanding of IBD, whether from the person living with the disease or within wider society, influences the

decision and experiences associated with disclosure. Therefore, clinicians have a responsibility to provide knowledge, which is not only factual but also accessible (without medical jargon) and adapted to meet individual needs, to support individuals understanding of their disease, especially in the time following diagnosis, as per IBD standards (IBD UK, n.d.). By ensuring information, is accessible to family members, as well as those living with IBD, clinicians can promote the benefits of self-disclosure and encourage more open discussions within the family. By encouraging conversations around IBD at a more systemic level, it may become a more open and acceptable topic, which is important at reducing the stigma assigned to this diagnosis (Taft et al., 2017).

The barriers to disclosing information, such as perceived stigma, may also influence what information patients share, including what they report to clinicians and when they engage in help-seeking behaviours (Nuttall, 2019). Non-disclosure to clinicians may contribute to individuals' needs not being met, especially as healthcare professionals may underestimate the effect IBD symptoms have on the individuals living with it (Schreiber et al., 2012). Therefore, Clinicians should consider how they are supporting their patients to discuss their difficulties and ensure that they offer the opportunity for disclosure in a safe, non-judgemental way. Furthermore, healthcare professionals may be in a useful position to support individuals to consider their disclosure decisions and the potential benefits of this. Supporting individuals with this may contribute to addressing the stress associated with non-disclosure, which may allow for a better QoL and disease outcomes (Boye et al., 2011; Sainsbury & Heatley, 2005).

Public Health

This current review highlighted that, although disclosure decisions are often more forced in school settings, young people face teasing and bullying. As IBD can have an early onset, with between 10 to 20% of individuals receiving a diagnosis before the age of 18

(Wilson & Russell, 2017), this review highlights the need to raise awareness and support for individuals in this age range. Schools may benefit from receiving workshops which raise awareness of IBD or provide education for teachers to ensure they have the knowledge needed to support pupils with their IBD (Kim et al., 2019). Healthcare professionals specialising in IBD, and IBD charitable organisations, such as Crohn's and Colitis UK (CCUK) and CICRA, could support with the development and/or delivery of these workshops to ensure accurate and evidence-based information is provided.

This review also highlights that, despite the positive impact of disclosure on coping and interpersonal relationships, it remains avoided due to it being a "not talked about" topic. Healthcare professionals and charitable organisations both play an important role in providing information, advice, and guidance not only to the patient with IBD, but also to their wider support network who are also impacted by the disease (Shukla et al., 2018; Thapwong et al., 2023). Therefore, it is important that these services share information about the invisible challenges of IBD more widely. As individuals used social media to gain information and discuss their IBD (O'Leary et al., 2020; Zigron & Bronstein, 2018), this might provide a useful platform that services can use to both provide information for those with IBD and go beyond this to raise public awareness.

Limitations and future research

This is the first review to collate information on disclosure across the life span, providing a comprehensive synthesis of the individuals' experiences of disclosure, the barriers preventing people from disclosing and the reasons why people want to disclosure. However, there are important limitations that must be acknowledged.

Although including studies which provided qualitative data relating to disclosure was seen as a strength of this review, as it offered a wide range of data from different social contexts, it was acknowledged that only six studies directly address the topic of the review.

Therefore, despite a relatively high number of papers, the amount of data extracted and analysed from some studies was limited. Additionally, not having direct aims to explore the disclosure experiences resulted in the studies data collection methods not being developed or used to elicit information related to this experience, which may have limited, and potentially biased, the data extracted (Kvale, 1994). Additionally, this resulted in most data contributing to the themes coming from the papers that talked more directly about disclosure. Therefore, some themes may be biased by the information presented by these papers.

Papers were excluded if they contained a sample of different chronic illnesses and did not distinguish between those with IBD and those with other diagnosis. As many individuals with IBD experience comorbidities with other illnesses, such as IBS, pancreatic disease, and coeliac disease (San Román & Muñoz, 2011; Stanisic & Quigley, 2014), the exclusion of these studies may result in the understanding of disclosure for individuals with multiple diagnoses being lost. This highlights the need for future research to review the experiences of disclosure in IBD within a wider sample.

It is also important to consider the quality of papers included in this review. Although these were generally considered high, which suggests that their findings may be considered reliable, it is acknowledged that there were several areas of weakness. Despite most papers obtaining appropriate ethical approval, the details provided around ethical considerations and, how these were addressed, were often limited. Reflexivity was a weakness across most studies, with limited details regarding the researcher positioning or relationship to participants being provided. Although some papers named their positioning or previous experience, it was often not detailed how this influenced their approach to research or the interpretation of the research. This raises concern around the bias that may emerge due to the researchers positioning and experiences, which may influence their methodology and interpretations (Braun & Clarke, 2019), especially in those where their theme development

was not detailed. This, along with the overall quality of papers, should be considered in the interpretation and application of the current review. Although it is acknowledged that papers submitted to journals may not provide explicit details on their reflexivity, theme development or ethical considerations due to word count limitations, it would be beneficial for future research to provide these details to ensure more accurate quality appraisals and to ensure reliable interpretations are made in future review papers.

Within this review, papers exploring disclosure directly were limited. However, experiences of disclosure were identified within the wider "experiences" literature, indicating that it is an important aspect of the IBD journey. This highlights the need for future research to address this phenomenon more directly within IBD, especially given the impact disclosure has on personal and social aspects of an individual's life (Omarzu, 2000). Future research is needed to develop the understanding of IBD disclosure across different contexts, including school, work, relationships, friendships, and medical settings. Exploring the facilitators and barriers of disclosure across these settings, and identifying how experience differs between them, can provide useful information, and enable services to implement support measures to address these barriers and encourage help-seeking when needed.

Conclusions

This review provides a synthesis of individuals' experiences when disclosing IBD and identified contexts and outcomes that are perceived to both encourage and prevent disclosures. The findings from this review further highlight the complexity of this decision, influenced by the interaction of personal and societal factors and dependent on the believed impact of the disclosure. A paucity of research directly exploring the experience of self-disclosure in this population was identified, despite disclosure being a frequent occurrence, impacting on individual's social lives and personal identity. Therefore, there is a need for future research to focus on exploring factors associated with self-disclosure more directly.

References

Adeoye-Agboola, D. I., Evans, H., Hewson, D., & Pappas, Y. (2016). Factors influencing HIV disclosure among people living with HIV/AIDS in Nigeria: A systematic review using narrative synthesis and meta-analysis. *Public Health, 136*, 13–28. https://doi.org/10.1016/j.puhe.2016.02.021

Barned, C., Stinzi, A., Mack, D., & O'Doherty, K. C. (2016). To tell or not to tell: A qualitative interview study on disclosure decisions among children with inflammatory bowel disease. *Social Science and Medicine, 162*, 115-123. https://doi.org/10.1016/j.socscimed.2016.06.023

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology*, *9*(59), 1-11. https://doi.org/10.1186/1471-2288-9-59

Benson, A., O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2015). To tell or not to tell: A systematic review of the disclosure practices of children living with epilepsy and their parents. *Epilepsy & Behavior*, *51*(1), 73–95. https://doi.org/10.1016/j.yebeh.2015.07.013

Boye, B., Lundin, K. E., Jantschek, G., Leganger, S., Mokleby, K., Tangen, T., Jantschek, I., Pripp, A. H., Wojniusz, S., Dahlstroem, A., Rivenes, A. C., Benninghoven, D., Hausken, T., Roseth, A., Kunzendorf, S., Wilhelmsen, I., Sharpe, M., Blomhoff, S., Malt, U. F., & Jahnsen, J. (2011). INSPIRE study: Does stress management improve the course of inflammatory bowel disease and disease-specific quality of life in distressed patients with ulcerative colitis or Crohn's disease? A randomized controlled trial. *Inflammatory Bowel Diseases, 17*(9), 1863–1873. https://doi.org/10.1002/ibd.21575

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Burns, E. A. (2003). Bathroom politics: Introducing students to sociological thinking from the bottom up. *Teaching Sociology, 31*(1), 110-118. https://doi.org/10.2307/3211429

Carter, B., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., & Qualter, P. (2020). "I don't like to make a big thing out of it": A qualitative interview-based study exploring factors affecting whether young people tell or do not tell their friends about their IBD. *International Journal of Chronic Diseases, 2020*(1059025), 1-11. https://doi.org/10.1155/2020/1059025

Catona, D., Greene, K., Magsamen-Conrad, K., & Carpenter, A. (2016). Perceived and experienced stigma among people living with HIV: Examining the role of prior stigmatization on reasons for and against future disclosures. *Journal of Applied Communication Research, 44*(2), 136–155. https://doi.org/10.1080/00909882.2016.1155726

Chaudoir, S. R. (2009). *HIV/AIDS disclosure decision-making and outcomes: A longitudinal, event-based analysis* [Doctoral thesis, University of Connecticut]. https://www.proquest.com/docview/304870254

Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision making and post-disclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin, 136*(2), 236–256. https://doi.org/10.1037/a0018193

Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure: A review and application of the disclosure processes model. *Social Science & Medicine, 72*(10), 1618–1629. https://doi.org/10.1016/j.socscimed.2011.03.028

Chelune, G. J. (1979). Measuring openness in interpersonal communication. In G. J. Chelune (Ed.), *Self disclosure: Origins, patterns and implications of openness in interpersonal relationships* (pp.1-27). Jossey-Bass Inc.

Clifford, L. M., Brothers, S. L., & Lang, A. (2023). Self-Disclosure patterns among children and youth with epilepsy: Impact of perceived-stigma. *Adolescent Health, Medicine and Therapeutics*, *2023*(14), 27–43. https://doi.org/10.2147/AHMT.S336124

Colmer, L. J. (2021). *Working with IBD: Employee disclosure to managers* [Masters thesis, University of Amsterdam]. https://www.innovatiefinwerk.nl/sites/innovatiefinwerk.nl/files/field/bijlage/02_mthesis_lee_colmer.pdf

Corrigan, P. W., Watson, A. C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology*, *25*(8), 875–884. https://doi.org/10.1521/jscp.2006.25.8.875

Critical Appraisal Skills Programme. (2018). *CASP qualitative checklist*. https://casp-uk.net/casp-tools-checklists/

Crohn's & Colitis Foundation. (2023). *Living with IBD: Pain and fatigue.* https://www.crohnscolitisfoundation.org/pain-and-fatigue

Crohn's & Colitis UK. (2022). *A guide for employers.* https://crohnsandcolitis.org.uk/news-stories/news-items/new-research-shows-over-1-in-123-people-in-uk-living-with-crohn-s-or-colitis

Daniel, J. M. (2002). Young adults' perceptions of living with chronic inflammatory bowel disease. *Gastroenterology Nursing*, *25*(3), 83–94. https://doi.org/10.1097/00001610-200205000-00002

Devlen, J., Beusterien, K., Yen, L., Ahmed, A., Cheifetz, A. S., & Moss, A. C. (2014). The burden of inflammatory bowel disease: A patient-reported qualitative analysis and

development of a conceptual model. *Inflammatory Bowel Diseases, 20*(3), 545-552. https://doi.org/10.1097/01.MIB.0000440983.86659.81

Dibley, L., Norton, C., & Whitehead, E. (2017). 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., Williams, E., & Young, P. (2020). 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

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology, 6*(35), 1-13. https://doi.org/10.1186/1471-2288-6-35

Donoghue, P. J., & Siegel, M. E. (2000). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. WW Norton & Company.

Engebretson, J. (2013). Understanding stigma in chronic health conditions: Implications for nursing. *Journal of the American Association of Nurse Practitioners, 25*(10), 545–550. https://doi.org/10.1111/1745-7599.12009

Farrell, D., McCarthy, G., & Savage, E. (2016). Self-reported symptom burden in individuals with inflammatory bowel disease. *Journal of Crohn's & Colitis, 10*(3), 315–322. https://doi.org/10.1093/ecco-jcc/jjv218

Feagan, B. G., Reinisch, W., Rutgeerts, P., Sandborn, W. J., Yan, S., Eisenberg, D., Bala, M., Johanns, J., Olson, A., & Hanauer, S. B. (2007). The effects of infliximab therapy on

health-related quality of life in ulcerative colitis patients. *The American Journal of Gastroenterology*, *102*(4), 794–802. https://doi.org/10.1111/j.1572-0241.2007.01094.x

Frank, L., Lloyd, A., Flynn, J. A., Kleinman, L., Matza, L. S., Margolis, M. K., Bowman, L., & Bullock, R. (2006). Impact of cognitive impairment on mild dementia patients and mild cognitive impairment patients and their informants. *International Psychogeriatrics*, *18*(1), 151–162. https://doi.org/10.1017/S1041610205002450

Franz, M., Salize, H. J., Lujic, C., Koch, E., Gallhofer, B., & Jacke, C. O. (2013). Illness perceptions and personality traits of patients with mental disorders: The impact of ethnicity. *Acta Psychiatrica Scandinavica*, *129*(2), 143–155. https://doi.org/10.1111/acps.12134

Frohlich, D. O. (2014). Support often outweighs stigma for people with inflammatory bowel disease. *Gastroenterology Nursing*, *37*(2), 126-136. https://doi.org/10.1097/SGA.0000000000000030

Gelech, J., Desjardins, M., Mazurik, K., Duerksen, K., McGuigan-Scott, K., & Lichtenwald, K. (2021). Understanding gut feelings: Transformations in coping with inflammatory bowel disease among young adults. *Qualitative Health Research*, *31*(10), 1918-1936. https://doi.org/10.1177/10497323211011442

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Penguin.

Gonsalves, P. P., Nair, R., Roy, M., Pal, S., & Michelson, D. (2023). A systematic review and lived experience synthesis of self-disclosure as an active ingredient in interventions for adolescents and young adults with anxiety and depression. *Administration and Policy in Mental Health*, *50*(3), 488–505. https://doi.org/10.1007/s10488-023-01253-2

Gray, R. E., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-oncology*, *9*(4), 273–282. https://doi.org/10.1002/1099-1611(200007/08)9:4<273::aid-pon463>3.0.co;2-f

Green, G. (2009). *The end of stigma? Changes in the social experience of long-term illness*. Routledge.

Greene, K. (2000). Disclosure of chronic illness varies by topic and target: The role of stigma and boundaries in willingness to disclose. In S. Petrino (Ed.), *Balancing the secrets of private disclosures* (pp. 123-135). Lawrence Erlbaum Associates.

Guo, L., Rohde, J., & Farraye, F. A. (2020). Stigma and disclosure in patients with inflammatory bowel disease. *Inflammatory Bowel Diseases*, *26*(7), 1010–1016. https://doi.org/10.1093/ibd/izz260

Hall, N. J., Rubin, G. P., Dougall, A., Hungin, A. P., & 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*(3), 443–455. https://doi.org/10.1177/1359105305051433 https://ovidsp.ovid.com/athens/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc14&AN=2015-99090-356

IBD UK. (n.d.). *IBD standards core statements.* https://s3.eu-west-2.amazonaws.com/sr-crohns-craft/documents/IBD-Standards-Core-Statements.pdf

Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, *32*(1), 243–248. https://doi.org/10.1046/j.1365-2648.2000.01466.x

Kalla, R., Ventham, N. T., Satsangi, J., & Arnott, I. D. (2014). Crohn's disease. *The BMJ*, *349*(g6670), 1-11. https://doi.org/10.1136/bmj.g6670

Kim, E. S., Kwon, K. T., Kim, S. K., Kim, M., Lee, H. S., Jang, B. I., Kim, K. O., Kim, E. Y., Lee, Y. J., Hong, S. J., Yang, C. H., Kang, B., Choe, B. H., & Crohn’s and Colitis Association in Daegu-Gyeongbuk (CCAiD). (2019). Impact of education on school nurses' knowledge of inflammatory bowel disease. *Gut and Liver*, *13*(1), 48–53. https://doi.org/10.5009/gnl18139

Kitchen, H., Farrar, M., Al-Zubeidi, T., Pegram, H., Hunter, T., Naegeli, A. N., Delbecque, L., & Jairath, V. (2020). Patient's perspective on disease burden, remission definition, and symptoms associated with treatment seeking: A qualitative study in adult and adolescent patients with Crohn's disease. *Crohn's & Colitis 360*, *2*(2), 1-12. https://doi.org/10.1093/crocol/otaa033

Kluthe, C., Migliarese Isaac, D., Hiller, K., Carroll, M., Wine, E., van Manen, M., & Huynh, H. Q. (2018). Qualitative analysis of pediatric patient and caregiver perspectives after recent diagnosis with inflammatory bowel disease. *Journal of Pediatric Nursing, 38*, 106-113. https://doi.org/10.1016/j.pedn.2017.11.011

Kouveli, S. (2022). *"But you don't look ill" – A research project on social stigma & Inflammatory Bowel Disease (IBD).* Crohn's & Colitis UK. https://crohnsandcolitis.org.uk/news-stories/blog-posts/but-you-don-t-look-ill-a-research-project-on-social-stigma-inflammatory-bowel-disease-ibd

Krsmanovic, A., & Dean, M. (2022). How women suffering from endometriosis disclose about their disorder at work. *Health Communication*, *37*(8), 992–1003. https://doi.org/10.1080/10410236.2021.1880053

Kvale, S. (1994). Ten standard objections to qualitative research interviews. *Journal of Phenomenological Psychology, 25*(2), 147-173. https://doi.org/10.1163/156916294X00016

Ledford, C. J. W., Villareal, C., Williams, E. W., Cafferty, L. A., Jackson, J. T., & Seehusen, D. A. (2022). Patient decision-making about self-disclosure of a type 2 diabetes diagnosis: A qualitative study. *Diabetes Spectrum*, *35*(3), 327–334. https://doi.org/10.2337/ds21-0043

Lewko, J., Polityńska, B., Kochanowicz, J., Zarzycki, W., Okruszko, A., Sierakowska, M., Jankowiak, B., Górska, M., Krajewska-Kułak, E., & Kowalczuk, K. (2007). Quality of

life and its relationship to the degree of illness acceptance in patients with diabetes and peripheral diabetic neuropathy. *Advances in Medical Sciences*, *52*(1), 144–146. http://www.advms.pl/?q=system/files/33_52SLewko.pdf

Liverani, E., Scaioli, E., Digby, R. J., Bellanova, M., & Belluzzi, A. (2016). How to predict clinical relapse in inflammatory bowel disease patients. *World Journal of Gastroenterology*, *22*(3), 1017–1033. https://doi.org/10.3748/wjg.v22.i3.1017

Lolli, J. N. (2022). *Inflammatory bowel disease & social (in)visibility: An interpretive study of food choice, self-blame and coping in women living with IBD* [Doctoral dissertation, University of South Florida]. https://digitalcommons.usf.edu/cgi/viewcontent.cgi?article=10595&context=etd

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*,*1*(1), 31-42. https://doi.org/10.1177/2632084320947559

MacLeod, J. S., & Austin, J. K. (2003). Stigma in the lives of adolescents with epilepsy: A review of the literature. *Epilepsy & Behavior*, *4*(2), 112–117. https://doi.org/10.1016/s1525-5050(03)00007-6

Majid, U., & Vanstone, M. (2018). Appraising qualitative research for evidence syntheses: A compendium of quality appraisal tools. *Qualitative Health Research*, *28*(13), 2115–2131. https://doi.org/10.1177/1049732318785358

Major, B., & O'Brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology*, *56*(1), 393–421. https://doi.org/10.1146/annurev.psych.56.091103.07013

Matini, L., & Ogden, J. (2016). A qualitative study of patients' experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation. *Journal of Health Psychology*, *21*(11), 2493–2502. https://doi.org/10.1177/1359105315580463

Micallef-Konewko, E. (2013). *Talking about an invisible illness: the experience of young people suffering from inflammatory bowel disease (IBD)* [Doctoral thesis, University of East London]. https://repository.uel.ac.uk/item/85x5y

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, *6*(7), Article e1000097. https://doi.org/10.1371/journal.pmed.1000097

Murphy, R., Harris, B., & Wakelin, K. (2022). Too shamed to tell: The impact of shame on illness disclosure in women living with inflammatory bowel disease. *Gastrointestinal Nursing, 20*(5), 42-48. https://doi.org/10.12968/gasn.2022.20.5.42

Muse, K., Johnson, E., & David, A. L. (2021). A feeling of otherness: A qualitative research synthesis exploring the lived experiences of stigma in individuals with inflammatory bowel disease. *International Journal of Environmental Research and Public Health, 18*(15), 8038. https://doi.org/10.3390/ijerph18158038

Nehasil, M. J. (2014). *Health-related quality of life outcomes of participants in a Montana-specific, online support community for people in Montana with inflammatory bowel disease* [Doctoral dissertation, Montana State University]. http://resolver.ebscohost.com/openurl?sid=OVID:psycdb&id=pmid:&id=doi:&issn=0419-4209&isbn=9781321085334&volume=75&issue=11-A%28E%29&spage=No&date=2015&title=Dissertation+Abstracts+International+Section+A%3A+Humanities+and+Social+Sciences&atitle=Health-related+quality+of+life+outcomes+of+participants+in+a+montana-specific%2C+online+support+community+for+people+in+montana+with+inflammatory+bowel+disease.&aulast=Nehasil

Nicholas, D. B., Otley, A., Smith, C., Avolio, J., Munk, M., & Griffiths, A. M. (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

Nuttall, R. (2019). *"It's the complete stigma behind it." Exploring how and why mental health stigma impacts on disclosure and help-seeking behaviours: A thematic analysis* [Masters thesis, University of Huddersfield]. https://eprints.hud.ac.uk/id/eprint/35183/1/FINAL%20THESIS%20-%20Nuttall.pdf

O'Leary, K., Coulson, N., Perez-Vallejos, E., & McAuley, D. (2020). Towards understanding how individuals with inflammatory bowel disease use contemporary social media platforms for health-related discourse. *Computers in Human Behavior, 112*(106463), 1-11. https://doi.org/10.1016/j.chb.2020.106463

Omarzu, J. (2000). A disclosure decision model: Determining how and when individuals will self-disclose. *Personality and Social Psychology Review, 4*(2), 174-185. https://doi.org/10.1207/S15327957PSPR0402_05

Palant, A., & Himmel, W. (2019). Are there also negative effects of social support? A qualitative study of patients with inflammatory bowel disease. *BMJ Open, 9*(1), 1-10. https://doi.org/10.1136/bmjopen-2018-022642

Park, S. G., Bennett, M. E., Couture, S. M., & Blanchard, J. J. (2013). Internalized stigma in schizophrenia: Relations with dysfunctional attitudes, symptoms, and quality of life. *Psychiatry Research, 205*(1-2), 43–47. https://doi.org/10.1016/j.psychres.2012.08.040

Pathmalingam, T., Moola, F. J., & Woodgate, R. L. (2023). Illness conversations: Self-disclosure among children and youth with chronic illnesses. *Chronic Illness, 19*(3), 475–494. https://doi.org/10.1177/17423953221110152

Peters, L. A., & Brown, E. M. (2022). The relationship between illness identity and the self-management of Inflammatory Bowel Disease. *British Journal of Health Psychology, 27*(3), 956–970. https://doi.org/10.1111/bjhp.12584

Plant, M., & Brody, B. (2023). *What people don't understand about crohn's.* WebMD Perspectives. https://www.webmd.com/ibd-crohns-disease/crohns-disease/features/crohns-misunderstood

Potocka, A., Turczyn-Jabloñska, K., & Merecz, D. (2009). Psychological correlates of quality of life in dermatology patients: The role of mental health and self-acceptance. *Acta dermatovenerologica Alpina, Pannonica, et Adriatica, 18*(2), 53–62. http://s3-eu-west-1.amazonaws.com/thejournalhub/10.15570/archive/acta-apa-09-2/2.pdf

Restall, G. J., Simms, A. M., Walker, J. R., Graff, L. A., Sexton, K. A., Rogala, L., Miller, N., Haviva, C., Targownik, L. E., & Bernstein, C. N. (2016). Understanding work experiences of people with inflammatory bowel disease. *Inflammatory Bowel Diseases, 22*(7), 1688-1697. https://doi.org/10.1097/MIB.0000000000000826

Robertson, N., Gunn, S., & Piper, R. (2022). The experience of self-conscious emotions in inflammatory bowel disease: A thematic analysis. *Journal of Clinical Psychology in Medical Settings, 29*(2), 344–356. https://doi.org/10.1007/s10880-021-09778-0

Rouncefield-Swales, A., Carter, B., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., & Qualter, P. (2020). Sustaining, forming, and letting go of friendships for young people with inflammatory bowel disease (IBD): A qualitative interview-based study. *International Journal of Chronic Diseases, 2020*(166), Article e7254972. https://doi.org/10.1155/2020/7254972

Ruan, J., & Zhou, Y. (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*(1), 87-96. https://doi.org/10.1016/j.ijnurstu.2019.02.015

Sainsbury, A., & Heatley, R. V. (2005). Review article: Psychosocial factors in the quality of life of patients with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics*, *21*(5), 499–508. https://doi.org/10.1111/j.1365-2036.2005.02380.x

Salazar, G., & Heyman, M. B. (2014). Benefits of attending a summer camp for children with inflammatory bowel disease. *Journal of Pediatric Gastroenterology & Nutrition, 59*(1), 33-38. https://doi.org/10.1097/MPG.0000000000000359

Sammut, J., Borg Xuereb, R., & Scerri, J. (2017). The experience of living with an ileoanal pouch: An interpretative phenomenological analysis. *Gastroenterology Nursing*, *40*(5), 401-409. https://doi.org/10.1097/SGA.0000000000000215

San Román, A. L., & Muñoz, F. (2011). Comorbidity in inflammatory bowel disease. *World Journal of Gastroenterology*, *17*(22), 2723–2733. https://doi.org/10.3748/wjg.v17.i22.2723

Saunders, B. (2014). Stigma, deviance and morality in young adults' accounts of inflammatory bowel disease. *Sociology of Health & Illness*, *36*(7), 1020-1036. https://doi.org/10.1111/1467-9566.12148

Savard, J., & Woodgate, R. (2009). Young peoples' experience of living with ulcerative colitis and an ostomy. *Gastroenterology Nursing, 32*(1), 33-41. https://doi.org/10.1097/SGA.0b013e3181965d40

Schreiber, S., Panés, J., Louis, E., Holley, D., Buch, M., & Paridaens, K. (2012). Perception gaps between patients with ulcerative colitis and healthcare professionals: An online survey. *BMC Gastroenterology*, *12*(108), 1-11. https://doi.org/10.1186/1471-230X-12-108

Schwenk, H. T., Lightdale, J. R., Arnold, J. H., 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. https://doi.org/10.1097/MIB.0000000000000124

Sheehan, L., Palermo, C. V., & Corrigan, P. (2022). Theoretical models to understand stigma of mental illness. In D. L. Vogel & N. G. Wade (Eds.), *The Cambridge Handbook of Stigma and Mental Health* (pp. 11–30). Cambridge University Press.

Sheridan, K., Salmon, N., & O'Connell, N. (2016). Experiences of university students disclosing epilepsy to peers: 'It's a shared thing now'. *British Journal of Occupational Therapy, 79*(8), 484-491. https://doi.org/10.1177/0308022616638672

Shukla, R., Thakur, E., Bradford, A., & Hou, J. K. (2018). Caregiver burden in adults with inflammatory bowel disease. *Clinical Gastroenterology and Hepatology*, *16*(1), 7–15. https://doi.org/10.1016/j.cgh.2017.05.020

Stangl, A. L., Earnshaw, V. A., Logie, C. H., van Brakel, W., C Simbayi, L., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*(1), Article 31. https://doi.org/10.1186/s12916-019-1271-3

Stanisic, V., & Quigley, E. M. (2014). The overlap between IBS and IBD: What is it and what does it mean? *Expert Review of Gastroenterology & Hepatology*, *8*(2), 139–145. https://doi.org/10.1586/17474124.2014.876361

Stone, S. D. (2005). Reactions to invisible disability: The experiences of young women survivors of hemorrhagic stroke. *Disability and Rehabilitation*, *27*(6), 293–304. https://doi.org/10.1080/09638280400008990

Taft, J., & Keefer, L. (2016). A systematic review of disease-related stigmatization in patients living with inflammatory bowel disease. *Clinical and Experimental Gastroenterology*, *2016*(9), 49–58. https://doi.org/10.2147/CEG.S83533

Taft, T. H., Bedell, A., Naftaly, J., & Keefer, L. (2017). Stigmatization toward irritable bowel syndrome and inflammatory bowel disease in an online cohort. *Neurogastroenterology and Motility*, *29*(2), 1-16. https://doi.org/10.1111/nmo.12921

Taft, T. H., Keefer, L., Leonhard, C., & Nealon-Woods, M. (2009). Impact of perceived stigma on inflammatory bowel disease patient outcomes. *Inflammatory Bowel Diseases*, *15*(8), 1224–1232. https://doi.org/10.1002/ibd.20864

Thapwong, P., Norton, C., Rowland, E., Farah, N., & Czuber-Dochan, W. (2023). A systematic review of the impact of inflammatory bowel disease (IBD) on family members. *Journal of Clinical Nursing*, *32*(9-10), 2228–2238. https://doi.org/10.1111/jocn.16446

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(45), 1-10. https://doi.org/10.1186/1471-2288-8-45

Ungaro, R., Mehandru, S., Allen, P. B., Peyrin-Biroulet, L., & Colombel, J. F. (2017). Ulcerative colitis. *Lancet*, *389*(10080), 1756–1770. https://doi.org/10.1016/S0140-6736(16)32126-2

Vaughan, H., & Jolliffe, P. (2023). "Why it's important to talk about our toilet needs in the workplace" – Using Maslow's needs theory to shine a light on workers living with IBD in the workplace. *Qualitative Report, 28*(3), 929-959. https://doi.org/10.46743/2160-3715/2023.5102

Venema, K., Conn, B.M., Tanaka, D., Silge, K., & Iverson, E. (2023). Sharing a secret: Disclosure practices among adolescents and young adults with chronic illness. *Current Psychology, 43*(1), 5742-5752. https://doi.org/10.1007/s12144-023-04453-z

Vickers, M. H. (1997). Life at work with "invisible" chronic illness (ICI): The "unseen", unspoken, unrecognized dilemma of disclosure. *Journal of Workplace Learning, 9*(7), 240–252. https://doi.org/10.1108/13665629710190040

Vidali, A. (2010). Out of control: The rhetoric of gastrointestinal disorders. *Disability Studies Quarterly, 30*(3/4), Article 1287. https://dsq-sds.org/index.php/dsq/article/view/1287/1313

Wåhlin, M., Stjernman, H., & Munck, B. (2019). Disease-related worries in persons with Crohn disease: An interview study. *Gastroenterology Nursing*, *42*(5), 435–442. https://doi.org/10.1097/SGA.0000000000000395

Wang, Y., Zhang, C., & Zhou, Y. (2023). Reconstructing self from the illness: A constructivist grounded theory study of posttraumatic growth in patients with Crohn's disease. *BMC Gastroenterology*, *23*(1), Article 244. https://doi.org/10.1186/s12876-023-02878-1

Wanjala, S. W., Nyongesa, M. K., Mapenzi, R., Luchters, S., & Abubakar, A. (2023). A qualitative inquiry of experiences of HIV-related stigma and its effects among people living with HIV on treatment in rural Kilifi, Kenya. *Frontiers in public health*, *11*(1188446), 1-12. https://doi.org/10.3389/fpubh.2023.1188446

Wilson, D. C., & Russell, R. K. (2017). Overview of paediatric IBD. *Seminars in Pediatric Surgery*, *26*(6), 344–348. https://doi.org/10.1053/j.sempedsurg.2017.10.002

Wong, E. C., Collins, R. L., Cerully, J., Seelam, R., & Roth, B. (2017). Racial and ethnic differences in mental illness stigma and discrimination among Californians experiencing mental health challenges. *Rand Health Quarterly*, *6*(2), Article 6. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5568160/

Woodgate, R. L., Tennent, P., Barriage, S., & Legras, N. (2022). The centrality of disclosure decisions to the illness experience for youth with chronic conditions: A qualitative

study. *Journal of health psychology*, *27*(3), 521–533. https://doi.org/10.1177/1359105320962242

Woodward, S., Dibley, L., Coombes, S., Bellamy, A., Clark, C., Czuber-Dochan, W., Everelm, L., Kutner, S., Sturt, J., & Norton, C. (2016). Identifying disease-specific distress in patients with inflammatory bowel disease. *British Journal of Nursing, 25*(12), 649-660. https://doi.org/10.12968/bjon.2016.25.12.649

Zigron, S., & Bronstein, J. (2018). "Help is where you find it": The role of weak ties networks as sources of information and support in virtual health communities. *Journal of the Association for Information Science & Technology, 70*(2), 130-139. https://doi.org/10.1002/asi.24106

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SELF-DISCLOSURE AND DISORDERED EATING IN INFLAMMATORY BOWEL DISEASE (IBD)

SECTION B:

Prevalence and predictors of developing Avoidant Restrictive Food Intake Disorder in Inflammatory Bowel Disease

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Abstract

Introduction: People with Inflammatory Bowel Disease (IBD) often seek dietary solutions to manage their gastrointestinal symptoms. Avoidant/Restrictive intake disorder (ARFID) is high in this population, however, understanding of the risk factors for this is limited. The current research aims to estimate the prevalence of, and explore the biopsychosocial factors associated with, ARFID in the UK IBD population. **Method:** Participants accessed an online survey containing six self-report questionnaires examining IBD symptoms, ARFID symptoms, and several psychosocial factors. A total of 164 adults with IBD (70.12% male, 59.8% Crohn's disease), aged between 23 and 74 (M = 36.08, SD = 7.94), met the eligibility criteria for participation and were included in the analysis. After 6-months, participants were invited to complete a follow-up of these questionnaires. **Results:** 123 participants (75%, 95% CI [68.4%-81.6%]) scored within the positive range for ARFID symptomology. Regression analysis identified that the psychosocial variables, apart from desirability of control, were predictive of ARFID symptoms. When controlling for other IBD related factors, visceral sensitivity (gastrointestinal-specific anxiety) remained predictive of ARFID. Due to the attrition rate, the longitudinal hypotheses could not be tested, however, initial correlations did not find any relationships between the change in variable scores. **Conclusions:** The findings suggest that individuals with IBD may have a high prevalence of ARFID, with biopsychosocial factors, particularly visceral sensitivity, potentially contributing to this. Areas of future research, including exploring the impact and value of screening for and/or delivering interventions to address visceral sensitivity, and the potential implications for healthcare and charitable services are discussed.

Key words: Inflammatory Bowel Disease (IBD), ARFID, Disordered Eating, Crohn's Disease, Ulcerative Colitis.

Introduction

Inflammatory Bowel disease (IBD), namely Crohn's disease (CD) and Ulcerative Colitis (UC), are chronic gastrointestinal illnesses effecting approximately 0.81% of the UK population (Crohn's & Colitis UK, 2022). Diet can play an important role in managing IBD, with some individuals requiring temporary restrictive or liquid diets for IBD-related surgeries (Crohn's & Colitis Foundation, n.d.; Heerasing et al., 2017). For others, complex relationships may develop with food, due to individuals associating diet with the uncomfortable gastrointestinal symptoms which are characteristic of the disease (Cohen et al., 2013; Czuber-Dochan et al., 2020; Di Giorgio et al., 2023; Limdi et al., 2016; Reddavide et al., 2018).

Eating Disorders in IBD

Individuals living with gastrointestinal disorders, like IBD, are at greater risk of developing disordered eating (Peters et al., 2022; Satherley et al., 2015; Wardle et al., 2018), with between 16 and 24.5% meeting the criteria for diagnosable eating disorders (ED) (Kuźnick & Neubauer, 2021; Robelin et al., 2021; Wabich et al., 2020). The perceived association between food and IBD symptoms may lead to people changing their diet in attempt to control symptoms and prevent flare ups (Day et al., 2021; Nowlin et al., 2021), including eliminating specific foods/whole food groups if they have been perceived as harmful by the individual (Czuber-Dochan et al., 2020; Di Giorgio et al., 2023). Understanding the risk of EDs in IBD is important as, when these dietary changes are implemented independently, and are unsupervised by a dietitian, individuals' risk experiencing physical health complications, including delayed growth and nutritional difficulties (Di Giorgio et al., 2023; Ilzarbe et al., 2017) and may be at more risk of developing restrictive eating (Ilzarbe et al., 2017; Wardle et al., 2018).

Avoidant Restrictive Food Intake Disorder

Avoidant Restrictive Food Intake Disorder (ARFID) is an ED diagnosis which was introduced into the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) in 2013. An ARFID diagnosis is given to individuals of any age who avoid or restrict food due to its sensory properties ("picky eating'), low appetite or limited interest in eating and/or due to fear of negative/uncomfortable consequences (e.g., choking or sickness) from food (Zimmerman & Fisher, 2017). Despite ARFID potentially contributing to weight loss, this diagnosis is distinct from other forms of ED as a focus on weight, or shape concerns, are not required within its diagnostic criterion (BEAT, 2024). Although there are limitations to using a diagnostic category (Johnstone, 2018; Kapadia et al., 2020), the current research refers to ARFID due to this typically being used within IBD services.

Due to the perceived relationship between gastrointestinal symptoms and dietary intake, individuals with IBD may be at higher risk of developing eating patterns which may, within a diagnostic framework, meet the criteria for ARFID. It has been estimated that the prevalence of ARFID in those with IBD is between 10.2 – 32.5% (Robelin et al., 2021; Yelencich et al., 2022; Yin et al., 2023) compared to approximately 1.2-4.7% in the general population (D'Adamo et al., 2023; Hay et al., 2017; Van Buuren et al., 2023). The variation in ARFID prevalence rates for this population may reflect the differences in participant inclusion criteria, with some studies excluding individuals on specific diets, such as vegan and gluten free, which may influence self-reports of food avoidance (Yin et al., 2023). Although food restriction may be an appropriate response to IBD treatment, especially when advised by a dietitian, it has been found that dietary treatments can increase an individual's risk of developing ARFID (Fink et al., 2022).

Recently, Yelencich et al. (2022) reported 17% of their sample to score within a range indicative of ARFID. However, they also found that nearly all participants (92%) avoided

one or more foods when experiencing active IBD symptoms, with 74% continuing to avoid foods when in remission. Although avoidance of one or more food does not necessarily meet the diagnostic criteria for ARFID, this finding suggests that avoidant eating behaviours may continue, even in the absence of IBD symptoms, potentially reflecting the beliefs or fears that certain food may trigger symptoms in the future (Yelencich et al., 2022; Yin et al., 2023).

For individuals with IBD, ARFID has been associated with poorer physical and mental health outcomes, including a risk of malnutrition (Yelencich et al., 2022) and reports of lower quality of life (QoL) (Fink et al., 2022). However, to date, studies looking at the prevalence of ARFID in IBD have been conducted within American and Chinese samples, where there may be different perceptions towards IBD and its treatment (Schrieber et al., 2013) compared to the United Kingdom (UK). Therefore, the understanding of ARFID in IBD in the UK remains limited. Increasing the understanding of ARFID, and its risk factors, is vital for ensuring adequate support and interventions are available, especially given its potential impact on physical and mental health for this population.

Biopsychosocial factors contributing to ARFID in IBD

The Biopsychosocial model of health (Engel, 1977) theorises the interplay between biological factors (genetics, physiology, cell formation), psychological factors (experiences, emotions, and behaviours) and social factors (relationships and levels of support) in influencing health and the development of illness (Dent et al., 2022; Gatchel et al., 2007). Although the biopsychosocial model has been applied to both EDs (Frank, 2016) and gastrointestinal disorders (Dent et al., 2022) independently, there remains limited knowledge regarding the biopsychosocial drivers/risk factors for ARFID within an IBD population.

Biological Factors and IBD related factors

When living with chronic gastrointestinal disorders, biological factors associated with the disease itself, including stomach discomfort, appear to influence eating behaviours,

potentially increasing the risk of these individuals developing EDs (Satherley et al., 2015). Within IBD specifically, several factors related to the diagnosis, including being diagnosed at a younger age and having more IBD-related surgeries, have been associated with a higher risk of EDs (Cao et al., 2019; Stoleru et al., 2022; Wabich et al., 2020). Additionally, having a stoma bag may increase the risk of ED's for individuals with IBD, as it can contribute to poorer body image (Bullen et al., 2012; Cooley & Toray, 2001).

IBD related factors have also been found to predict the risk of ARFID specifically. Yelencich et al. (2022) identified that higher levels of IBD activity (the severity and presence of symptoms) and higher levels of physical inflammation significantly predicted ARFID symptoms, supporting the role of physical factors in this presentation. The finding that IBD activity predicts ARFID symptoms has been further supported within Chinese populations (Tu et al., 2023; Yin et al., 2023). Although not identified by Yelencich et al. (2022), other research has found IBD diagnosis to predict ARFID, with individuals with CD presenting higher ARFID symptoms than those with UC (Tu et al., 2023; Yin et al., 2023). It is possible that this may reflect the extent of digestive symptoms experienced, which are higher in CD compared to UC (Bergeron et al., 2018). However, to date, the findings in relation to the IBD-related factors potentially associated with the risk of ARFID appear inconsistent.

Psychosocial Factors

For individuals with IBD, specific psychological factors, such as dissatisfaction with weight, anxiety, and dietary beliefs, have been associated with a higher risk of ED (David et al., 2022; Wabich et al., 2020; Wardle et al., 2018). However, to date, the direct exploration of psychological and social factors influencing the risk of ARFID in individuals with IBD is limited.

One psychological construct which may increase the risk of ARFID in an IBD population is anxiety, which is generally higher in this population when compared to the

general population (Byrne et al., 2017; Neuendorf et al., 2016). According to Mowrer's two-factor theory (1947, as cited in Krypotos et al., 2015), classical conditioning and the avoidance of distress are fundamental components increasing and maintaining fear/anxiety (except in the short term). Drawing on Mowrer's theory, Brown and Hildebrandt (2020) theorise that anxiety is a fundamental component in the development of ARFID. Within their two-stage model, it is proposed that, when an association between food and anxiety is formed (such as through a negative experience), avoidance of the food contributes to a reduction in anxiety, which further increases the avoidance behaviour through the process of negative reinforcement (Brown & Hildebrandt, 2020; Kazdin, 2012).

For individuals living with IBD, experiencing unpleasant gastrointestinal symptoms after the consumption of food may contribute to gastrointestinal-specific anxiety (GSA), with this specific food/food group becoming an aversive stimulus (Czuber-Dochan et al., 2020; Di Giorgio et al., 2003). By avoiding this food, it not only reduces the GSA, but is also perceived to prevent IBD symptoms, which reinforces the avoidance behaviour and potentially contributes to the risk of ARFID (Brown & Hildebrandt, 2020). Therefore, it may be expected that those with high levels of GSA, as well as those that have lower tolerance of emotional distress (Keough et al., 2010), would be at higher risk of developing ARFID symptoms, due to the avoidance being reinforced.

Another psychological factor that may contribute to ARFID within IBD is an individual's desire for personal control. ARFID, which was conceptualised outside of IBD, was historically theorised as a method enabling children to seek control over their parents or general life (Kring & Johnson, 2018; Zimmerman & Fisher, 2017), suggesting that control potentially contributes to the development of these eating patterns. This adheres to the more general ED literature, which identifies control, including desirability for control, as an important factor in the aetiology and maintenance of ED presentations (Froreich et al., 2017;

Sarra & Abar, 2022). For example, those diagnosed with an ED tend to report an external locus of control and present with a higher fear of losing self-control (Froreich et al., 2017; Tiggemann & Raven, 1998; Williams et al., 1990). The role of control has also been associated with disordered eating in Type 1 diabetes, with a lower sense of control, including bodily control, being associated with more severe disordered eating (Schwartz et al., 2002).

Within IBD specifically, the perception of control varies across individuals, with some reporting that lower control increases psychological distress, while others use reduced feelings of control as a coping mechanism (Cooper et al., 2010; Olbrisch & Ziegler, 1982). Although it appears that individuals' desirability for control influences the risk of ED more generally, there is currently no research exploring the relationship between this and ARFID in an IBD population.

Within IBD, the presence of social support is often considered protective, contributing to increased QoL, resilience, and acting as a buffer against psychological distress (Katz et al., 2016; Sewitch et al., 2001). As theorised by the stress-buffering hypothesis, the perceived availability of social support can weaken or reduce the negative relationship between stress and negative mental or physical outcomes (Cohen & Wills, 1985), with the absence of social support contributing to the development of physical/mental health difficulties, including EDs (Ghaderi, 2003; Limbert, 2010; Sluzki, 1996, as cited in Leonidas & Dos Santos, 2014).

Within the ED literature, it has been theorised that a lack of emotional warmth or support within a family can prevent children developing the required skills to manage stress, with ED's emerging as a coping mechanism for this psychological distress (Cunha et al., 2009; Leonidas & Dos Santos, 2014). Additionally, limited social support has been associated with poorer outcomes, as it can create a barrier to help-seeking (Ali et al., 2017), whereas adequate levels of social interaction contribute to ED recovery (Bertera, 2005; Cusack & Hughes, 2014; Hughes-Jones, 2009; Linville et al., 2012). However, individuals'

perceptions of/satisfaction with their support may be more associated with their ED outcome, compared to the actual level of support available (Limbert, 2010).

To date, there is an absence of research exploring the role of social support in ARFID directly. However, due to the association between social support and EDs more generally, it may be expected that perceptions of social support may be associated with an individual's risk of developing ARFID, especially for individuals with IBD who may experience stress related to their disorder (Lix et al., 2008; Sun et al., 2019).

The current research

In summary, research has focused on the prevalence of ARFID in individuals with IBD within the USA and China and identified key IBD- related factors associated with IBD (IBD activity, inflammation, diagnosis) that might increase this risk. However, the prevalence of ARFID in the UK IBD population, and psychosocial factors potentially contributing to this, have not been researched. Due to the impact ARFID can have on an individual's physical and mental health (Fink et al., 2022; Yelencich et al., 2022), it is important to develop an understanding of the biopsychosocial factors associated with it, to inform clinical care and support individuals presenting with, or at risk of developing, ARFID symptoms.

The current research aims to contribute to the understanding of ARFID risk within IBD, particularly in the UK, and enhance the knowledge of potential psychosocial risk factors contributing to ARFID in IBD. This has the potential to enhance the healthcare services supporting individuals with IBD, promote high quality care and improve lives, in line with the NHS values (The Department of Health & Social Care, 2023). There were two main aims of this research:

1.To estimate the prevalence of ARFID in adults with IBD in the UK; and

2. To identify predictors, including psychological and social predictors, of ARFID risk in this population.

Regarding the latter aim of this research, based on the research and theory described above, the following was hypothesised.

Hypothesis 1: IBD related factors (the diagnosis received (having CD rather than UC), younger age of diagnosis, higher number of IBD-related surgeries, having a stoma, and not having access to IBD support team/hotlines) will predict higher levels of ARFID.

Hypothesis 2**: a.** Greater IBD activity will predict higher levels of ARFID symptoms, in cross-sectional data.

b. Change in IBD activity between two time-points separated by six months will predict change in ARFID symptom over the same time period, with an increase in activity predicting an increase in ARFID symptoms.

Hypothesis 3**: a**. Higher levels of perceived social support will predict lower levels of ARFID symptoms, in cross-sectional data.

b. Change in levels of social support between two time-points separated by six months will predict change in ARFID symptom over the same time period, with a decrease in social support predicting an increase in ARFID symptoms.

Hypothesis 4: **a**. Higher levels of gastrointestinal-specific anxiety, higher desirability of control and lower distress tolerance, will predict higher levels of ARFID symptoms, in cross-sectional data.

b. Change in the above-mentioned predictors between two time-points separated by six months will predict change in ARFID, in the same direction as specified in 4a.

Hypothesis 5: **a.** The above-mentioned psychological and social factors will continue to predict ARFID symptomatology in the direction specified in 3a and 4a when controlling for disease activity and IBD related factors.

b. Change in the above mentioned psychological and social factors will continue to predict change in ARFID symptomatology between two time-points separated by six months in the same direction as specified in 3a and 4a when controlling for change in disease activity.

Hypothesis 6: **a.** The above-mentioned psychological and social factors will continue to predict ARFID symptoms (in cross-sectional data) in the direction specified in 3a and 4a when they are all included in a single predictive model.

b. Change in the above-mentioned psychological and social factors will continue to predict change in ARFID symptoms between two time-points separated by six months when entered into a single predictive model.

Method

Design

This research used a non-experimental, repeated measures survey design, with cross-sectional and longitudinal elements. The cross-sectional element explored the predictive relationship between ARFID symptomology and predictor variables including IBD activity, IBD factors (diagnosis, age at diagnosis, number of surgeries, having a stoma, access to IBD support/hotlines) and psychosocial factors (distress tolerance, visceral sensitivity (as a measure of GSA), desirability for control, perceived social support). The longitudinal element examined whether a change in psychosocial factors predicted a change in ARFID at follow up (six-months), while controlling for changes in IBD activity.

Patient and Public Involvement (PPI)

During design of this study, advertising through Crohn's and Colitis UK (CCUK) was used to recruit PPI consultants. Three consultants met with the author to discuss the research and to advise on the design and method. Following these meetings, advice was taken around

the length of the online survey and the language used throughout the research (e.g., "living with IBD" rather than "suffering from IBD").

Participants

Participants were recruited (Appendix G) from a volunteer sample of adults who completed an online survey which was accessible via online Organisation/Charity advertising (Crohn's & Colitis UK, IBD relief, Ileostomy Association, Guts Charity, Colostomy UK), support forums on social media and word of mouth. Participants were eligible to take part in this research if they met the criteria detailed in Table 1. Participants were offered entry into a draw for a prize of £100 as a reward for participating in the research.

Table 1

Participant inclusion criteria

	Criteria
Inclusion	- Ages 18 and over - Obtained a diagnosis of Crohn's Disease or Ulcerative Colitis from a medical doctor. - Currently residing in the UK
Exclusion	- Individuals who feel they may become distressed when thinking about aspects of their IBD or their eating behaviours.

A total of 558 responses were recorded for the study. Numerous responses (n = 394) were removed due to meeting a predetermined exclusion criterion designed to remove spurious data, such as that generated by bots or those not meeting the inclusion criteria (Figure 1). The final sample consisted of 164 participants (115 male, 49 female). No participants identified as non-binary or preferred not to disclose their gender. Participants were aged between 23 and 74 (M = 36.08, SD = 7.94) and most identified as White British (79.9%), married/civil partnership (79.9%) and in full-time employment (89%). Ninety-eight participants had a diagnosis of CD and 66 were diagnosed with UC, with the average age of diagnosis ranging between 10 and 63 (M = 28.84, SD = 7.44). There were 111 participants

that reported that they were currently living with a stoma. Within the current sample, most participants (86.7% CD and 92.4% UC) were identified as having active IBD, as measured by a cut-off of >24 for CD and >17 for UC on the Inflammatory Bowel Disease Symptom Inventory (IBD-SI, Sexton et al., 2019). Table 2 displays demographic data for the sample. As seen in Figure 1, the attrition rate for the follow up data collection was 91.5% (14 participants retained).

Figure 1

Screening and selection of data set for inclusion in data analysis

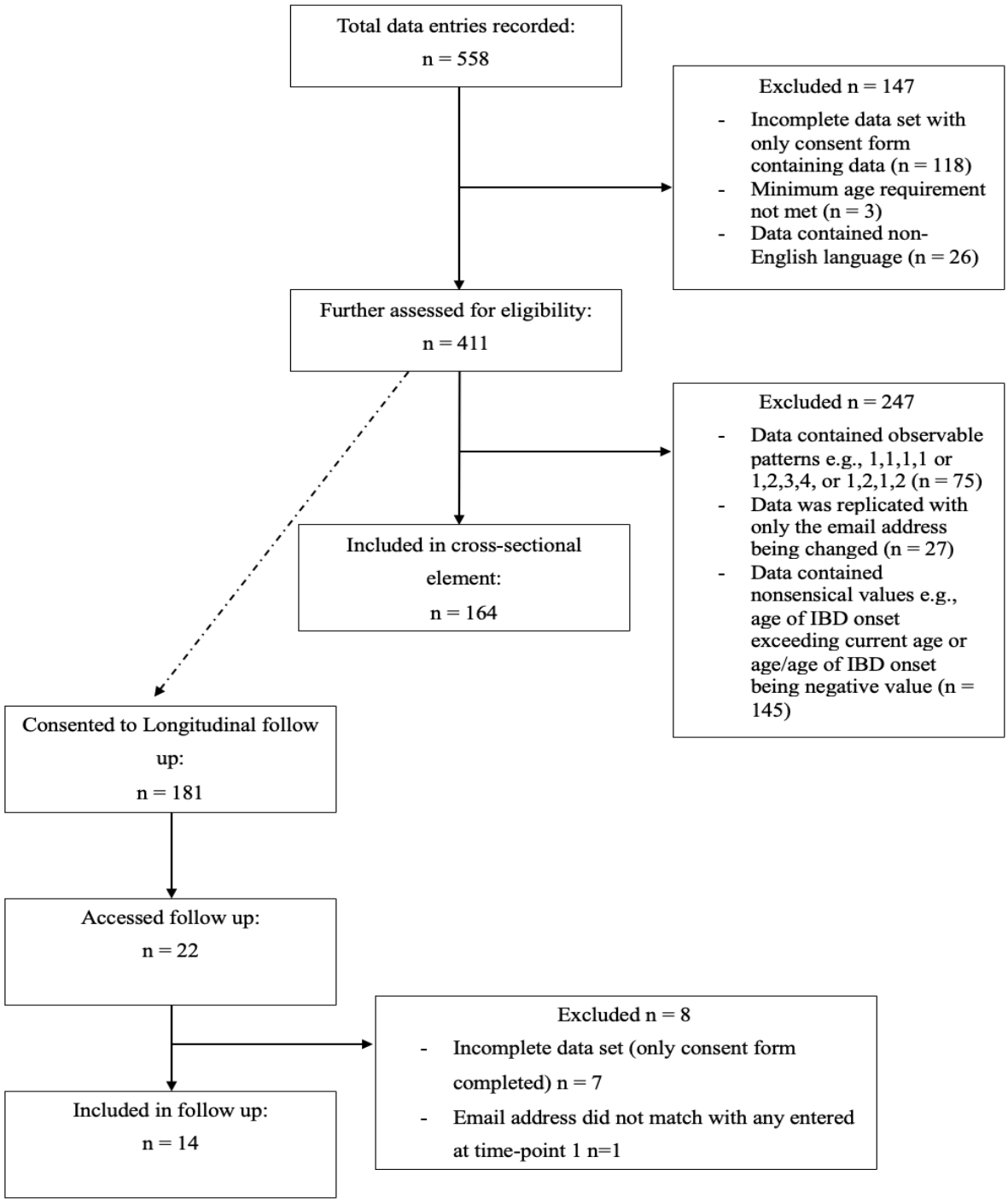


Table 1

Participant Demographics

Characteristic	First-time point N (%)	Follow-up N (%)
Gender		
Male	115 (70.12)	6 (42.86)
Female	49 (29.88)	8 (57.14)
Ethnicity		
White British	131 (79.88)	11 (78.57)
Black British	1 (0.61)	
White Irish	21 (12.80)	
Black Caribbean	4 (2.44)	
Indian	3 (1.83)	1 (7.14)
Pakistani	1 (0.61)	
Bangladeshi	1 (0.61)	
Other Asian Background	1 (0.61)	1 (7.14)
Another ethnicity	1 (0.61)	1 (7.14)
Marital Status		
Married/Civil Partnership	131 (79.88)	4 (28.57)
Living with partner/cohabiting	7 (4.27)	1 (7.14)
Single	15 (9.15)	5 (35.71)
Divorced/separated	9 (5.49)	4 (28.57)
Widowed	1 (0.61)	
Prefer not to say	1 (0.61)	
Employment		
Full time employed	146 (89.02)	6 (42.87)
Part time employed	4 (2.44)	1 (7.14)
Self employed	6 (3.66)	4 (28.57)
Unemployed	1 (0.61)	1 (7.14)
Retired	6 (3.66)	1 (7.14)
Student	1 (0.61)	1 (7.14)
IBD Diagnosis		
Crohn's Disease	98 (59.76)	5 (35.71)
Ulcerative Colitis	66 (40.24)	9 (64.29)
Having a stoma		
Yes	111 (67.68)	5 (35.71)
No	52 (31.71)	9 (64.29)
Prefer not to say	1 (0.61)	

Measures

An online survey using Gorilla Survey Software was developed. Within this survey, a demographic questionnaire (Appendix H), developed for the purpose of this research, was used to obtain descriptive information about the sample (age, gender, ethnicity, marital status) and for identifying IBD related factors which would be included in the regression analysis (IBD diagnosis, age of IBD diagnosis, number of surgeries, stoma use and access/use of IBD support teams/hotlines). This demographic questionnaire was only administered at time-point one. In addition, the following measures, which were administered at both time points, were included (Appendices I-N):

Inflammatory Bowel Disease Symptom Inventory – Long form (IBD-SI, Sexton et al., 2019)

The IBD-SI is a 35-item self-report measure which assesses IBD-symptoms, with higher scores indicating higher IBD activity. This scale provides an overall score of IBD-symptoms for both CD and UC and has been found to have very good internal consistency, convergent validity, and excellent sensitivity and specificity to clinician-rated active disease (Sexton et al., 2019), with a cut-off >24 for CD and >17 for UC being recommended for identifying IBD activity (Sexton et al., 2019). Within the current research, the IBD-SI was found to have strong internal consistency (α = .927).

Nine item Avoidant/Restrictive Food intake Disorder Screen (NIAS, Zickgraf & Ellis, 2018)

In this study, the NIAS was used to measure the level of ARFID symptoms (outcome variable). The NIAS presents nine self-report questions which are rated on a 6-point Likert scale ranging from 0 “strongly disagree” to 5 “strongly agree”, with a total score of 24 or more reflecting the presence of ARFID symptomology (Ellis et al., 2017, as cited in Yelencich et al., 2022). This scale has been found to have high internal consistency

(Cronbach alpha = 0.90), test-retest reliability, convergent/discriminant validity for adults aged 18-65 (Zickgraf & Ellis, 2018) and good specificity and sensitivity in identifying ARFID diagnosis (Burton Murray et al., 2021). In the current sample, the NIAS demonstrated good internal consistency (Cronbach alpha = 0.88).

Distress Tolerance Scale (DTS, Simons & Gaher, 2005)

This scale consists of 15 items rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (Strongly agree). Item 6 "I can tolerate being distressed or upset as well as most people" is the only item reverse scored. The DTS examines different theoretical constructs related to distress tolerance including an individuals perceived ability to tolerate emotional distress, subjective appraisal of distress, attention being absorbed by negative emotions and regulation efforts to alleviate distress. Higher scores on this scale reflect worse tolerance of emotional distress. This scale has been found to have good internal consistency (α= .890) as well as validity (Simons & Gaher, 2005) and has previously been used in samples of IBD populations (Wright et al., 2020). Within the current sample, the DTS demonstrated good internal consistency (α = . 87).

Desirability of control scale (DCS, Burger & Cooper, 1979)

This 20-item self-report scale measures an individual's general desire for control over their life events. The DCS uses a 7-point Likert scale ranging from "The statement does not apply to me at all" to "The statement always applies to me" with higher scores indicating a higher desire for control. This scale has been found to have internal consistency (α =.80), and test-retest reliability (α =.75; Gebhardt & Brosschot, 2002; McCutcheon, 2000**)**, as well as discriminant validity from measures of locus of control (Gebhardt et al., 2002). Within the current sample this scale demonstrated moderate internal consistency (α = .73).

The Visceral Sensitivity Index (VSI, Labus et al., 2004)

This is a 15-item self-report measure was developed to measure unique aspects of fear, anxiety, and hypervigilance to the cognitive appraisals of gastrointestinal symptoms (GSA). This scale uses a 6-point Likert scale from 1 (strongly agree) to 6 (strongly disagree) with lower scores indicating higher levels of anxiety related to gastrointestinal symptoms. The VSI has been validated in samples of adults with IBD (Trieschmann et al., 2021), where it was found to have good internal consistency (α = .860). It has also been found to have concurrent validity, with a medium effect size correlation being identified between the VSI and another anxiety measure (Trieschmann et al., 2021). Within the current sample, the VSI was found to have good internal consistency (α = .920).

The Duke–UNC Functional Social Support Questionnaire (DFSS, Broadhead et al., 1988; Epino et al., 2012)

This eight-item questionnaire is rated on a 5-point Likert-type scale from 1 (much less than I would like) to 5 (as much as I would like), with higher scores reflecting better perceived social support. Items in this measure examine both emotional aspects of social support (e.g., love and affection) and more practical aspects (e.g., help when sick in bed). The consideration of practical aspects makes it applicable for use in physical health research. This measure has been widely used and has demonstrated good validity and internal consistency in adult populations within medical centres (α = .96; Broadhead et al., 1988; Epino et al., 2012) and in adults with IBD (α=.89, Gick & Sirois, 2010). Within the current sample, this scale was found to have good internal consistency (α = .86).

Procedure

Participants were able to access this survey by following the online link which was provided through the recruitment strategies. Once on the link, participants were provided with an information sheet (Appendix O) and a consent form (Appendix P). After providing consent, participant proceeded with the online survey where they were asked to complete the

demographic questionnaire and the six self-report questionnaires. Following completion of the survey, participants were presented with a debrief form (Appendix Q) providing details of the potential research outcomes and support lines if required. Participants were also offered the opportunity to provide their email address and "opt in" to this being used for the prize draw and/or contact in 6-months for participation in follow-up data collection.

Participants who consented to follow-up data collection were emailed another survey link 6-months after their initial survey. This link contained an adapted consent form (Appendix R) and readministered the six self-report questionnaires. The data from both time points was matched by email address and a change score was calculated for all variables.

Ethical Approval

Approval was granted by the Canterbury Christ Church University, Salomons Institute for Applied Psychology, ethics committee (Appendix S). Particular attention was given to the potential psychological distress that may be triggered due to the topic of disordered eating patterns this survey explored. To address this, all participants were provided an information sheet detailing what details the questionnaires would be collected during the online questionnaire. Within this, it was advised that if they felt thinking about their IBD or eating pattens could cause distress, then participation should not proceed. Details of support lines, including NHS 111, their IBD support team and BEAT, were provided in the event of any distress or concern regarding eating or IBD generally. Participants were also informed of their right to withdraw and how to do this at different stages of the research and were required to provide informed consent.

Data analysis and statistical power

The software IBM SPSS was used to analyse the data. Initial data checks were completed to identify normality, outliers and internal consistency using Cronbach alphas. To provide an initial overview of the data, descriptive and correlational statistics for continuous

variables were conducted. Primary analysis was then completed on the data. To test Aim 1, descriptive statistics were used to identify the frequency of participants scoring ≥24 on the NIAS. Due to parametric assumptions being violated when comparing ARFID scores across Gender and IBD diagnosis, non-parametric inferential analysis was used to examine differences between these groups.

Aim 2 was explored through conducting regression analysis to examine the predictive relationship between the predictor variables (including IBD activity, IBD factors and Psychosocial factors) and ARFID symptoms (NIAS scores). The assumptions for linear, multiple, and hierarchical regression were checked for each predictor variable in relation to the outcome variable. Scatterplots, histograms, and P-P plots, inspected to check for linearity, homoscedacity, and normal distribution of residuals (Field, 2013), were deemed satisfactory for all predictor variables. Correlation coefficients and variance inflation factors (VIF) were checked, all of which were satisfactory for the assumption of multicollinearity. There appeared to be independence of observations between the predictor variables, as measured by a Durbin-Watson statistic of between 1 and 3 (Field, 2013). There were some "unusual points" identified by studentised deleted residuals and leverage point values. However, none of these had a concerning Cooks distance exceeding 1 (Cook & Weisberg, 1982, as cited in Field, 2013) and therefore these points were not deemed to be influential points on the regression model. Analysis was run with and without these unusual points, with no difference emerging for significance. Due to this, and as they were deemed reasonable values, the decision was made to keep these points in the analysis.

According to the power analysis for regression analysis, a minimum of 98 participants is required to obtain a medium effect size (Field, 2013). The current sample exceeded this and was considered to have adequate power.

Results

Overview of the variables

Table 3 displays demographic and correlational data for the continuous variables. There appeared to be a relatively wide spread of scores across all variables. Scores were typically normally distributed, however, for *number of surgeries*, most people scored between zero and three.

Table 2

Descriptive statistics and Pearson's correlational analysis for continuous variables.

						Correlations							
Variable		**Min score**	**Max Score**	**M**	**SD**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
1.	**NIAS**	*4*	*41*	*26.76*	*7.83*	-							
2.	**Distress Tolerance**	*20*	*72*	*47.20*	*9.13*	*.17**	-						
3.	**Visceral Sensitivity**	*15*	*83*	*51.37*	*13.25*	*-.34****	*.06*	-					
4.	**Desirability of control**	*57*	*113*	*91.51*	*9.72*	*.15*	*-.16**	*-.00*	-				
5.	**Perceived Social Support**	*8*	*39*	*20.67*	*6.18*	*-.28****	*-.34****	*-.26****	*.02*	-			
6.	**IBD Activity**	*5*	*96*	*55.07*	*21.38*	*.46****	*.04*	*-.17**	*-.02*	*-.24***	-		
7.	**Number of Surgeries**	*0*	*11*	*1.33*	*1.72*	*.14*	*-.06*	*-.07*	*.14*	*.04*	*.19**	-	
8.	**Age at diagnosis**	*10*	*63*	*28.84*	*7.44*	*-.14*	*.04*	*.03*	*.08*	*.10*	*-.39****	*-.19**	-

Note. *** p<0.001; **p<0.01; *p<0.05. M = Mean score, SD = Standard deviation.

Aim 1: To estimate the prevalence of ARFID in adults with IBD in the UK

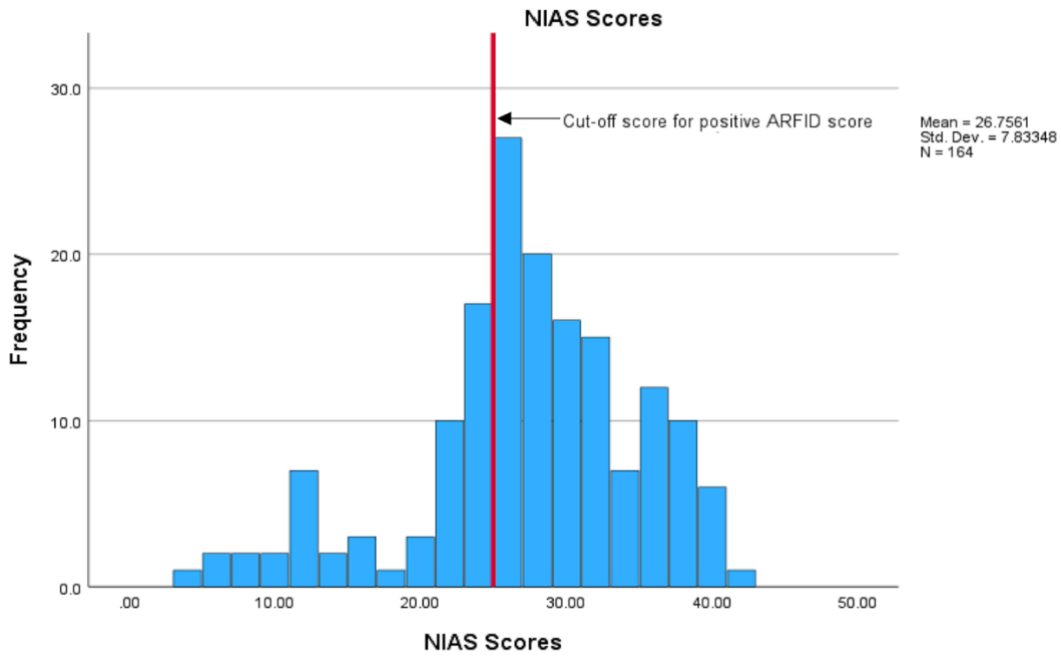
Descriptive statistics for NIAS scores can be seen in Table 3. Yelencich et al. (2022) identified a score of ≥24 on the *NIAS* as the cut off for positive ARFID symptomology. Within the current sample, it was identified that 123 participants (75%) scored within the positive ARFID symptom range (Figure 2). If the sample is representative, then a 95%

confidence interval (CI) for the prevalence of ARFID within the UK IBD population would be 68.4%-81.6%.

Non-parametric test of difference identified that scores on the NIAS did not significantly differ between CD and UC, $U = 2978$, $z = -0.86$, $p = .39$. However, there was a statistically significant difference between genders, with males scoring higher on the NIAS (*Mdn* = 28, *IQR* = 7) than females (*Mdn* = 25, *IQR* = 11), $U = 1977$, $z = -3.02$, $p = .002$. The effect size was small, $r = -.24$. Frequency data identified that 95 males (82.61%, 95% CI [75.7%-89.5%]) scored within the positive ARFID symptom range, compared to 28 females (57.14%, 95% CI [43.3%-71.0%]), which was a significantly higher proportion ($\chi^2(1) = 11.88$, $p < .001$).

Figure 2

Distribution of scores on the NIAS



Aim 2. To identify predictors, including psychological and social predictors, of ARFID risk in this population.

Hypothesis 1

To test Hypothesis 1, namely that IBD related factors (*IBD diagnosis* (CD vs. UC), *age at diagnosis, number of surgeries, having a stoma, access to IBD support team/hotlines*) would predict levels of ARFID, these five predictor variables were entered into one multiple linear regression model. As can be seen from Table 4, the model containing the IBD factors had a significant fit and explained 22% of the variance in ARFID scores. Within this model, it was identified that having a greater *number of surgeries*, *having a stoma*, and not having *access to IBD support/hotlines* significantly predicted higher ARFID symptoms.

Table 3

Multiple regression Analysis for IBD factors predicting NIAS scores

Predictor variable	R^2	Adj. R^2	F (df)	B	t	p	95% CI for B	
							LL	UL
Model	.22	.19	8.65 (5, 154)			<.001***		
IBD Diagnosis				-1.32	-1.13	.259	-3.63	0.98
Age at Diagnosis				-0.11	-1.48	.140	-0.26	0.04
Number of Surgeries				0.96	2.79	.006**	0.28	1.64
Having a Stoma				-7.33	-5.61	<.001***	-9.92	-4.75
Access to IBD support/hotlines				4.95	3.04	.003**	1.73	8.17

Note. Model = "Enter" method in SPSS statistics; R^2 = coefficient of determination; Adj.R2 = adjusted R2; F = explained variance; df = degrees of freedom; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LL = lower limit; UL = upper limit; *** p<0.001; **p<0.01; *p<0.05

Hypotheses 2a, 3a, 4a

To test these hypotheses, simple linear regression was used with the predictor variables being entered into single models independently. Table 5 displays these findings, with each row of the table representing a single analysis. As can be seen, Hypotheses 2a, namely that greater *IBD activity* would predict higher levels of ARFID, was supported, with *IBD activity* explaining 21% of the variance in ARFID scores. Similarly, Hypothesis 3a was supported, since higher levels of *perceived social support* predicted lower ARFID scores and explained 8% of their variance. In partial support for Hypothesis 4a, the simple linear regressions identified that higher *visceral sensitivity* (lower scores on VSI) and lower *distress tolerance* (higher scores on DTS) produced significant regression models in predicting higher ARFID scores. However, contrary to Hypothesis 4a, which also stated that higher levels of *desirability of control* would significantly predict ARFID scores, no such relationship was found, though it is worth noting that this effect was close to reaching significance (see Table 5).

Table 4

Regression analysis of IBD activity, psychological factors, and perceived social support on ARFID scores, with each row representing single analysis.

Regression analysis	Predictor variable	R^2	Adj. R^2	F (df)	B	t	p	95% CI for B	
								LL	UL
Simple Linear Regression	***IBD Activity***	.21	.20	42.87 (1, 162)	0.17	6.55	<.001***	0.12	0.22
	Distress Tolerance	.03	.02	4.95 (1, 162)	0.15	2.23	.027*	0.02	0.28
	Visceral Sensitivity	.12	.11	21.38 (1, 162)	-0.20	-4.62	<.001***	-0.29	-0.12
	Desirability of Control	.02	.02	3.65 (1, 162)	0.12	1.91	.058	-0.00	0.24
	Perceived Social Support	.08	.07	13.78 (1, 162)	-0.36	-3.71	<.001***	-0.54	-0.17

Note. Model = "Enter" method in SPSS statistics; R^2 = coefficient of determination; Adj.R2 = adjusted R2; F = explained variance; df = degrees of freedom; B = unstandardized regression coefficient; t = parameter

estimate divided by its standard error; p = significance value; CI = confidence interval; LL = lower limit; UL = upper limit; *** p<0.001; **p<0.01; *p<0.05

Hypothesis 5:

To test this hypothesis, namely that psychological and social factors will continue to predict ARFID symptomatology when controlling for disease activity and IBD-related factors, hierarchical regression models were used. For this analysis, *IBD activity* and IBD factors (*diagnosis (CD vs US), age of receiving diagnosis, number of surgeries, having a stoma, access to IBD support team/hotlines*) were entered into the first block as "controls" (Model 1). Each predictor (*distress tolerance, visceral sensitivity, desirability of control,* and *perceived social support*) was then entered independently into block two (Model 2a, 2b, 2c, 2d). Table 6 displays the output for each psychological and social predictor.

Table 5

Hierarchical Multiple Regression for Psychological and Social predictors

Model	**Predictor variable**	**R^2**	**Adj. R^2**	**F (df)**	**ΔF from Model 1 (df)**	**ΔR^2 from Model 1**	**B**	**t**	**95% CI for B**	
									LL	**UL**
Model 1 (Controls)		.34	.31	12.98 (6,153)***	not applicable					
	IBD Activity						0.14	5.22***	0.10	.19
	IBD Diagnosis						-1.21	-1.12	-3.34	0.92
	Age at Diagnosis						0.04	0.47	-0.12	0.19
	Number of Surgeries						0.69	2.15 *	0.06	1.33
	Having a Stoma						-5.91	-4.77***	-8.36	-3.46
	Access to IBD support/hotlines						4.81	3.19**	1.84	7.79
Model 2a		.35	.32	11.80 (7,152)***	3.46 (1,152)	.02				
	IBD Activity						0.14	5.11 ***	0.08	0.19
	IBD Diagnosis						-1.15	-1.07	-3.26	0.97
	Age at Diagnosis						0.03	0.33	-0.13	0.17
	Number of Surgeries						0.71	2.21*	0.07	1.34

	Having Stoma						-5.79	-4.70***	-8.22	-3.36
	Access to IBD support/hotlines						4.18	2.73**	1.15	7.21
	Distress Tolerance						0.11	1.86	-0.01	0.22
Model 2b		.42	.39	15.79 (7,152)***	21.98 (1,152)***	.084				
	IBD Activity						0.12	4.54***	0.07	0.17
	IBD Diagnosis						-1.04	-1.03	-3.04	0.96
	Age at Diagnosis						0.02	0.24	-0.12	0.16
	Number of Surgeries						0.73	2.42*	0.13	1.33
	Having a Stoma						-6.62	-5.65***	-8.94	-4.31
	Access to IBD support/hotlines						4.46	3.15**	1.66	7.25
	Visceral Sensitivity						-0.18	-4.69***	-0.25	-0.10
Model 2c		.36	.33	12.26 (7,152)***	5.63 (1,152)*	.02				
	IBD Activity						0.14	5.33 ***	0.09	0.19
	IBD Diagnosis						-1.56	-1.45	-3.66	0.56
	Age at Diagnosis						0.02	0.26	-0.13	0.17
	Number of Surgeries						0.56	1.73	-0.08	1.20
	Having a Stoma						-5.74	-4.69 ***	-8.15	-3.32
	Access to IBD support/hotlines						4.78	3.22**	1.85	7.71
	Desirability of Control						0.13	2.37*	0.02	0.23
Model 2d		.35	.32	11.72 (7,152)***	3.11 (1,152)	.01				
	IBD Activity						0.13	4.76***	0.08	0.18
	IBD Diagnosis						-1.17	-1.09	-3.28	0.95
	Age at Diagnosis						0.04	0.50	-0.11	0.19
	Number of Surgeries						0.71	2.22 *	0.08	1.34
	Having a Stoma						-5.55	-4.45 ***	-8.01	-3.08
	Access to IBD support/hotlines						4.22	2.75**	1.19	7.25
	Perceived Social Support						-0.16	-1.76	-0.33	0.02

Model 2e		.51	.48	15.40 (10,149)***	12.95 (4, 149)***	.17			
	IBD Activity						0.09	3.56 ***	0.04	0.14
	IBD Diagnosis						-1.23	-1.29	-3.11	0.66
	Age at Diagnosis						-0.01	-0.17	-0.14	0.12
	Number of Surgeries						0.64	2.24*	0.08	1.21
	Having a Stoma						-5.86	-5.32 ***	-8.04	-3.68
	Access to IBD support/hotlines						2.63	1.91	-0.10	5.35
	Distress Tolerance						0.11	1.98*	0.00	0.21
	Visceral Sensitivity						-0.22	-6.01 ***	-0.30	-0.15
	Desirability of Control						0.14	2.90 **	0.04	0.23
	Perceived Social Support						-0.28	-3.25 ***	-0.45	-0.11

Note. Model = "Enter" method in SPSS statistics; R^2 = coefficient of determination; Adj.R2 = adjusted R2; F = explained variance; df = degrees of freedom; ΔF= difference in variance between models; ΔR^2 = difference in determination coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; CI = confidence interval; LL = lower limit; UL = upper limit; *** p<0.001; **p<0.01; *p<0.05

As can be seen in Table 6, higher *visceral sensitivity* predicted ARFID scores, above and beyond the control variables, explaining 8.4% more of the variance than Model 1. Despite being significant predictors in simple linear models, *distress tolerance* (p = .065) and *perceived social support* (p = .080) were no longer significant when entered in the hierarchical model. To explore the potential relationships which may have contributed to this finding, correlations (as seen in Table 3) and non-parametric tests (due to violating the Shapiro-Wilk test, see Table 7) were conducted. This analysis found significant differences for *access to IBD support/hotlines* on both *distress tolerance* and *perceived social support*. *Having a stoma* was also significant for *perceived social support*.

Despite not being identified as a significant predictor independently, higher *desirability of control* was identified to predict ARFID scores when entered in a model with control variables (p = .018), explaining 2.3% of the model variance. It is possible that this represents

a suppression effect (Horst, 1941, as cited in Tzelgov & Henik, 1991; Pandey & Elliott, 2010; Tu et al., 2008) which is discussed further in the discussion.

Table 6

Mann-Whitney U test to explore differences between nominal control variables on distress tolerance and perceived social support.

Predictor Variable	Control Variable	MR		U	Z
		Group 1	Group 2		
Distress Tolerance	IBD Diagnosis (*Group 1: CD vs. Group 1: UC)*	83.20	81.46	3165.50	- 0.23
	Having a Stoma *(Group 1: Yes vs. Group 2: No)*	82.76	80.38	2801.50	-0.30
	Access to IBD support/hotlines *(Group 1: Yes vs. Group 2: No)*	76.06	105.54	2471.50**	3.00
Perceived Social Support	IBD Diagnosis *(Group 1: CD vs. Group 1: UC)*	82.28	82.83	3255.50	0.07
	Having a Stoma *(Group 1: Yes vs. Group 2: No)*	76.76	93.19	3468.00*	2.08
	Access to IBD support/hotlines *(Group 1: Yes vs. Group 2: No)*	85.03	60.98	1268.50*	-2.45

Note. MR = Mean rank score; U = test statistic; Z = standardised test statistic; *** p<0.001; **p<0.01; *p<0.05

Hypothesis 6a:

Hypothesis 6 was examined by entering all the psychosocial predictor variables into the second block of a regression model (Table 6, Model 2e). This produced a significant model, which explained approximately 17% more variance in ARFID symptoms than Model 1 (control variables). All four psychosocial variables remained significant predictors of ARFID.

Longitudinal hypotheses (2b,3b,4b and 5b)

Due to the small sample size, there was not adequate power to complete regression analysis (Field, 2013) as required to test the hypotheses. However, to provisionally explore the relationships between the variables over time, non-parametric correlations were

conducted (Table 8). As can be seen in Table 8, the findings do not support that the change in predictor variables would predict change in ARFID over time, though this may be a Type II error arising from smaller sample size.

Table 7

Spearman's Rho Correlation coefficients between change in predictor variables and change in ARFID (N=14)

Variable	1	2	3	4	5	6
1. NIAS change	-					
2. IBD Activity change	*.29*	-				
3. Distress Tolerance change	*-.28*	*.33*	-			
4. Visceral Sensitivity change	*-.41*	*-.25*	*.50*	-		
5. Desirability of control change	*.29*	*.64**	*.38*	*-.03*	-	
6. Perceived Social Support change	*.09*	*-.05*	*.05*	*-.01*	*.32*	-

Note. *** p<0.001; **p<0.01; *p<0.05. Due to the small sample size, Spearman's Rho correlations were run to explore the relationship between the change in predictor variables and change in ARFID scores. Change scores were calculated by subtracting scores on scales at time 2 from the score at time 1.

Discussion

This research aimed to examine the prevalence of ARFID within the UK IBD population, and to the author's knowledge, is the first research exploring the contribution of psychosocial factors in predicting ARFID symptomology within this population.

Prevalence of ARFID in IBD

The findings from this research identified a high prevalence of ARFID, with 75% of the sample scoring above the cut off for ARFID symptoms. This prevalence is higher than the 10.2 – 32.5% previously reported within US and Chinese IBD populations (Robelin et al., 2021; Yelencich et al., 2022; Yin et al., 2023). One explanation for these differences may reflect the high proportion of participants with a stoma (67.7%), compared to the 10-30% previously observed in IBD populations (Ross et al., 2014), as this treatment often requires

significant dietary changes/restrictions and can make the reintegration of food difficult (Migdanis et al., 2023; Mitchel et al., 2023; NHS, 2023). Therefore, it is possible that the current sample were more restrictive or fearful around food compared to a more general IBD population. This is further supported by the *number of surgeries* being a significant predictor of ARFID in the regression models, which is consistent with the possibility that dietary changed linked to surgery may influence dietary behaviours associated with ARFID.

To date, the association between gender and ARFID symptoms in IBD remains unclear, with Yelencich et al. (2022) reporting no differences. In contrast, Yin et al. (2023) demonstrated that those identifying as female presented with higher ARFID symptomology. Although the current research supports a significant gender difference, ARFID symptoms were more frequent in males compared to females, contrasting with previous findings. It is possible that this difference may reflect Yin et al. (2023) using a more stringent exclusion criteria for participants, including those with known food allergies and those following specific dietary patterns, including low FODMAP, vegetarian or vegan diets. Although ARFID must be independent from food avoidance due to dietary or religious beliefs (Szymanska, 2022), it is possible that, when providing self-report data, as collected by the NIAS, individuals do not exclude these reasons, which may inflate ARFID levels in the sample which was predominantly male. Although this current finding conflicts with the existing reports of ARFID in IBD (Yelencich et al., 2022; Yin et al., 2023), it aligns with some findings from the general paediatric and adult populations (Cañas et al., 2021; D'Adamo et al., 2023), and those within an ED population (Nicely et al., 2014), which report that, in contrast to other EDs, ARFID levels are higher in males.

Predictors of ARFID in IBD

The physical characteristics of IBD, including activity and inflammation, have previously been found to predict the risk of ARFID symptoms in individuals with IBD within

the USA and China (Yelencich et al., 2022; Yin et al., 2023). The current findings support IBD activity as a significant predictor, indicating that this finding generalises to a UK population. In contrast to Yelencich et al. (2022), other IBD-related factors, including having a stoma and more IBD-related surgeries, were also found to significantly predict ARFID symptoms. This may suggest that, at least within the UK, the diet changes required for IBD surgery, such as Exclusive Enteral Nutrition (Crohn's & Colitis Foundation, n.d.; Heerasing et al., 2017), and potential anxiety associated with the reintroduction of foods following surgery (Day et al., 2021; Whelan et al., 2021) may contribute to peoples' risk of developing ARFID. However, it is possible that this difference may reflect the sample demographics, with 66.46% of the current sample having experienced some form of surgery, compared to only 21.18% in the sample used by Yelencich et al. (2022). As the current findings, namely that the number of surgeries and having a stoma predict ARFID symptoms, have not been previously reported, replication is required to ensure this is not reflecting Type 1 errors.

In general, the current findings support the application of a biopsychosocial model of ARFID within IBD, as the psychosocial variables, when considered together, were predictive of ARFID, even when controlling for other IBD-related factors. A key finding was that individual's visceral sensitivity (which measured levels of GSA), predicted ARFID scores both independently and when controlling for IBD related factors. This suggests that, regardless of IBD-related factors, experiencing high levels of GSA may result in individuals being more likely to present with ARFID symptoms, which may explain the high proportion of individuals who continue avoiding food despite being in remission (Yelencich et al., 2022). Although causation cannot be determined, these findings appear consistent with the two-stage model of ARFID (Brown & Hildebrandt, 2020), with ARFID symptoms potentially developing due to GSA, with avoidance being an attempt to reduce this anxiety and prevent the perceived aversive association between food and IBD symptoms (Godala et al., 2022).

Within the general eating disorder literature, it has been identified that avoidant eating behaviours are more present in those less able to tolerate their emotional distress (Anestis et al., 2007; Corstorphine et al., 2007). In support of this, the current research identified distress tolerance as a predictive factor of ARFID when considered independently, suggesting that these eating patterns might develop as an emotion regulation mechanism or attempt to avoid emotional distress (Anestis et al., 2007). However, in contrast to visceral sensitivity, distress tolerance was not found to predict ARFID scores when controlling for other IBD-related factors. It is possible that *access to IBD support/hotlines* may account for this finding, as those with those with support may be more resilient and better able to cope with distress than those without (Hernandez et al., 2020).

Theoretically, it is believed that higher levels of social support act as a "buffer" against stress, protects against the development of disease, and promotes wellbeing (Cohen & Wills, 1985; Katz et al., 2016; Sewitch et al., 2001). The current findings appear to support this as, higher *perceived social support* was found to predict lower ARFID symptoms, when examined on its own. In accordance with ED literature outside of the IBD context (Hughes-Jones, 2009; Limbert, 2010; Linville et al., 2012), this suggests that feeling supported by others may be protective for individuals with IBD and prevent the development of ARFID symptoms. However, *perceived social support* was not predictive when controlling for IBD factors. However, *access to IBD support/hotlines* was a significant IBD-factor, with the two groups also differing on scores of *perceived social support.* It is possible that receiving specific IBD support from professionals, including dieticians, as recommended within the IBD standards (IBD UK, n.d.), explains this finding as it enables individuals to seek informed advice around dietary changes which may reduce the risk of ARFID symptoms, especially as misinformation and limited understanding of food and nutrition have been associated with food avoidance behaviours (Day et al., 2021; Yin et al., 2023).

This research found that although desirability of control was not a significant predictor independently, when added into a model that controls for IBD activity and IBD factors, it became a significant predictor of ARFID scores. One explanation for this may be that, when in a model with other factors, there is a suppression effect (also known as an enhancement effect), whereby a relationship between *desirability of control* and another variable reduces the irrelevant aspects of the variables and increases its predictive effect (McFatter, 1979; Pandey & Elliott, 2010). To illustrate this, one possible explanation could be that *desirability of control* relates to *IBD diagnosis*, with the need for control differing between those with CD and those with UC (Boye et al., 2008). Therefore, when added to a control model, the part of *desirability of control* that is not associated with *IBD diagnosis*, becomes predictive itself. Although this is one possible explanation, it is acknowledged that the current research does not explore this and therefore, future research would be needed to further examine this potential suppression effect.

Although suppression effects can be beneficial as they allow more accurate regressions to be determined, improve the predictive power of the model, and contribute to enhancing theory building (Pandey & Elliott, 2010), replication studies are required to further explore which parts of the desirability of control are unique within a model controlling for IBD factors.

Implications of Research

As ARFID, especially in relation to IBD, is an emerging research area, the current findings contribute to the academic understanding and provide direction for healthcare professionals and charitable organisations working within this area. As there is potentially a high prevalence of ARFID within IBD (Robelin et al., 2021; Yelencich et al., 2022; Yin et al., 2023), which may put individuals at risk of malnutrition (Yelencich et al., 2022), it appears important that healthcare professionals are aware of, and consider the

biopsychosocial factors associated with ARFID symptoms in their care for individuals with IBD. As psychosocial factors collectively predicted ARFID when controlling for IBD-related factors, it is important that services supporting those with IBD ensure a holistic approach, considering the individuals psychological health and support systems, within their care.

This research identifies a relationship between GSA and ARFID symptomology which, along with limited knowledge of food and nutrition (Yin et al., 2023) and misunderstanding/overestimating the relationship between diet and symptoms (de Vries et al., 2019; Zangara et al., 2020) may increase an individual's risk. This highlights the importance of IBD teams providing comprehensive information and support around diet, with education being a key part of treatment. Due to individuals often seeking support from multiple sources (Godala et al., 2022), it is important that IBD healthcare teams and IBD charitable organisations provide consistent information around diet to prevent individuals receiving contradicting information.

Within IBD care, patient-reported outcome measures are frequently used within clinical practice and clinical trials (Bojic et al., 2017; Pallis & Mouzas, 2000; van Andel et al., 2020). By using outcome measures as screening tools, IBD services may be able to identify biopsychosocial risk factors that may increase an individual's vulnerability of developing ARFID, and therefore, provide interventions to address these risks. For example, screening for biological risk may allow for medical optimisation, which may reduce IBD activity and potentially reduce associated GSA. Based on the findings of this research, it also appears important to screen for visceral sensitivity. By identifying individuals experiencing high visceral sensitivity (GSA), IBD services may be able to provide psychoeducation and/or psychological interventions specifically addressing this anxiety (Davis et al., 2020), which may reduce individuals attempting independent dietary changes. Additionally, incorporating dietitian screening may help to identify those potentially at higher risk of ARFID, such as

those who have required dietary changes due to surgery (Day et al., 2021; Whelan et al., 2021). Research evaluating screening and interventions (such as CBT for GSA) would be beneficial for examining how the use of these tools can reduce the risk of ARFID within IBD.

The findings from this research reinforce the importance of feeling supported and having direct access to support networks for individuals with IBD (Katz et al., 2016; Limbert, 2010; Sewitch et al., 2001). Therefore, it may be beneficial for healthcare services, and charitable organisations, to ensure individuals have access to support teams specifically for their IBD, as laid out in national IBD standards (IBD UK, n.d.). Outside the context of IBD, the perception of social support has often been linked with help-seeking behaviours (Ali et al., 2017; Nagai, 2015; O'Connor et al., 2014). Therefore, it is important for all members of the IBD team to provide accurate information and to ensure clear signposting to appropriate sources, to ensure individuals know where direct support is available. Additionally, it may be beneficial for healthcare professionals to support individuals to feel knowledgeable about their disease and for them to encourage talking about their disease to others, as self-disclosure may increase individuals' perceptions of support (Carter et al., 2020; Matini & Ogden, 2016; Micallef-Konewko, 2013).

Limitations and future research

This research is the first to explore the potential psychosocial predictors of ARFID within an IBD population. However, there are several important limitations that should be considered. Firstly, the validity of the findings from this research may be impacted by the recruitment strategy used. Although the online survey provided wide access to a UK based IBD population, this approach to recruitment poses the risk of fraudulent data (Bauermeister et al., 2012; Levi et al., 2022; Teitcher et al., 2015). To enhance the validity of the current data, a protocol was developed for screening data for fraudulent and nonsensical entries.

Although, the current findings appear plausible and frequently consistent with existing literature, the genuineness of the data cannot be guaranteed.

Additionally, the recruitment may create bias due to the people who volunteer to participate (Buchanan, 2018; Rosenthal & Rosnow, 1975). As seen in Table 2, the sample in this research was similar in age to that reported in previous research (Pasvol et al., 2020). However, there were more individuals with CD, a higher proportion of individuals who reported having a stoma (67.7%) and predominantly those identifying as male (70.12%) compared to the sample identified within the wider UK IBD population, which identifies more females and higher incidences of UC (Crohn's and Colitis UK, n.d.; Pasvol et al., 2020). Therefore, the current sample over-represents males and CD compared to a wider population. Although this sample may be representative of those accessing the organisations/charities used for recruitment and are a useful sample to research provided that males have a higher prevalence of ARFID (Nicely et al., 2014), the demographics may not be reflective of the IBD population more generally. This means that the relationships between biopsychosocial factors and ARFID may not be applicable to a wider IBD population, especially due to IBD potentially having a larger psychological and physical impact on those identifying as female (Greuter et al., 2020 Lungaro et al., 2023). Therefore, caution should be taken when interpreting and generalising these findings to the wider IBD population. It is important that future research, using more robust data collection methods such incorporating the use of IP addresses to prevent multiple entries (Teitcher et al., 2015) and using different sampling methods, examines the reliability of the current findings and their applicability to a wider IBD population within the UK.

As the first study to examine psychosocial predictors of ARFID in an IBD population, it was not possible to explore all the possible factors. Therefore, the findings are limited to those, and the specific scales, that were chosen. To build on the current research and develop

a more comprehensive understanding of the psychosocial aspects related to the development of ARFID in IBD, future research is needed to explore different psychosocial phenomena to ensure a comprehensive understanding of the biopsychosocial factors associated with ARFID symptoms is developed.

Another limitation arises from the attrition rate observed in the longitudinal aspect of this research. As the longitudinal hypotheses could not be tested, the cross-sectional results do not allow for causational conclusions to be drawn. Future longitudinal research is needed to support the understanding of ARFID symptoms and the role of psychosocial factors in relation to changes in IBD activity. Additionally, to date, there is no research providing an in depth understanding of how ARFID develops within IBD, despite this having the potential to guide how healthcare professionals support individuals with IBD. It appears that further research, preferably qualitative literature or that determining causation, which explores experiences of the development of ARFID, is required to provide a more comprehensive understanding of ARFID and its development for those with IBD.

Conclusions

This research identified a high prevalence of ARFID symptoms in individuals living with IBD and offers initial insight into psychosocial predictors. It was found that GSA potentially increases the risk of individuals presenting with ARFID symptoms, regardless of other IBD-related factors. Therefore, it is suggested that screening for GSA, and potentially providing psychological interventions for this, may play an important role in supporting individuals with IBD. The findings from this research provide a first step in considering how healthcare professionals and charitable organisations can consider and address psychological risk factors, such as GSA, to potentially reduce the risk of ARFID within an IBD population.

References

Ali, K., Farrer, L., Fassnacht, D. B., Gulliver, A., Bauer, S., & Griffiths, K. M. (2017). Perceived barriers and facilitators towards help-seeking for eating disorders: A systematic review. *The International Journal of Eating Disorders*, *50*(1), 9–21. https://doi.org/10.1002/eat.22598

Anestis, M. D., Selby, E. A., Fink, E. L., & Joiner, T. E. (2007). The multifaceted role of distress tolerance in dysregulated eating behaviors. *The International Journal of Eating Disorders*, *40*(8), 718–726. https://doi.org/10.1002/eat.20471

Bauermeister, J., Pingel, E., Zimmerman, M., Couper, M., Carballo-Diéguez, A., & Strecher, V. J. (2012). Data Quality in web-based HIV/AIDS research: Handling invalid and suspicious data. *Field Methods*, *24*(3), 272–291. https://doi.org/10.1177/1525822X12443097

BEAT. (2024). *ARFID*. https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/

Bergeron, F., Bouin, M., D'Aoust, L., Lemoyne, M., & Presse, N. (2018). Food avoidance in patients with inflammatory bowel disease: What, when and who? *Clinical Nutrition*, *37*(3), 884–889. https://doi.org/10.1016/j.clnu.2017.03.010

Bertera, E. M. (2005). Mental health in U.S. adults: The role of positive social support and social negativity in personal relationships. *Journal of Social and Personal Relationships*, *22*(1), 33–48. https://doi.org/10.1177/0265407505049320

Bojic, D., Bodger, K., & Travis, S. (2017). Patient reported outcome measures (PROMs) in Inflammatory Bowel Disease: New data. *Journal of Crohn's & Colitis*, *11*(suppl_2), S576–S585. https://doi.org/10.1093/ecco-jcc/jjw187

Boye, B., Jahnsen, J., Mokleby, K., Leganger, S., Jantschek, G., Jantschek, I., Kunzendorf, S., Benninghoven, D., Wilhelmsen, I., Sharpe, M., Blomhoff, S., Malt, U. F., & Lundin,

K. E. (2008). The INSPIRE study: Are different personality traits related to disease-specific quality of life (IBDQ) in distressed patients with ulcerative colitis and Crohn's disease? *Inflammatory Bowel Diseases*, *14*(5), 680–686. https://doi.org/10.1002/ibd.20367

Broadhead, W. E., Gehlbach, S. H., de Gruy, F. V., & Kaplan, B. H. (1988). The Duke-UNC functional social support questionnaire: Measurement of social support in family medicine patients. *Medical Care*, *26*(7), 709–723. https://doi.org/10.1097/00005650-198807000-00006

Brown, M., & Hildebrandt, T. (2020). Parent-facilitated behavioral treatment for avoidant/restrictive food intake disorder: A case report. *Cognitive and Behavioral Practice*, *27*(2), 231–251. https://doi.org/10.1016/j.cbpra.2019.05.002

Buchanan, T. (2018). Personality biases in different types of 'internet samples' can influence research outcomes. *Computers in Human Behavior*, *86*, 235–244. https://doi.org/10.1016/j.chb.2018.05.002

Bullen, T. L., Sharpe, L., Lawsin, C., Patel, D. C., Clarke, S., & Bokey, L. (2012). Body image as a predictor of psychopathology in surgical patients with colorectal disease. *Journal of Psychosomatic Research*, *73*(6), 459–463. https://doi.org/10.1016/j.jpsychores.2012.08.010

Burger, J. M., & Cooper, H. M. (1979). The desirability of control. *Motivation and Emotion*, *3*(4), 381–393. https://doi.org/10.1007/BF00994052

Burton Murray, H., Dreier, M. J., Zickgraf, H. F., Becker, K. R., Breithaupt, L., Eddy, K. T., & Thomas, J. J. (2021). Validation of the nine item ARFID screen (NIAS) subscales for distinguishing ARFID presentations and screening for ARFID. *The International Journal of Eating Disorders*, *54*(10), 1782-1792. https://doi.org/10.1002/eat.23520

Byrne, G., Rosenfeld, G., Leung, Y., Qian, H., Raudzus, J., Nunez, C., & Bressler, B. (2017). Prevalence of anxiety and depression in patients with inflammatory bowel disease. *Canadian Journal of Gastroenterology & Hepatology*, *2017*(6496727), 1-6. https://doi.org/10.1155/2017/6496727

Cañas, L., Palma, C., Molano, A. M., Domene, L., Carulla-Roig, M., Cecilia-Costa, R., Dolz, M., & Serrano-Troncoso, E. (2021). Avoidant/restrictive food intake disorder: Psychopathological similarities and differences in comparison to anorexia nervosa and the general population. *European Eating Disorders Review*, *29*(2), 245–256. https://doi.org/10.1002/erv.2815

Cao, Q., Huang, Y. H., Jiang, M., & Dai, C. (2019). The prevalence and risk factors of psychological disorders, malnutrition and quality of life in IBD patients. *Scandinavian Journal of Gastroenterology*, *54*(12), 1458–1466. https://doi.org/10.1080/00365521.2019.1697897

Carter, B., Rouncefield-Swales, A., Bray, L., Blake, L., Allen, S., Probert, C., Crook, K., & Qualter, P. (2020). "I don't like to make a big thing out of it": A qualitative interview-based study exploring factors affecting whether young people tell or do not tell their friends about their IBD. *International Journal of Chronic Diseases, 2020*(1059025), 1-11. https://doi.org/10.1155/2020/1059025

Cohen, A. B., Lee, D., Long, M. D., Kappelman, M. D., Martin, C. F., Sandler, R. S., & Lewis, J. D. (2013). Dietary patterns and self-reported associations of diet with symptoms of inflammatory bowel disease. *Digestive Diseases and Sciences, 58*(5), 1322–1328. https://doi.org/10.1007/s10620-012-2373-3

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310–357. https://doi.org/10.1037/0033-2909.98.2.310

Cooley, E., & Toray, T. (2001). Body image and personality predictors of eating disorder symptoms during the college years. *The International Journal of Eating Disorders*, *30*(1), 28–36. https://doi.org/10.1002/eat.1051

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*(12), 1500–1509. https://doi.org/10.1016/j.ijnurstu.2010.05.008

Corstorphine, E., Mountford, V., Tomlinson, S., Waller, G., & Meyer, C. (2007). Distress tolerance in the eating disorders. *Eating Behaviors*, *8*(1), 91–97. https://doi.org/10.1016/j.eatbeh.2006.02.003

Crohn's & Colitis Foundation. (n.d.). *Special IBD diets.* https://www.crohnscolitisfoundation.org/patientandcaregivers/diet-and-nutrition/special-ibd-diets

Crohn's and Colitis UK. (2022). *New research shows over 1 in 123 people in UK living with Crohn's or Colitis.* https://crohnsandcolitis.org.uk/news-stories/news-items/new-research-shows-over-1-in-123-people-in-uk-living-with-crohn-s-or-colitis

Crohn's and Colitis UK. (n.d.). *Epidemiology summary: Incidence and prevalence of IBD in the United Kingdom.* https://crohnsandcolitis.org.uk/media/4e5ccomz/epidemiology-summary-final.pdf

Cunha, A. I., Relvas, A. P., & Soares, I. (2009). Anorexia nervosa and family relationships: Perceived family functioning, coping strategies, beliefs, and attachment to parents and peers. *International Journal of Clinical and Health Psychology*, *9*(2), 229–240. https://www.redalyc.org/pdf/337/33712028003.pdf

Cusack, C. E., & Hughes, J. L. (2014). Women with eating disorders and perceived social support. *Undergraduate Research Journal for the Human Sciences*, *13*(1). https://publications.kon.org/urc/v13/cusack.html

Czuber-Dochan, W., Morgan, M., Hughes, L. D., Lomer, M. C. E., Lindsay, J. O., & Whelan, K. (2020). Perceptions and psychosocial impact of food, nutrition, eating and drinking in people with inflammatory bowel disease: A qualitative investigation of food-related quality of life. *Journal of Human Nutrition and Dietetics*, *33*(1), 115–127. https://doi.org/10.1111/jhn.12668

D'Adamo, L., Smolar, L., Balantekin, K., Taylor, C. B., Wilfley, D., & Fitzsimmons-Craft, E. (2023). Prevalence, characteristics, and correlates of avoidant/restrictive food intake disorder among adult respondents to the national eating disorders association online screen: A cross-sectional study. *Research Square*, *11*(214),1-15. https://doi.org/10.21203/rs.3.rs-3007049/v1

David, J. G., Chute, D., Reed, B., Saeed, S., DeMatteo, D., Atay, O., Maddux, M., & Daly, B. (2022). Assessing the prevalence of and risk factors for disordered eating attitudes and behaviors in adolescents with inflammatory bowel disease. *Inflammatory Bowel Diseases*, *28*(1), 143–145. https://doi.org/10.1093/ibd/izab154

Davis, S. P., Bolin, L. P., Crane, P. B., & Crandell, J. (2020). Non-pharmacological interventions for anxiety and depression in adults with inflammatory bowel disease: A systematic review and meta-analysis. *Frontiers in Psychology*, *11*(538741), 1-15. https://doi.org/10.3389/fpsyg.2020.538741

Day, A. S., Yao, C. K., Costello, S. P., Andrews, J. M., & Bryant, R. V. (2021). Food avoidance, restrictive eating behaviour and association with quality of life in adults with inflammatory bowel disease: A systematic scoping review. *Appetite*, *167*(105650), 1-16. https://doi.org/10.1016/j.appet.2021.105650

Dent, E., Davinson, N., & Wilkie, S. (2022). The impact of gastrointestinal conditions on psychosocial factors associated with the biopsychosocial model of health: A scoping review. *Applied Psychology: Health & Well-Being, 14*(2), 626-644. https://doi.org/10.1111/aphw.12323

de Vries, J. H. M., Dijkhuizen, M., Tap, P., & Witteman, B. J. M. (2019). Patient's dietary beliefs and behaviours in inflammatory bowel disease. *Digestive Diseases*, *37*(2), 131–139. https://doi.org/10.1159/000494022

Di Giorgio, F. M., Melatti, P., Ciminnisi, S., & Cappello, M. (2023). A narrative review on eating disorders and disordered eating in inflammatory bowel diseases: Need for increased awareness. *Dietetics*, *2*(2), 150-160. https://doi.org/10.3390/dietetics2020012

Engel G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*(4286), 129–136. https://doi.org/10.1126/science.847460

Epino, H. M., Rich, M. L., Kaigamba, F., Hakizamungu, M., Socci, A. R., Bagiruwigize, E., & Franke, M. F. (2012). Reliability and construct validity of three health-related self-report scales in HIV-positive adults in rural Rwanda. *AIDS Care*, *24*(12), 1576–1583. https://doi.org/10.1080/09540121.2012.661840

Field, A. (2013). *Discovering statistics using IBM SPSS statistics*. Sage Publications Ltd.

Fink, M., Simons, M., Tomasino, K., Pandit, A., & Taft, T. (2022). When is patient behavior indicative of avoidant restrictive food intake disorder (ARFID) vs reasonable response to digestive disease? *Clinical Gastroenterology and Hepatology*, *20*(6), 1241–1250. https://doi.org/10.1016/j.cgh.2021.07.045

Frank, G. K. (2016). The perfect storm - A bio-psycho-social risk model for developing and maintaining eating disorders. *Frontiers in Behavioral Neuroscience*, *10*(44), 1-4. https://doi.org/10.3389/fnbeh.2016.00044

Froreich, F. V., Vartanian, L. R., Zawadzki, M. J., Grisham, J. R., & Touyz, S. W. (2017). Psychological need satisfaction, control, and disordered eating. *The British Journal of Clinical Psychology*, *56*(1), 53–68. https://doi.org/10.1111/bjc.12120

Gatchel, R. J., Peng, Y. B., Peters, M. L., Fuchs, P. N., & Turk, D. C. (2007). The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychological Bulletin*, *133*(4), 581–624. https://doi.org/10.1037/0033-2909.133.4.581

Gebhardt, W. A., & Brosschot, J. F. (2002). Desirability of control: Psychometric properties and relationships with locus of control, personality, coping, and mental and somatic complaints in three Dutch samples. *European Journal of Personality, 16*(6), 423–438. https://doi.org/10.1002/per.463

Ghaderi, A. (2003). Structural modeling analysis of prospective risk factors for eating disorder. *Eating Behaviors*, *3*(4), 387–396. https://doi.org/10.1016/s1471-0153(02)00089-2

Gick, M. L., & Sirois, F. M. (2010). Insecure attachment moderates women's adjustment to inflammatory bowel disease severity. *Rehabilitation Psychology*, *55*(2), 170–179. https://doi.org/10.1037/a0019358

Godala, M., Gaszyńska, E., Zatorski, H., & Małecka-Wojciesko, E. (2022). Dietary interventions in inflammatory bowel disease. *Nutrients*, *14*(4261), 1-21. https://doi.org/10.3390/nu14204261

Greuter, T., Manser, C., Pittet, V., Vavricka, S. R., Biedermann, L., & on behalf of Swiss IBDnet, an official working group of the Swiss Society of Gastroenterology. (2020). Gender Differences in Inflammatory Bowel Disease. *Digestion*, *101*(l), 98–104. https://doi.org/10.1159/000504701

Hay, P., Mitchison, D., Collado, A. E. L., González-Chica, D. A., Stocks, N., & Touyz, S. (2017). Burden and health-related quality of life of eating disorders, including avoidant/restrictive food intake disorder (ARFID), in the Australian population. *Journal of Eating Disorders*, *5*(1), 1-10. https://doi.org/10.1186/s40337-017-0149-z

Heerasing, N., Thompson, B., Hendy, P., Heap, G. A., Walker, G., Bethune, R., Mansfield, S., Calvert, C., Kennedy, N. A., Ahmad, T., & Goodhand, J. R. (2017). Exclusive enteral nutrition provides an effective bridge to safer interval elective surgery for adults with Crohn's disease. *Alimentary Pharmacology & Therapeutics*, *45*(5), 660–669. https://doi.org/10.1111/apt.13934

Hernandez, D. C., Daundasekara, S. S., Zvolensky, M. J., Reitzel, L. R., Maria, D. S., Alexander, A. C., Kendzor, D. E., & Businelle, M. S. (2020). Urban Stress indirectly influences psychological symptoms through its association with distress tolerance and perceived social support among adults experiencing homelessness. *International Journal of Environmental Research and Public Health*, *17*(15), 5301. https://doi.org/10.3390/ijerph17155301

Hughes-Jones, M. (2009). *Women's recovery in the eating disorders: Exploring the role of perceived mutuality in close relationships and social support satisfaction* [Masters thesis, University of British Columbia]. https://open.library.ubc.ca/collections/ubctheses/24/items/1.0053987

IBD UK. (n.d.). *IBD standards core statements.* https://s3.eu-west-2.amazonaws.com/sr-crohns-craft/documents/IBD-Standards-Core-Statements.pdf

Ilzarbe, L., Fàbrega, 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

Johnstone, L. (2018). Psychological formulation as an alternative to psychiatric diagnosis. *Journal of Humanistic Psychology*, *58*(1), 30-46. https://doi.org/10.1177/0022167817722230

Kapadia, M., Desai, M., & Parikh, R. (2020). Fractures in the framework: Limitations of classification systems in psychiatry. *Dialogues in Clinical Neuroscience*, *22*(1), 17–26. https://doi.org/10.31887/DCNS.2020.22.1/rparikh

Katz, L., Tripp, D. A., Ropeleski, M., Depew, W., Curtis Nickel, J., Vanner, S., & Beyak, M. J. (2016). Mechanisms of quality of life and social support in inflammatory bowel disease. *Journal of Clinical Psychology in Medical Settings*, *23*(1), 88–98. https://doi.org/10.1007/s10880-015-9431-x

Kazdin, A. E. (2012). *Behavior modification in applied settings* (7th ed.). Wadsworth/Thomson Learning.

Keough, M. E., Riccardi, C. J., Timpano, K. R., Mitchell, M. A., & Schmidt, N. B. (2010). Anxiety symptomatology: The association with distress tolerance and anxiety sensitivity. *Behavior Therapy*, *41*(4), 567–574. https://doi.org/10.1016/j.beth.2010.04.002

Kring, A. M., & Johnson, S. L. (2018). *Abnormal psychology: The science and treatment of psychological disorders*. John Wiley & Sons.

Krypotos, A. M., Effting, M., Kindt, M., & Beckers, T. (2015). Avoidance learning: A review of theoretical models and recent developments. *Frontiers in Behavioral Neuroscience, 9*(189), 1-16. https://doi.org/10.3389/fnbeh.2015.00189

Kuźnicki, P., & Neubauer, K. (2021). Emerging comorbidities in inflammatory bowel disease: eating disorders, alcohol and narcotics misuse. *Journal of Clinical Medicine, 10*(19), 4623. https://doi.org/10.3390/jcm10194623

Labus, J. S., Bolus, R., Chang, L., Wiklund, I., Naesdal, J., Mayer, E. A., & Naliboff, B. D. (2004). The visceral sensitivity index: Development and validation of a gastrointestinal symptom-specific anxiety scale. *Alimentary Pharmacology & Therapeutics*, *20*(1), 89–97. https://doi.org/10.1111/j.1365-2036.2004.02007.x

Leonidas, C., & Dos Santos, M. A. (2014). Social support networks and eating disorders: An integrative review of the literature. *Neuropsychiatric Disease and Treatment*, *2014*(10), 915–927. https://doi.org/10.2147/NDT.S60735

Levi, R., Ridberg, R., Akers, M., & Seligman, H. (2022). Survey fraud and the integrity of web-based survey research. *American Journal of Health Promotion*, *36*(1), 18–20. https://doi.org/10.1177/08901171211037531

Lim, H. S., Kim, S. K., & Hong, S. J. (2018). Food elimination diet and nutritional deficiency in patients with inflammatory bowel disease. *Clinical Nutrition Research*, *7*(1), 48–55. https://doi.org/10.7762/cnr.2018.7.1.48

Limbert C. (2010). Perceptions of social support and eating disorder characteristics. *Health Care for Women International*, *31*(2), 170–178. https://doi.org/10.1080/07399330902893846

Limdi, J. K., Aggarwal, D., & McLaughlin, J. T. (2016). Dietary practices and beliefs in patients with inflammatory bowel disease. *Inflammatory Bowel Diseases*, *22*(1), 164–170. https://doi.org/10.1097/MIB.0000000000000585

Linville, D., Brown, T., Sturm, K., & McDougal, T. (2012). Eating disorders and social support: Perspectives of recovered individuals. *Eating Disorders*, *20*(3), 216–231. https://doi.org/10.1080/10640266.2012.668480

Lix, L. M., Graff, L. A., Walker, J. R., Clara, I., Rawsthorne, P., Rogala, L., Miller, N., Ediger, J., Pretorius, T., & Bernstein, C. N. (2008). Longitudinal study of quality of life and psychological functioning for active, fluctuating, and inactive disease patterns in

inflammatory bowel disease. *Inflammatory Bowel Diseases*, *14*(11), 1575–1584. https://doi.org/10.1002/ibd.20511

Lungaro, L., Costanzini, A., Manza, F., Barbalinardo, M., Gentili, D., Guarino, M., Caputo, F., Zoli, G., De Giorgio, R., & Caio, G. (2023). Impact of female gender in inflammatory bowel diseases: A narrative review. *Journal of personalized medicine*, *13*(2), 165. https://doi.org/10.3390/jpm13020165

Matini, L., & Ogden, J. (2016). A qualitative study of patients' experience of living with inflammatory bowel disease: A preliminary focus on the notion of adaptation. *Journal of Health Psychology*, *21*(11), 2493–2502. https://doi.org/10.1177/1359105315580463

McCutcheon, L. E. (2000). The desirability of control scale: Still reliable and valid twenty years later. *Current Research in Social Psychology*, *5*(15), 225-235. https://crisp.org.uiowa.edu/sites/crisp.org.uiowa.edu/files/2020-04/5.15.pdf

McFatter, R. M. (1979). The use of structural equation models in interpreting regression equations including suppressor and enhancer variables. *Applied Psychological Measurement, 3*(1), 123–135. https://doi.org/10.1177/014662167900300113

Micallef-Konewko, E. (2013). *Talking about an invisible illness: the experience of young people suffering from inflammatory bowel disease (IBD)* [Doctoral thesis, University of East London]. https://repository.uel.ac.uk/item/85x5y

Migdanis, A., Migdanis, I., & Koukoulis, G. D. (2023). Nutritional considerations in colorectal surgery in diverting ileostomy patients: A review. *Cureus*, *15*(11), e48102. https://doi.org/10.7759/cureus.48102

Mitchell, A., Herbert, G., England, C., Atkinson, C., & Searle, A. (2023). Healthcare professionals' perspectives on dietary advice provided to people with an ileostomy. *Journal of Human Nutrition and Dietetics*, *36*(3), 716–728. https://doi.org/10.1111/jhn.13169

Nagai, S. (2015). Predictors of help-seeking behavior: Distinction between help-seeking intentions and help-seeking behavior. *Japanese Psychological Research, 57*(4), 313–322. https://doi.org/10.1111/jpr.12091

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

NHS. (2023). *Recovering and lifestyle changes after an ileostomy.* https://www.nhs.uk/conditions/ileostomy/recovery/#:~:text=While%20you%20recover%20from%20ileostomy,have%20a%20healthy%2C%20balanced%20diet.

Nicely, T. A., Lane-Loney, S., Masciulli, E., Hollenbeak, C. S., & Ornstein, R. M. (2014). Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *Journal of Eating Disorders*, *2*(21), 1-8. https://doi.org/10.1186/s40337-014-0021-3

Nowlin, S., Manning, L., Keefer, L., & Gorbenko, K. (2021). Perceptive eating as part of the journey in inflammatory bowel disease: Lessons learned from lived experience. *Clinical Nutrition ESPEN*, *41*, 299–304. https://doi.org/10.1016/j.clnesp.2020.11.017

O'Connor, P. J., Martin, B., Weeks, C. S., & Ong, L. (2014). Factors that influence young people's mental health help-seeking behaviour: A study based on the health belief model. *Journal of Advanced Nursing*, *70*(11), 2577–2587. https://doi.org/10.1111/jan.12423

Olbrisch, M. E., & Ziegler, S. W. (1982). Psychological adjustment to inflammatory bowel disease: informational control and private self-consciousness. *Journal of Chronic Diseases*, *35*(7), 573–580. https://doi.org/10.1016/0021-9681(82)90077-7

Pallis, A. G., & Mouzas, I. A. (2000). Instruments for quality of life assessment in patients with inflammatory bowel disease. *Digestive and Liver Disease, 32*(8), 682–688. https://doi.org/10.1016/s1590-8658(00)80330-8

Pandey, S., & Elliott, W. (2010). Suppressor variables in social work research: Ways to identify in multiple regression models. *Journal of the Society for Social Work and Research, 1*(1), 28–40. https://doi.org/10.5243/jsswr.2010.2

Pasvol, T. J., Horsfall, L., Bloom, S., Segal, A. W., Sabin, C., Field, N., & Rait, G. (2020). Incidence and prevalence of inflammatory bowel disease in UK primary care: A population-based cohort study. *BMJ Open, 10*(7), e036584. https://doi.org/10.1136/bmjopen-2019-036584

Peters, J. E., Basnayake, C., Hebbard, G. S., Salzberg, M. R., & Kamm, M. A. (2022). Prevalence of disordered eating in adults with gastrointestinal disorders: A systematic review. *Neurogastroenterology and motility, 34*(8), e14278. https://doi.org/10.1111/nmo.14278

Reddavide, R., Rotolo, O., Caruso, M. G., Stasi, E., Notarnicola, M., Miraglia, C., Nouvenne, A., Meschi, T., De' Angelis, G. L., Di Mario, F., & Leandro, G. (2018). The role of diet in the prevention and treatment of inflammatory bowel diseases. *Acta Biomedica, 89*(9-S), 60–75. https://doi.org/10.23750/abm.v89i9-S.7952

Robelin, K., Senada, P., Ghoz, H., Sim, L., Lebow, J., Picco, M., Cangemi, J., Farraye, F. A., & Werlang, M. (2021). Prevalence and clinician recognition of avoidant/restrictive food intake disorder in patients with inflammatory bowel disease. *Gastroenterology & Hepatology, 17*(11), 510–514. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9021160/

Rosenthal, R., & Rosnow, R. L. (1975). *The volunteer subject.* John Wiley & Sons.

Ross, H., Steele, S. R., Varma, M., Dykes, S., Cima, R., Buie, W. D., Rafferty, J., & Standards Practice Task Force of the American Society of Colon and Rectal Surgeons.

(2014). Practice parameters for the surgical treatment of ulcerative colitis. *Diseases of the Colon and Rectum*, *57*(1), 5–22. https://doi.org/10.1097/DCR.0000000000000030

Sarra, S. R., & Abar, C. C. (2022). Perceptions of control and disordered eating behaviors during college transitions. *Journal of American college health*, *70*(7), 2091–2098. https://doi.org/10.1080/07448481.2020.1842745

Satherley, R., Howard, R., & Higgs, S. (2015). Disordered eating practices in gastrointestinal disorders. *Appetite*, *84*(1), 240–250. https://doi.org/10.1016/j.appet.2014.10.006

Schreiber, S., Panés, J., Louis, E., Holley, D., Buch, M., & Paridaens, K. (2013). National differences in ulcerative colitis experience and management among patients from five European countries and Canada: An online survey. *Journal of Crohn's & Colitis*, *7*(6), 497–509. https://doi.org/10.1016/j.crohns.2012.07.027

Schwartz, S. A., Weissberg-Benchell, J., & Perlmuter, L. C. (2002). Personal control and disordered eating in female adolescents with type 1 diabetes. *Diabetes Care*, *25*(11), 1987–1991. https://doi.org/10.2337/diacare.25.11.1987

Sewitch, M. J., Abrahamowicz, M., Bitton, A., Daly, D., Wild, G. E., Cohen, A., Katz, S., Szego, P. L., & Dobkin, P. L. (2001). Psychological distress, social support, and disease activity in patients with inflammatory bowel disease. *The American Journal of Gastroenterology*, *96*(5), 1470–1479. https://doi.org/10.1111/j.1572-0241.2001.03800.x

Sexton, K. A., Walker, J. R., Targownik, L. E., Graff, L. A., Haviva, C., Beatie, B. E., Petty, S. K., Bernstein, M. T., Singh, H., Miller, N., & Bernstein, C. N. (2019). The inflammatory bowel disease symptom inventory: A patient-report scale for research and clinical application. *Inflammatory Bowel Diseases*, *25*(8), 1277–1290. https://doi.org/10.1093/ibd/izz038

Simons, J. S., & Gaher, R. M. (2005). The distress tolerance scale: Development and validation of a self-report measure. *Motivation & Emotion*, *29*(2), 83-102. https://doi.org/10.1007/s11031-005-7955-3

Stoleru, G., Leopold, A., Auerbach, A., Nehman, S., & Wong, U. (2022). Female gender, dissatisfaction with weight, and number of IBD related surgeries as independent risk factors for eating disorders among patients with inflammatory bowel diseases. *BMC Gastroenterology*, *22*(438), 1-5. https://doi.org/10.1186/s12876-022-02526-0

Sun, Y., Li, L., Xie, R., Wang, B., Jiang, K., & Cao, H. (2019). Stress triggers flare of inflammatory bowel disease in children and adults. *Frontiers in Pediatrics*, *7*(432), 1-12. https://doi.org/10.3389/fped.2019.00432

Szymanska, D. (2022). Compensatory behaviors in avoidant restrictive food intake disorder. *HSOA Journal of Psychiatry, Depression & Anxiety*, *8*(45), 1-2. https://doi.org/10.24966/PDA-0150/100045

Teitcher, J. E., Bockting, W. O., Bauermeister, J. A., Hoefer, C. J., Miner, M. H., & Klitzman, R. L. (2015). Detecting, preventing, and responding to "fraudsters" in internet research: Ethics and tradeoffs. *The Journal of Law, Medicine & Ethics*, *43*(1), 116–133. https://doi.org/10.1111/jlme.12200

The Department of Health & Social Care. (2023). *The NHS constitution for England.* https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

Tiggemann, M., & Raven, M. (1998). Dimensions of control in bulimia and anorexia nervosa: Internal control, desire for control, or fear of losing self-control? *Eating Disorders: The Journal of Treatment & Prevention*, *6*(1), 65–71. https://doi.org/10.1080/10640269808249248

Trieschmann, K., Chang, L., Park, S., Naliboff, B., Joshi, S., Labus, J. S., Sauk, J. S., Limketkai, B. N., & Mayer, E. A. (2022). The visceral sensitivity index: A novel tool for measuring GI-symptom-specific anxiety in inflammatory bowel disease. *Neurogastroenterology and Motility*, *34*(9), e14384. https://doi.org/10.1111/nmo.14384

Tu, W., Li, Y., Yin, T., Zhang, S., Zhang, P., & Xu, G. (2023). Association between avoidant/restrictive food intake disorder risk, dietary attitudes and behaviors among Chinese patients with inflammatory bowel disease: A cross-sectional study. *Research Square, 1*, 1-15. https://doi.org/10.21203/rs.3.rs-3675391/v1

Tu, Y. K., Gunnell, D., & Gilthorpe, M. S. (2008). Simpson's paradox, lord's paradox, and suppression effects are the same phenomenon-the reversal paradox. *Emerging Themes in Epidemiology*, *5*(2), 1-9. https://doi.org/10.1186/1742-7622-5-2

Tzelgov, J., & Henik, A. (1991). Suppression situations in psychological research: Definitions, implications, and applications. *Psychological Bulletin, 109*(3), 524–536. https://doi.org/10.1037/0033-2909.109.3.524

van Andel, E. M., Koopmann, B. D. M., Crouwel, F., Noomen, C. G., de Boer, N. K. H., van Asseldonk, D. P., & Mokkink, L. B. (2020). Systematic review of development and content validity of patient-reported outcome measures in inflammatory bowel disease: Do we measure what we measure? *Journal of Crohn's & Colitis, 14*(9), 1299–1315. https://doi.org/10.1093/ecco-jcc/jjaa057

Van Buuren, L., Fleming, C. A. K., Hay, P., Bussey, K., Trompeter, N., Lonergan, A., & Mitchison, D. (2023). The prevalence and burden of avoidant/restrictive food intake disorder (ARFID) in a general adolescent population. *Journal of Eating Disorders*, *11*(1), 104. https://doi.org/10.1186/s40337-023-00831-x

Wabich, J., Bellaguarda, E., Joyce, C., Keefer, L., & Kinsinger, S. (2020). Disordered eating, body dissatisfaction, and psychological distress in patients with inflammatory bowel disease (IBD). *Journal of Clinical Psychology in Medical Settings*, *27*(2), 310–317. https://doi.org/10.1007/s10880-020-09710-y

Wardle, R. A., Thapaliya, G., Nowak, A., Radford, S., Dalton, M., Finlayson, G., & Moran, G. W. (2018). An examination of appetite and disordered eating in active Crohn's disease. *Journal of Crohn's & Colitis*, *12*(7), 819–825. https://doi.org/10.1093/ecco-jcc/jjy041

Whelan, K., Murrells, T., Morgan, M., Cummings, F., Stansfield, C., Todd, A., Sebastian, S., Lobo, A., Lomer, M. C. E., Lindsay, J. O., & Czuber-Dochan, W. (2021). Food-related quality of life is impaired in inflammatory bowel disease and associated with reduced intake of key nutrients. *The American Journal of Clinical Nutrition*, *113*(4), 832–844. https://doi.org/10.1093/ajcn/nqaa395

Williams, G. J., Chamove, A. S., & Millar, H. R. (1990). Eating disorders, perceived control, assertiveness and hostility. *The British Journal of Clinical Psychology*, *29*(3), 327–335. https://doi.org/10.1111/j.2044-8260.1990.tb00889.x

Wright, C. D., Nelson, C. I., Brumbaugh, J. T., & McNeil, D. W. (2020). The role of distress tolerance as a potential mechanism between anxiety sensitivity and gut-specific anxiety. *International Journal of Behavioral Medicine*, *27*(6), 717–725. https://doi.org/10.1007/s12529-020-09912-6

Yelencich, E., Truong, E., Widaman, A. M., Pignotti, G., Yang, L., Jeon, Y., Weber, A. T., Shah, R., Smith, J., Sauk, J. S., & Limketkai, B. N. (2022). Avoidant restrictive food intake disorder prevalent among patients with inflammatory bowel disease. *Clinical Gastroenterology and Hepatology*, *20*(6), 1282-1289. https://doi.org/10.1016/j.cgh.2021.08.009

Yin, T., Tu, W., Li, Y., Yang, M., Huang, L., Zhang, S., & Xu, G. (2023). Risk of avoidant/restrictive food intake disorder in patients with inflammatory bowel disease: Predictive value of disease phenotype, disease activity and food literacy. *Journal of Eating Disorders*, *11*(211), 1-11. https://doi.org/10.1186/s40337-023-00936-3

Zangara, M. T., Bhesania, N., Liu, W., Cresci, G. A. M., Kurowski, J. A., & McDonald, C. (2020). Impact of diet on inflammatory bowel disease symptoms: an adolescent viewpoint. *Crohn's & Colitis 360*, *2*(4), 1-10. https://doi.org/10.1093/crocol/otaa084

Zickgraf, H. F., & Ellis, J. M. (2018). Initial validation of the nine-item avoidant/restrictive food intake disorder screen (NIAS): A measure of three restrictive eating patterns. *Appetite*, *123*, 32-42. https://doi.org/10.1016/j.appet.2017.11.111

Zimmerman, J., & Fisher, M. (2017). Avoidant/restrictive food intake disorder (ARFID). C*urrent Problems in Pediatric and Adolescent Health Care*, *47*(4), 95-103. https://doi.org/10.1016/j.cppeds.2017.02.005

Section C:
Major Research Project Appendices

Appendix A - Examples of existing recent reviews into disordered eating and IBD

Balestrieri, P., Cicala, M., & Ribolsi, M. (2023). Psychological distress in inflammatory bowel disease. *Expert Review of Gastroenterology & Hepatology*, *17*(6), 539–553. https://doi.org/10.1080/17474124.2023.2209723

Day, A. S., Yao, C. K., Costello, S. P., Andrews, J. M., & Bryant, R. V. (2021). Food avoidance, restrictive eating behaviour and association with quality of life in adults with inflammatory bowel disease: A systematic scoping review. *Appetite*, *167*, 105650. https://doi.org/10.1016/j.appet.2021.105650

Di Giorgio, F. M., Melatti, P., Ciminnisi, S., & Cappello, M. (2023). A narrative review on eating disorders and disordered eating in inflammatory bowel diseases: need for increased awareness. *Dietetics*, *2*(2), 150-160. https://doi.org/10.3390/dietetics2020012

Kuźnicki, P., & Neubauer, K. (2021). Emerging comorbidities in inflammatory bowel disease: eating disorders, alcohol and narcotics misuse. *Journal of Clinical Medicine*, *10*(19), 4623. https://doi.org/10.3390/jcm10194623

Peters, J. E., Basnayake, C., Hebbard, G. S., Salzberg, M. R., & Kamm, M. A. (2022). Prevalence of disordered eating in adults with gastrointestinal disorders: A systematic review. *Neurogastroenterology and Motility*, *34*(8), e14278. https://doi.org/10.1111/nmo.14278

Rangel Paniz, G., Lebow, J., Sim, L., Lacy, B. E., Farraye, F. A., & Werlang, M. E. (2022). Eating disorders: Diagnosis and management considerations for the IBD practice. *Inflammatory Bowel Diseases*, *28*(6), 936–946. https://doi.org/10.1093/ibd/izab138

Section A: Literature Review Appendices

Appendix B - Evidence of PROSPERO registration

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Appendix C - CASP qualitative checklist

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Appendix D - Researchers reflexive account

Throughout the thematic analysis, I took a reflexive position which enabled me to think about my assumptions and expectations about the process, data, and themes. This helped me to challenge the assumptions I previously had around thematic analysis and enabled me to consider the data more holistically and generate themes that emerged within it. The reflexive position I took also helped me to remain aware of my prior knowledge, assumptions and experiences and enabled me to consider the influence of these on my processes throughout the analysis.

Prior to starting this review, I had no academic or research experience regarding Inflammatory Bowel Disease (IBD) or self-disclosure. However, I did have personal experience of both living with an invisible illness and having social relationships with others living with chronic illnesses. Due to this, I had assumptions and beliefs regarding self-disclosure based on my own experiences of disclosure decisions. Based on my experiences of disclosing and through observations of others in this context, I had prior assumptions of what factors may facilitate or prevent disclosures.

Despite my experiences having influenced my expectations of what possible themes may emerge in the data, I remained aware that my experiences were not with IBD, and that IBD presented key differences in relation to its symptoms and the potential stigma associated with this. Therefore, I did not have prior experience of IBD or disclosing this as an illness and felt able to analyse the data from an outsider perspective. However, throughout the completion of this review, I became aware of others in my social context and on my doctorate course, who were living with IBD. This further contributed to my experience of other's self-disclosure of the illness, and discussions around this widened my understanding of experiences relating to talking about IBD.

Being aware of my own knowledge and experiences was important throughout the thematic analysis in ensuring that themes were developed from what was data was generating, rather than my own expectations. I felt able to consider what the data was saying and having individuals with no prior knowledge of IBD, or disclosure, acted as a useful sounding board. Using supervision was also beneficial for this process as it provided a space to think about the data, the codes and how these fitted together. Having supervisors both with and without experience of IBD was useful for discussing themes and developing these to ensure they were meaningful and reflective of the d

Appendix E - CASP quality ratings for included papers

Author	Aims	Methods	Research Design	Recruitment	Data collection	Reflexivity	Ethical Issues	Data analysis	Findings	Research Value	Strengths and weaknesses of paper
Barned et al., (2016)	Y	Y	Y	Y	Y	P	Y	P	Y	Y	Clear details provided on recruitment; however, the paper does not provide consideration on why this population was chosen. This paper outlined who conducted coding and the steps taken, with quotes provided to support their themes. However, no information was provided on how conflicting/contradicting data was considered. It is not made clear what the relationship between the participants and what the research positioning was, it is unknown how this may have biased the results and findings. Ethical approval obtained and additional information provided about obtaining informed consent and confidentiality.
Murphy et al., (2022)	Y	Y	Y	P	Y	Y	Y	Y	Y	Y	A strength of this paper was the reflexivity with the author detailing their own experiences and how this influences the research. Although ethical approval was sought, it is unknown what ethical concerns were raised or what considerations were taken to address these. A weakness of this paper was recruitment, with limited information being provided around participant demographics. Therefore, it cannot be determined whether this population was representative of the female IBD population more widely.
Savard & Woodgate, (2009)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	This paper had strengths across several domains including having clear aims. appropriate methods, clear detail of analysis. Information was provided on data saturation and examples of questions in interview were used. However, despite obtaining ethical consideration, and considering informed consent, the details around potential issues and considerations were limited. A weakness of this paper was its reflexivity, with no information being provided about the researcher, their position, experience, or their relationship with the participants. Therefore, little is known about the how this may bias the results and interpretation of these findings.
Saunders, (2014)	Y	Y	Y	Y	Y	P	Y	P	Y	P	This paper had strengths in data collection and analysis, providing detailed information on how and why information was collected and analysed in the chosen way with considerations of how this approach helps to identify young people's experiences. It was a strength that interview questions were provided, as it could be seen that

											these allowed for appropriate data to be elicited. However, limited information as provided around the theoretical approach to analysis and who was involved in this. Weaknesses arose in reflexivity, with the research acknowledging how the work had been influenced, but with little information given about their experiences or how this influenced the interpretation of findings.
Frohlich, (2012)	Y	Y	P	Y	Y	Y	Y	P	Y	P	Reflexivity was a strength of this paper, with the research identifying their own experience of IBD and how this could have biased the analysis. It was also a strength that they recognised potential recruitment biases and how they overcame this. Weaknesses arose in their data analysis, with limited information being provided around how information was analysed and how themes emerged. Therefore, its uncertain why certain information was selected within the text.
Devlen et al., (2014)	Y	Y	P	Y	Y	N	Y	Y	Y	Y	This paper met the criteria for most of the domains, however the amount of information was limited, such as obtaining ethical approval but not detailing the considerations or actions arising. A weakness was reflexivity, with no information on the researchers' background, experience, position, or relationship with the participants. It was also uncertain whether the researcher had appropriately identified why the methodology was chosen. Strengths were identified in their research aims and presentation of findings, with clear themes. However, there were limited quotes to support these findings and therefore it cannot be identified how these themes emerged.
Sammut et al., (2017)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	A strength of this paper was their data collection, as they provided example questions and prompts used to obtain data. This helped to determine the suitability in relation to the research aims. Information regarding ethical considerations was also a strength as they provided formation regarding obtaining informed consent. However, despite detailing considerations of rigor, little information was provided about the researcher's experiences or potential bias, therefore the impact of reflexivity could not be determined.
Robertson et al., (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Reflexivity was a strength in this paper, with them taking action to audit biases that were arising within the process. Details of data analysis was also a strength with a step-by-

											step description of how analysis was conducted and the process of developing themes.
Dibley et al., (2017)	Y	Y	Y	Y	Y	P	Y	Y	Y	P	The aims and methodology were strengths for this paper, with the authors making these explicit and clear. The value of the paper was also a strength as the findings was applied to a wider chronic illness population. A strength of this study was their data analysis, which detailed their approaches to saturation. However, a weakness arose in their reflexivity as, although it recognised that researchers had previous experience with the phenomena, the potential impact and biases could not be identified.
Hall et al., (2005)	Y	Y	P	Y	Y	N	Y	Y	Y	Y	A strength of this study was their analysis, with detailed information provided, making it easy to determine their approach and how their results were created from the data. A weakness of this study was the reflexivity, as there is no information or evidence of consideration of researcher positioning/experiences provided. Therefore, it cannot be determined what impact this has on the reported findings of the study.
O'Leary et al., (2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Strengths for this paper arose from clear statements of their aims, with authors providing a section on “research focus” which explicitly stated research questions. Additionally, in approaching their analysis, details of how randomly assigned transcripts were examined by additional researchers to enhance inter-coder reliability, contributing to this area being a strength of this paper. However, the absence of information about the authors or their experiences of the phenomenon being examined was a weakness, as it cannot be determined whether the reflexivity contributed to any bias within their analysis or findings.
Gelech et al., (2021)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	The detail provided around the approach to analysis and how this enabled the aims of the study to be achieved was considered a strength of this review. Additionally, it was a strength that there were quotes provided to support their findings, as it enabled readers to understand how the data contributed to the themes. However, reflexivity was considered a weakness in this paper as the consideration was given to theoretical underpinnings rather than the researchers experiences and biases and therefore it could

											not be determined how the researchers may have influenced the findings or interpretations of this paper.
Restall et al., (2016)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	A strength of this paper was their clear statement of aims/goals of the research which outlined the purpose of the paper in a succinct way. Strengths were also noted in their approach to data analysis and approaches to make this trustworthy, including multiple researchers checking transcripts and codes to ensure comparable coding and keeping an audit trail to keep track of the processes and decisions. Although authors report writing a reflexive field note following each interview, which is a strength, the outcomes of these are not provided so it cannot be determined what the impact of this was.
Dibley et al., (2020)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y	A strength of this study was their design, as their philosophical framework was justified and their data analysis, with research detailing approaches to saturation. The analysis process for this paper was clearly detailed with authors providing the theoretical approach to analysis along with how they actioned this in their research, which makes this paper replicable. Although it is helpful that they state discussions around analysis and reflexivity were held, there is limited information provided about what the positions or biases were that emerged and how this influenced the findings. Therefore, it is difficult to determine the impact of the researcher positioning on this paper.
Zigron & Bronstein, (2018)	Y	Y	P	Y	Y	Y	N	Y	Y	Y	A strength of this research was the data analysis, with the authors providing details around the theoretical approach to analysis as well as details of how this was applied to the data. The findings were also clearly provided, and quotes were used to support the themes, which made it clear how they linked. However, a key weakness was the consideration of ethical considerations, with no information being provided around potential issues, management of ethics or approval from an ethical panel.
Matini & Ogden, (2016)	Y	Y	N	Y	Y	N	Y	Y	Y	P	Based on their aims, it could be inferred that the interview approach was an appropriate design, it was not explicitly justified. A key weakness for this paper was their approach to reflexivity, with no information being provided about the researchers positioning or relationship between the researchers and participants. Therefore, the reliability of this paper is unknown as the potential bias from the

											researchers positioning cannot be determined. However, a strength of this paper is their findings which were clearly presented, with quotes to support the discussion of findings. Quotes also included the age and diagnosis from the individual, which helps to understand that type of people contributing to each finding.
Palant & Himmel, (2018)	Y	Y	Y	P	Y	N	Y	Y	Y	P	A strength of this research was their clear statement of aims which clearly outlined what the purpose of the paper was. Additionally, their data analysis provided a step-by-step description of how coding took place, which makes it easy for others to replicate this. However, several weaknesses arose, including their recruitment with limited information being provided about the demographics of their sample or why these people were chosen. Additionally, reflexivity was a weakness with no information being provided about researchers positioning or that they had considered their role within the research process.
Salazar & Heyman, (2014)	Y	Y	Y	P	Y	N	Y	Y	Y	P	This paper provided a clear statement of their aims which allowed an understanding of the purpose and overview of what the paper would entail. There were also strengths in their methodology, with authors providing clear information regarding how interviews were conducted which allows for replication. However, less details were provided regarding recruitment strategies and why participants were chosen, leading the reader to assume/infer this themselves based on the research aims. A weakness arose in their reflexivity, with no information being provided regarding the relationship of the researchers and participants. Although this paper discuss their findings in relation to other summer camps and how they can be applied to other settings, there is little information provided about how this research informs future research and therefore it is uncertain how this paper is influencing future papers.
Nicholas et al., (2007)	Y	Y	Y	P	Y	N	Y	Y	Y	P	It was a strength that the full interview questions were provided, as it could be seen that these allowed for appropriate data to be elicited in relation to the aims of the research, which were also clearly stated. A weakness of this study was identified in the reflexivity of the researchers, as there was no mention of their previous experiences, their positioning or potential biases or their

											relationship with the participants, thus making it difficult to ensure the reliability or transparency of the findings.
Schwenk et al., (2014)	Y	Y	Y	Y	Y	Y	Y	P	Y	Y	This paper provided justification and a description of the theoretical underpinnings of their data analysis. This helped to understand why they did this and how this enabled them to achieve their aims. There was also a clear overview of the participants demographics, although ethnicity data was not provided. Although this paper provided information about the researchers' previous experience which allowed assumptions to be made about their positioning, this was not explicitly discussed and the potential bias was not detailed. A weakness arose in their data analysis as although the process was described, the role of the facilitator or how contradictory agreement on codes/findings were managed is not identified. Therefore, caution should be taken in determining the reliability of the reported findings.
Nehasil, (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	This was considered a strong paper overall, with the paper giving clear, explicit aims and purpose of the study and detailed information regarding the rationale for the study design. It was a strength that the full interview questions were provided, as it could be seen that these allowed for appropriate data to be elicited. The author also provided a section on reflexivity and positionality, including their own experience with CD, with consideration that this influenced their approach and interpretation of the findings. It is acknowledged that this being a dissertation rather than journal article may have allowed for more space to provide this information.
Woodward et al., 2016	Y	Y	Y	P	Y	P	Y	Y	Y	Y	It was a strength that the full interview questions were provided, as it could be seen that these allowed for appropriate data to be elicited. The authors also discussed their approach to saturation which provided more insight into their data analysis and the rigor used within this. A weakness arose in their reflexivity as, although it was stated that the analysis was a reflexive process with the use of a evidence trail for credibility, there was little evidence of this in the report which meant that it could not be determined what the researchers positioning was or how this potentially influenced/biased the research. A further weakness arose in their recruitment as there is no information provided about the sample demographics.

											Therefore, it cannot be determined whether this sample was reflective of the IBD population demographically.
Kluthe et al., (2018)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	This study had strengths in clearly stating the aims and design of the research. They also provide a clear summary of their findings and use appropriate quotes to support their findings. This allows the reader to understand the data that informed the findings. A weakness of this paper was their reflexivity, as there was no mention of considering this and it was unknown whether the researchers had a relationship with the participants or what their position was/how this influenced their findings.
Ruan & Zhou., |(2019)	Y	Y	Y	Y	Y	Y	Y	P	Y	Y	This paper provided a clear statement of their aims, design, recruitment strategy and approaches to analysis. This paper also demonstrated that they had considered certain ethical issues including informing participants, confidentiality and storing of data. This paper also had a strength in reflexivity, with it being clear how the researchers were related to the participants and consideration given to the influence their positioning and demographics, such as age, might have influenced the findings. A weakness in this paper arose in their data analysis as it was unclear how they considered contradictory findings, and it was uncertain how the development of themes emerged.
Vaughan & Jolliffe., (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	This paper was considered strong across all domains of quality appraisal. From the start of the paper, it clearly and explicitly states the aims, which makes it clear to the reader what the purpose of the research will be. There is also strength in the consideration of the researchers own positioning, with a statement of personal experience being given for the authors. This allows readers to understand the history of the researchers and consider how this influences the researchers approach to analysis and interpretation of findings. This paper clearly states their approach to data collection and analysis, providing a diagram of how themes were developed. This transparency makes the paper replicable and also provides it with rigor.
Micallef-Konewko, (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	This paper was considered strong across all domains, and it was acknowledged that being a dissertation provided more space to provide information about the research compared to journal articles. It was a strength that the full interview questions were provided, as it could be seen that these

											allowed for appropriate data to be elicited. Reflexivity was a particular strength with the authors not only providing information about their own positioning and experiences but also acknowledged this in relation to the findings as well. This paper had clear aim, comprehensive recruitment and data analysis and appropriately supported its findings with quotes, so it was clear to the reader how the research was conducted and how themes were formed.
Carter et al., (2020)	Y	Y	Y	Y	Y	N	Y	P	Y	P	This study had strengths in their clear statement of aims, design and recruitment strategy, which clearly provided a sample inclusion/exclusion criterion and how recruitment was approached. There was also a clear description of their method and ethical considerations, including how they attempted to reduce ethical concerns and supported participants to manage their distress. However, there were weaknesses in their data analysis and their reflexivity, as it could not be determined how themes were agreed or whether consideration had been given to the researchers' experiences and the impact of this on the interpretation of findings. Additionally, the value of the paper was considered a weakness as there was no details on future research or how the findings from this paper inform future investigations.
Lolli, (2022)	Y	Y	Y	P	Y	Y	Y	Y	Y	Y	It was a strength that the full interview questions were provided, with these appearing appropriate in relation to the clearly stated aims of the paper. It is acknowledged that the dissertation style allowed for this paper to report more on the reflexivity and personal reflections compared to other papers that were potentially limited by word count as required by the chosen journal. This allowed the author to provide a detailed account of her own experience and link her findings back to differences/similarities in her own experiences. However, a weakness of this paper emerged in the recruitment as, although details of how participants were recruited was provided, there was little information given about who the participants were. Therefore, it is difficult to determine whether the sample was reflective of the IBD population more generally.
Kitchen et al., (2020)	Y	Y	P	Y	Y	N	Y	Y	Y	Y	This study had strengths in clearly stating their aims, using an appropriate method to meet these aims and in their analysis/findings, with detailed themes being discussed and appropriate quotes provided to support these findings. There were also strengths in the value of this paper, with

											the authors discussing how the findings can be used to inform future clinical practice and making recommendations of how their findings inform future research. However, a key weakness was their reflexivity, with no information being provided regarding the researchers' relationship with the participants or their previous experiences/positioning. Therefore, it cannot be determined whether this creates a bias in how the research has been conducted or interpreted.
Wang et al., (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	This research was considered to meet all quality criteria. There were strengths in their reflexivity with a statement recognising that authors kept a reflective journal and considered their previous experiences to help reduce the impact this had on their approach to the research. There were also strengths in ethics, with the authors receiving appropriate approval and providing details on participants ability to withdraw, procedures of informed consent and consideration of supporting individuals if experiencing emotional distress. This study provided clear findings and appropriately used quotes to support these, making it clear how the data informed the development of themes.
Rouncefield-Swales et al., (2020)	Y	Y	P	Y	Y	N	Y	Y	Y	Y	This paper had had strengths in its methodology, clearly describing the approaches to data collection they used and a justification for this. They also clearly provided details of their ethical considerations, including how they approached informed consent. There was also a clear overview of their recruitment procedures, including demographics of their sample which allowed for readers to consider this sample in relation to their representation of the wider IBD population. There were weaknesses in their research design, as there was no justification for why this approach was used. Reflexivity was also a weakness as the researchers do not provide information regarding their positioning, experience, or relationship with the participants. Therefore, it cannot be determined whether the interpretation of findings or approach to research was biased due to the researchers' previous experiences or expectations.
Peters & Brown, (2022)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	This study had strengths in explicitly stating their aims and hypotheses, describing, and justifying their research design and using appropriate methodologies to meet their aims. This study also provided a clear overview of their recruitment strategy and detailed the demographics of their

											sample, allowing the reader to interpret whether this was representative of the wider IBD population. There was also a clear diagram displaying their thematic map, which supported the understanding of the theme development and interactions. However, there was a weakness in their reflexivity. Despite using open-ended questions, their results were analysed using thematic analysis. However, no information was provided about how the researchers experiences or positions influenced their analysis of the data.
Colmer, (2021)	Y	Y	P	P	Y	N	Y	Y	Y	Y	A strength of this paper was the findings which were clearly presented, with quotes to support their findings. There was also a good justification of the value of this paper, with authors discussing both the theoretical and practical implications of their work as well as providing direction for future research. Although stating that data was collected through surveys including open-ended questions, there was no justification provided for this and therefore it was unknown why this approach was chosen over other methods such as interviews. This study also had weaknesses in their recruitment as it could not be determined how or why the sample was selected and there was limited information provided to describe the final sample. Despite being a dissertation, there was no information provided on the reflexivity of the authors or how their experiences, expectations, or positioning may have biased the analysis and interpretation of the findings.
Wåhlin et al., (2017)	Y	Y	Y	P	Y	N	Y	Y	Y	Y	This paper had clearly justified their qualitative design in relation to their aims which were clearly stated. Although there was information on the demographics of the sample and clear information on how data was collected, there was limited information provided around why this population was chosen for this research. This paper had strengths in their ethical considerations which were approved by an appropriate board, and they provided information on specific considerations such as informed consent. Although authors report participants opportunity to reflect with the interviewer about their experience, there is no information provided about the researchers positioning or experiences or how this may have influenced/biased the interpretation or analysis.

	Summary of strengths and weaknesses: Papers generally identified appropriate aims and used designs/methodologies to meet these. Most also had strengths in detailing how data was collected, including information on the type of interviews that took place. However, details varied with most not providing the full interview schedule. Therefore, it cannot be determined if the questions appropriately collected information relevant to the research aims. Most papers appropriately described their recruitment strategy; however, it was noted that some papers did not provide details on the demographics of their sample, making it difficult to determine whether the samples used in these studies was representative of the wider IBD population. Although the papers appropriately sought ethical approval, there was often limited information on the potential issues arising and the approaches considerations taken to address the ethics. A weakness across most studies was the consideration of reflexivity and information researcher positioning and the potential bias/impact this has on the analysis and interpretation of findings. Although some papers named their positioning or previous experience, it could not be determined how this had been held reflexivity throughout the research or the impact of this on the wider findings.

Y = Criterion met, P = Criterion partially met, N = Criterion not met

Appendix F - Additional quotes contributing to theme development.

Theme	Subtheme	Example Quotes
Its an invisible, stigmatized illness	It's a taboo subject	"*They can be such disgusting aspects, having diarrhoea and the other things, I just think, do people really want to hear about that, about someone else?"*
		"…it was just a thing we didn't talk about".
		"Everyone gets a little squeamish when you start talking about your bowel habits."
		"I know it's like really an old school taboo subject thing that people should talk about but…I dunno, I don't talk about going to the bathroom with people."
		"…she was not happy to discuss anything poo-related. So I felt that I was not allowed to talk about it."
		"…people don't talk about colons or going to the bathroom and it is very hush hush, you don't hear a lot about it. "
		"Some felt there was a stigma attached to the illness and, therefore, felt more comfortable not talking about it to others".
	Its unseen by others	*"…relative invisibility of IBD allowed participants to keep their condition successfully concealed much of the time."*
		"…it's something for me that's private".
		"It's only when you tell people that you've got Crohn's disease and the fact that nobody had a clue, oh what's that then, you know what I mean, that's the sort of response you get, and nobody actually thinks there's anything wrong with you, and it's one of those invisible illnesses that you look OK on the outside but on the inside is a totally different story."

Reluctance to disclose	Talking is difficult and Embarrassing	*"…conversations even with close friends are emotionally taxing. Concealing one's illness, therefore, understandably appears as a safer, less demanding option".* *"…it was very difficult for me to explain, to cross this line and say that I've got this condition, and how I feel and everything. It took me a lot of time because it was not easy to explain how it is."* *"'Yeah, because I think it's very embarrassing. It's just that, oh, couldn't I just have something wrong with, I don't know, my eyes or my…? This is all a bit like, it's just too, it's just too personal".* *"I find it's, I don't know, may be a bit embarrassing sometimes".* *"…it's not that I can't tell people, it's that I choose not to because of my own emotions, feelings in general".*
	Telling burdens others	*"I don't want to make a lot of noise... (because) I'm a burden on my family".* *"Some attempted to protect close others and reduce their own guilt by limiting what they shared".* *" I always felt like it was going to fail, that it was going to be something. I say too much, and he would just leave."* *"…could not openly discuss IBD in their families to the extent desired sometimes because they were worried about their parents and or families".* *"…finds it challenging to express why she requires time off due to feeling a burden because of increased absences".* *"I am constantly thinking about it (IBD)... but it makes me feel guilty because my family worries about me".* *"I don't really want to think there's someone worrying about me all the time […] [mum]'ll say, "how's your stomach?" and I'm like "yeah, yeah it's fine" and she's like, "you wouldn't tell me if it wasn't would you?" I was like, "No!")"*

	Maintaining the appearance of normality	*"They might not know the illness very well, and I didn't want to make myself seem particularly different because of the illness."* *"I just don't want to be 'Holly with Crohn's', I just want to be 'Holly'".* *"I don't want things to really change, where my friends think […] that all I like to talk about is my illness, because that's all I can talk about."* *"I sometimes think maybe it might get too depressing or too boring for them and I don't want them to see me now, as oh I've been diagnosed with an illness so now I can't have fun, now it's all I talk about."* *"Knowing myself I couldn't do things, but not wanting others to be telling me I couldn't,"* *"I just didn't want anyone to think that I was different … And I didn't want to be the girl with the disease."* *"The learning competition was extremely fierce in our college, and no one wanted to be a weak person. In this environment, even if I was ill, I told none of my classmates."*
	Avoiding Pity	*"…feel[ing] sorry for me – a sympathy friendship".* *"Sometimes I don't want people to know I've got an illness. I don't want people to start the whole pity party, you know, 'Oh, you poor thing! I feel really sorry for you'"'.* *"Sometimes it feels like I'm being handled with kid gloves."* *"I have brought up my colostomy and Crohn's in Uni… it just turns people feeling sorry for me and which then puts me off talking about it more because I don't want them to feel sorry for me".* *"In the beginning I actually thought, […] well at least they [peers] care. They realise that I'm capable of knowing when I'm not feeling well and they will stop asking. But they didn't. And it just made me feel like a little child."*

	Fear of teasing and bullying	*"I'm afraid to tell my friends about the disease. I'm afraid they will laugh".* *"I felt scared about the way they [teachers] would react. And if they [teachers] would go around telling everyone, and then I would get bullied by people, because of my friends then telling everyone."* *"...worried about being judged or teased by their peers, and for that reason, hesitated to tell."* *"I didn't want them [peers] to hear [...] because some stupid stuff might happen [...] like making nasty remarks about it."* *"If people did tell other people, they might come to my school to bully me about the symptoms that I had, like the diarrhoea. That's my worst fear".*
A need to disclose	Its emotionally difficult not telling	*"I didn't tell anyone. I hid that for years, believe it or not. And that was agony".* *"When I could not tell (I had Crohn's disease), I felt really stressed"* . *"It was such a relief after I told them,"* *"bottling up" one's IBD struggles often led to social isolation and anxiety."* *"I think if I had tried to hide all the time, the stress levels would just make it so much worse."*
	The symptoms can't always be hidden	*"I talk about it less now, because in primary school, I couldn't really hide it, because I couldn't eat."* *"Decisions concerning who to tell and when to tell based on considerations related to the seriousness of their illness".* *"...you get to a certain point where you can't keep it secret."* *"They would clearly know that something was wrong, and I couldn't keep that from them anymore."*

	"…there's no point in trying to hide it".
To excuse or justify behaviours	*"I would have told him [referring to her husband] because he was thinking that I was making up excuses".*
	"I fear the regular days off I need for treatment or sudden emergency flares may be misconstrued as skipping work without reason. And this could be another reason for my employer to fire me."
	"If I tell my boss 'I can't come into work' and she's like 'you look perfectly fine.' I'm like 'well guess what I'm not.'"
	"I didn't want to tell them at first but then they realized ok he's not here a lot of days and then he shows up with a bandage on his arm so either he stays at home and stabs himself or he goes to the hospital".
	"I feel like you know, at work I bring all of my own food and people see me eating and I get those like squeeze pouches of baby food. Like they are small, and they are delicious, and I love them, but I had a co-worker one time, he's like, Noelle why are you eating baby food? Like literally my infant child eats those. And I was like well 'cause I can't digest my foods and so this is my go-to."
	"I felt like weird having to tell my professors because like a lot of them looked at you like, well what is wrong with you that you think you need to be out of school for a month, like you look fine to me type of thing".
Educate and help others	*"I can help somebody else with questions. Somebody needing help in something I had trouble with and found a way to help to make it work. I love sharing any of that if someone asks."*
	"They [friends] associate you with wanting to go to the toilet, and I'm like, 'No, it's not always about that'. There's a lot of different aspects, like, it goes from your mouth, like, to your bum, it goes all the way down, and so it's just trying to get that across".
	"Telling people] was definitely a challenge. I think it's better when you explain it to people, because then they understand".

		"…in my caption maybe explain that I've had a bad day or what symptoms I've experienced and try and use that as a call to action or a positive message for other people who might be feeling the same,"
Balancing the need to disclose and the reluctance to disclose	Forced vs voluntary disclosure	*"…disclosing to actual or potential romantic partners often shifted as the young people got older".* *]*
		"I talk about it less now, because in primary school, I couldn't really hide it, because I couldn't eat."
		"…if something bad has happened, I will tell a few months afterwards".
		"Some people might come up to me after class and go, 'Oh Will, why are you allowed to go to the toilet?', and then I'd have to tell them. Well, I wouldn't have to tell them, but I'd feel like, I was lying to them."
	How much to share	*"…because it's just telling someone about […] a part of you […], it's easier telling people like what I have to have done."*
		"…just like because I wasn't sure if if I'd like said something that wasn't actually how like if I said it was bad when it wasn't actually so bad or something".
		"So I tell them just enough to satisfy them really. Like, I say it has something to do with my stomach, it causes pain and that it makes me feel sick and that's it. "
		"I do not mind telling them how often I go to the bathroom either. I have no restrictions."
	Some people are easier to tell	*"…like an actual friend that I know that won't tease me about it or something like that so umm yeah I have really good friends that they all know that I have Crohn's".*
		"I wanted to keep it a secret so that no one else knows, except my best friends whom I trust."

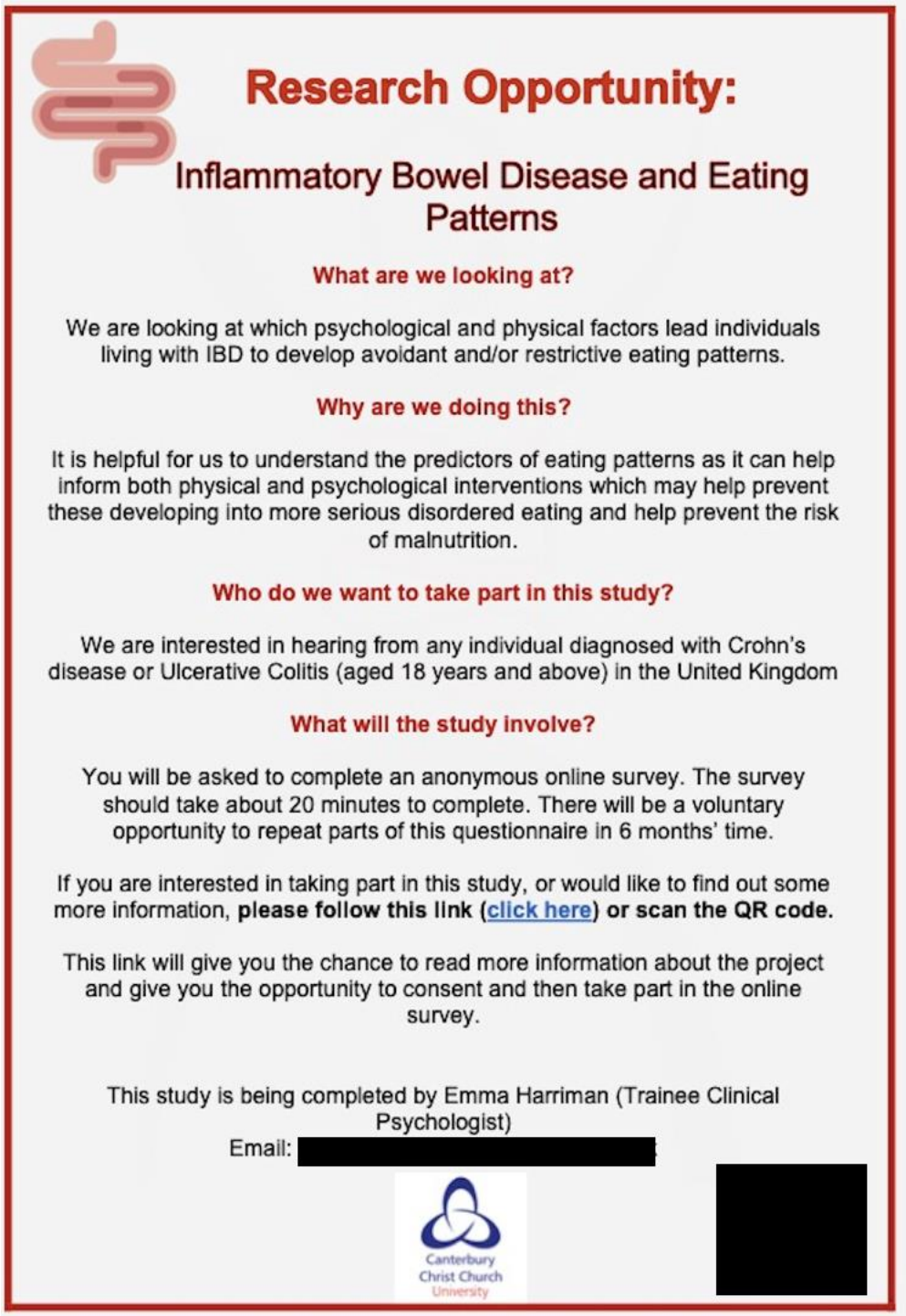
		"...comfort in talking to peers or members of staff at school (teachers, dinner lady) who had the same or similar diagnoses to them."
		"So, uh, I couldn't trust him; so I didn't share anything with him."
		"But the annoying thing with that is I don't care about informing him but then there's like all of my peers from my work group that I don't think it is any of their business to know and now I have to like disclose in front of all of them and so I think that is frustrating"
Varied Consequences of disclosure	Support and building relationships	*"I was like, 'I've got this' and they were like, 'Oh' and supportive of me and stuff"*
		"I think if anything those friends have become closer because I think they feel I've shared a lot".
		"...the three that I told were [...] making sure I was actually okay, okay."
		"It [talking to friends] feels good because [...] I know that they would listen to me and I know I can speak to someone about it and they won't go telling other people that I don't want to know."
		"...it helps a lot to talk about (IBD) with someone who has it".
		"*Transparency about their illness allowed many participants to form beneficial social connections, including relationships with other students with IBD".*
	Initial Shock and overreaction	*"When it's explained to them, they either don't take it seriously at all or they are profoundly shocked."*
		"...then you get new random people who find out and they're really shocked".
		"...tell you they'd be so shocked if they did find out 'cause that's people's reaction generally".
		"...new people's reactions that are the weirdest (.) it's like oh my god (.) at work and stuff they just don't get it the comment I had yesterday was 'isn't it really sad you're so young' and it's like 'so young what?' and they're like 'so young to be like this' and I don't think like that".

People can be mean and misunderstanding	*“They [peers] would say things like, “You’re a bit like a cripple really, aren’t you?” and […] then, they would start talking about bowel movements. I could take all of the other things but, for some reason, them [sic] making comments associated with bowel movements, that really upsets me. That's too much for me to deal with.”*
	“…cause people were just (.) so childish in school (.) you know (.) giggle about it and things like that (.) "
	“…[they] tease me about the things I drink.”
	“…some people think that because it’s a disease, Crohn’s - they say ‘Oh my God can I catch it off you?”
	“Regularly and openly ridiculed due to embarrassing nature of the condition."
	"…it kinda like offended me that saying that it shouldn’t she’s like “it shouldn’t hurt it shouldn’t do this, my friend doesn’t have” but your friend is different though, not everybody feels pain not everybody does".
	"…she was like well my friends got Crohn’s and she’s alright. But I’m like its different levels".
	"He still does not understand the true nature of my condition, and does not always take me seriously when I express need for time off to rest.”
	“Oh, I don’t know . . . you’re a bit complicated, it’s very complicated isn’t it?” I said, “No, not really, I have already told you.” There’s just no thought there at all."
	"I wish I could have talked to my mum, but she didn’t seem to understand my illness. She was always brushing it aside as if, “Oh no, it’s not a problem.” Only it was a problem."
Growth, Acceptance and coping	*"You kind of have that freedom once you tell people. You don’t have to hide it anymore".*
	"Because my parents and I talk things through about my IBD, I can deal with it".

	"I feel like I've spoken about it much more to my friends. I feel like I've been much more honest about it," *"If I hadn't given them [teachers] enough information, they wouldn't know that I had diarrhoea. If they hadn't already sussed it out, and if I needed to go to the toilet and they said no, then that would have been a problem. "* *"""...open up" to supportive friends who knew and understood was described as being "quite heartening""* .

Section B: Empirical Paper Appendices

Appendix G - Research poster



Appendix H - Demographic questionnaire

What is your age in years: (typed answer)

How would you describe your gender: (multiple choice)
- Male
- Female
- Non-binary
- Another Gender (please describe)
- Prefer not to say

How would you describe your ethnicity: (multiple choice)
- White British
- Black British
- White Irish
- Black Caribbean
- Black African
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Other Asian background
- Other black, African or Caribbean background
- Arab
- Another ethnicity (please specify)

What is your marital status: (multiple choice)
- Married/Civil partnership
- Living with partner/cohabiting
- Single
- Divorced/separated
- Widowed

What is your employment status: (multiple choice)
- Full time employed
- Part time employed
- Self employed
- Unemployed
- Retired
- Student

What is your IBD diagnosis: (please select all that apply)
- Crohn's disease
- Ulcerative Colitis

At what age did you receive a diagnosis? (typed answer)

How many surgeries FOR YOUR IBD have you had? (Typed answer)

Do you have a stoma: (multiple choice)
- Yes
- No
- Prefer not to say

Do you have access to a support team or hotline related to your IBD? (multiple choice)
- Yes
- No
- Prefer not to say

Appendix I - Inflammatory Bowel Disease Symptom Inventory (IBD-SI)

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Appendix J - Avoidant/Restrictive Food intake Disorder Screen (NIAS)

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Appendix K - Distress Tolerance Scale (DTS)

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Appendix L - Desirability of control scale (DCS)

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Appendix M - The Visceral Sensitivity Index (VSI)

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Appendix N - The Duke–UNC Functional Social Support Questionnaire (DFSS)

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Appendix O - Participant information sheet

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

Thank you for considering taking part in this survey which is looking at eating behaviours in Inflammatory Bowel Disease (IBD). My name is Emma Harriman and I am completing this research as part of my doctoral thesis which goes towards my qualification as a clinical psychologist. On completion of the survey, you will be entered into a prize draw for your chance to win a £100 Amazon voucher.

In order to participate, you'll need to be an adult (aged 18 and over) residing in the UK who has received a diagnosis of either Ulcerative Colitis or Crohn's disease from a doctor.

Before taking part, please read the information below and then click in the boxes at the bottom of the page if you understand the statements and freely consent to participate in the study.

What is the purpose of this survey?

This survey is part of a psychology research project looking at which psychological factors are involved in the development of avoidant or restrictive eating patterns in individuals living with IBD.

If you take part in this survey, you will be helping us to develop an understanding of eating behaviours which can help improve the psychological support available for individuals experiencing IBD.

This survey is being carried out by a research team primarily based at Canterbury Christ Church University and has been approved by a university research ethics committee.

Do I have to take part?

This research is completely voluntary and, therefore, it is up to you to decide whether to complete the survey or not. If you agree to take part, you are free to withdraw at any time, without giving a reason, by simply closing the internet browser during completion of the survey.

If you complete the survey but then want to withdraw your responses, you can do so by emailing [redacted] until two weeks after you initially completed the online questionnaire. There will be no consequences for you if you choose not to participate or choose to withdraw from the study.

To withdraw after submitting the online survey, you can do so by emailing [redacted].
If you wish to withdraw, you will need to have provided your email address at the end of the survey. The researchers need your email address to be able to identify your data and remove it. If you choose not to provide an email address, then you will not be able to withdraw your responses after submission.

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

This is an online survey (taking approximately 20 minutes) which will include questions about your IBD, such as age of onset, diagnosis, historical surgery and management. You will also be asked to complete several questionnaires about your gastro-intestinal symptom, feeling of control, eating behaviours, tolerance of distress and social support.

You will also be asked to provide some information about you, for example your age, gender and ethnicity. This information will help us know whether the people who have responded to the survey are representative of the population as a whole.

Nearly all the questions will be multiple choice questions. If you take part in this survey, we ask that you answer all questions as honestly as you can. The responses you give will be anonymous and not have any impact on the care you receive from your current healthcare providers.

We hope that you will take part so that we can collect information from a wide range of people. However, if you think that answering questions about your IBD experiences or eating will be distressing, we advise you not to participate. Similarly, if you start the survey, but begin to experience discomfort or distress while completing it, we'd advise you to stop.

At the end of the survey, you may submit your email address for a chance to win £100 of Amazon vouchers. You do not have to be entered into the draw if you do not want to be.

You will also be offered the option of completing a second survey about 6 months later, for another chance to win £100 of vouchers.

At the end of this research, you will be offered the opportunity to hear about more research into IBD being run by the university by providing your email address. If you agree to this, your email address will only be retained for this purpose until the end of 2023. Prior to then, if you'd like to withdraw your email address, please contact Emma Harriman [redacted].

What are the risks and benefits of taking part?

We cannot promise the study will help you directly. However, it has the potential to help improve the treatment of people with IBD in the future. You will be able to receive the results of the research at the end of the project if you wish.

As mentioned above, it is possible that some people may find answering questions about IBD and eating upsetting. If you think this will likely be true for you, please don't take part.

Where can I obtain further support?

If you feel participating in this research has caused distress, or identified a problem you were not previously aware of, you might wish to speak with your GP about what further support could be helpful, or contact NHS 111, by dialling 111 or using https://111.nhs.uk. Alternatively, please talk to those involved in your IBD treatment regarding any difficulties that are identified from participating in this survey.

How will my information be used?

Your answers to the survey will be kept confidential and stored on secure systems. More specifically, the surveys are being run on a platform called Gorilla. Details of Gorilla's security can be found here: https://app.gorilla.sc/gdpr.

Once the survey is complete, your answers will be downloaded from this software to a secure university filespace and at the end of the study they will be deleted from Gorilla.
The survey will not ask for your name, date of birth or address. However, if you wish to be entered into the prize draw, complete the follow up part of the research or receive a copy of the study's findings, we will need your email address. At the end of the research, your email will be removed from the data file.

Once the prize draw is complete and after we have emailed a summary of the study's findings to all the participants who choose to receive this, we will delete all the email addresses, making the data completely anonymous.

You can ask for your answers to be withdrawn from the study for up to 2 weeks after submitting your answers online. After this time, data analysis will begin and you will not be able to withdraw. However, we will only be able to withdraw your answers if we can identify them through your email address.

If you choose not to provide an email address, your responses cannot be withdrawn after submission.

This research is due to be completed by April 2024 and may be published in an academic journal.

Any reports or publications that we produce will only include anonymous findings, averaged across participants. We will keep your anonymous survey answers for 10 years after the study is complete.

For more information about data protection, please see the University's research privacy notice: https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx This privacy notice explains your rights and the legal basis on which we process research data. It also provides contact details in case you have any questions or complaints about how we handle your data.

What if I have any questions, feedback and complaints?

If you have any questions or feedback about the study, please contact the researcher team using [redacted]. This project is being supervised by Fergal Jones (Research Director, [redacted] and Alexa Duff (Clinical Psychologist, [redacted].

If you wish to make a complaint about the study, please either contact the study team using the above email address or Prof. Margie Callanan, Director of Salomons Institute of Applied Psychology, via [redacted]

Appendix P- Participant informed consent form

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

I confirm that I have read and understand the information provided on the previous information page?

- Yes
- No

I understand that my participation is voluntary and that I am free to withdraw at any time while completing the survey and up to two weeks after its completion without giving any reason?

- Yes
- No

I confirm that am aged 18 or older, live in the UK, and have received a diagnosis of either Crohn's disease (CD) or ulcerative colitis (UC) from a doctor?

- Yes
- No

I understand that my data will be kept for up to 10 years after the study is completed and that the anonymous study findings may be published?

- Yes
- No

I agree to take part in this study?

- Yes
- No

Appendix Q - Debrief form

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Debrief Sheet

Thank you for taking part in my research looking at the physical and psychological predictors of avoidant and restrictive eating patterns in individuals living with IBD.

This research is looking at whether IBD related factors (including IBD activity, diagnosis received, age of onset, surgical history, having a stoma, access to support team/hotlines) or psychological factors (including Symptom anxiety, personal control and perceived emotional support) predict the development of Avoidant/Restrictive Food intake disorder (ARFID). ARFID is a form of disordered eating pattern where people cut out or limit certain food types or meals, which can put them at risk of malnutrition. By understanding the physical and psychological predictors of individuals developing this eating pattern, it provides information of area's where physical or psychological support can be offered to prevent the development of this. Therefore, this research hopes to provide insights that can improve the psychological care for those living with IBD and help prevent the development of mental health difficulties.

Within this questionnaire, you were asked questions relating to your eating behaviours. Although this is not being used as a diagnostic tool, it can highlight concerns. If the answers you gave during this questionnaire have raised any concerns regarding your eating behaviours, we recommend you contact your GP regarding this or seek support from healthcare professionals within your IBD team. You can also get support from BEAT, a charity offering support for disordered eating, by using the following details:

Website: https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/helplines/

Contacting from England: Telephone on 0808 801 0677 or email on help@beateatingdisorders.org.uk
Contacting from Scotland: Telephone on 0808 801 0432 or email on Scotlandhelp@beateatingdisorders.org.uk
Contacting from Wales: Telephone on 0808 801 0433 or email on Waleshelp@beateatingdisorders.org.uk

Contacting from Northern Ireland: Telephone on 0808 801 0434 or email on NIhelp@beateatingdisorders.org.uk

If you have any questions regarding the information, please get in touch via email. Additionally, if you wish to withdraw your data, please send an email providing your individual identification code and your data will be deleted. Please note, you do not need to provide any reason for withdrawing.

Researcher: Emma Harriman [email redacted]
Project Supervisors: Fergal Jones and Alexa Duff

Appendix R - Adapted consent form for follow-up data collection

Information

Thank you for registering your interest in completing this online survey again. This helps tell us if the findings from the original data collection remain the same over time.

In this second part, you will be asked to re-complete some of the questionnaires that were presented in the original survey.

If you complete the survey but then want to withdraw your responses, you can do so by emailing [redacted] weeks after you initially completed the online questionnaire. There will be no consequences for you if you choose not to participate or choose to withdraw from the study.

To continue with this survey, please provide the same email address that you gave during the original survey(this allows us to match up your responses).

Next

I confirm that I have received and understand the information sheet originally provided during the initial stage of data collection?

- Yes
- No

I understand that my participation is voluntary and that I am free to withdraw at any time while completing the survey and up to two weeks after its completion without giving any reason?

- Yes
- No

I agree to take part in this follow up survey?

- Yes
- No

Next

Appendix S - Evidence of ethical approval

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Appendix T- Report to feedback to participants

Eating Patterns in Inflammatory Bowel Disease

Dear Participant,

Thank you for taking part in my research which was looking at avoidant and restrictive eating patterns, particularly those associated with Avoidant and Restrictive Food Intake Disorder (ARFID), in individuals living with Inflammatory Bowel Disease (IBD). I am writing to give you a summary of my research and share the results from this with you.

Aims:

- To investigate how common symptoms associated with Avoidant and restrictive food intake disorder (ARFID) are in adults with Inflammatory Bowel Disease (IBD) in the UK.
- To identify factors that may predict levels of ARFID symptoms in this population.

Methods:

Participants took part in an online survey which explored ARFID symptoms, IBD activity, gastrointestinal-specific anxiety, desirability of control and perceived social support. After a period of 6-months, participants were invited to complete these questionnaires again.

Results:

- A total of 164 participants were included in this research.
- The analysis showed that a high proportion of participants (75%) scored as having ARFID symptoms.
- It was found that ARFID symptoms were higher in those identifying as male, compared to females. However, there were no differences in ARFID symptoms between those with Crohn's disease or those with Ulcerative Colitis.

- Certain factors related to IBD, including more active IBD, having a higher number of surgeries, having a stoma, and not having access to IBD support/hotlines, significantly predicted higher ARFID symptoms.
- Psychosocial factors, including a lower ability to tolerate emotional distress and lower levels of perceived social support, significantly predicted ARFID symptoms. However, these factors were not found to predict ARFID over and above the IBD-related factors mentioned above.
- The findings showed that anxiety about gastrointestinal symptoms also significantly predicted ARFID symptoms. This anxiety was found to predict ARFID symptoms over and above the IBD-related factors. This suggests that gastrointestinal-specific anxiety may increase the risk of people developing symptoms of ARFID, regardless of factors associated with their IBD (such as levels of active symptoms, number of surgeries or whether they have a stoma).
- As the response to the follow-up data collection was small (14 participants), full analysis could not be conducted.

Conclusions:

The results from this research suggest that avoidant and restrictive eating patterns may be common in those with IBD. Although it was found that this may be linked to disease related factors, such as more active symptoms or more surgeries, it was also found that having high levels of anxiety around gastrointestinal symptoms may also increase the risk of these eating patterns. Due to this, it is suggested that healthcare services should be aware of, and offer support, for individuals with high levels of this specific anxiety. Future research should explore whether providing support for gastrointestinal anxiety helps with ARFID symptoms an in IBD population. Additionally, future research should focus on continuing to develop the understanding of ARFID, and its risk factors, for those living with IBD.

Thank you again for participating in my research project. I really appreciate the time you have taken to complete my online survey and contribute to this research.

If you have any questions about the research, please contact me using the details below. As this is my final year, I will only have access to this email until October 2024.

Best wishes,

Emma Harriman

Trainee Clinical Psychologist (Salomons Institute of Applied Psychology)

Canterbury Christ Church University

Appendix U - Report to feedback to ethics

Prevalence and Predictors of developing Avoidant and Restrictive Food Intake Disorder in Inflammatory Bowel Disease

Aims:

- To estimate the prevalence of Avoidant and Restrictive Food Intake Disorder (ARFID) in adults with Inflammatory Bowel Disease (IBD) in the UK.
- To identify predictors, including IBD-related factors and psychosocial factors, of ARFID risk in this population.

Methods:

Participants took part in an online survey which was accessible via online Organisation/Charity advertising, support forums on social media and word of mouth. This online survey included questions about participants demographics, ARFID symptoms, IBD activity, gastrointestinal-specific anxiety (visceral sensitivity), desirability of control and perceived social support. Participants were invited to complete these questionnaires again, 6-months after the initial data collection. Descriptive statistics and confidence intervals were used to test the prevalence of ARFID within the sample. Regression analysis was used to examine whether IBD activity, other IBD-related factors (IBD diagnosis, age of diagnosis, number of surgeries, having a stoma, access to IBD support/hotlines) and psychosocial factors (visceral sensitivity, distress tolerance, desirability of control, and perceived social support) were predictive of ARFID symptoms when entered in single models. Hierarchical regression analysis was used to examine whether the above-mentioned psychosocial factors continued to predict ARFID, while controlling for IBD activity and other IBD-related factors.

Results:

- There were 164 adults with IBD included in this research.

- There was a high proportion (75%) of participants scoring above the "cut-off" for ARFID symptoms.
- It was found that those identifying as male scored significantly higher for ARFID symptoms compared to those identifying as females. No differences were found for IBD diagnosis.
- IBD-related factors explained 22% of the variance in ARFID scores, with higher *number of surgeries*, *having a stoma* and not having *access to IBD support/hotlines,* significantly predicting higher ARFID symptoms.
- *IBD activity, distress tolerance, visceral sensitivity* and *perceived social support* were all significant predictors of ARFID when entered in single models.
- When controlling for IBD activity and other IBD-related factors, *visceral sensitivity* remained a significant predictor of ARFID symptoms. *Distress tolerance* and *perceive social support* were no longer significant, whereas *desirability of control* became predictive.
- Due to a low follow-up response rate (14 respondents), full analysis could not be completed. Correlational analysis identified no significant relationships between the change in psychosocial predictors and the change in ARFID scores. However, this may reflect a type II error due to 91.44% attrition rate.

Conclusions:

The results from this research suggest that individuals with IBD may present with a high prevalence of ARFID. As well as factors associated with IBD, including IBD activity, psychosocial factors also appeared to predict ARFID symptoms. In particular, higher gastrointestinal-specific anxiety predicted higher levels of ARFID symptoms, even when controlling for IBD factors. This finding suggests that within healthcare services, staff should be aware of the impact psychosocial factors have on the potential development of ARFID in

those living with IBD. It is also suggested that screening for, and offering psychological interventions/education, to support individuals with gastrointestinal-specific anxiety, may be an important action in managing/preventing the risk of ARFID for this population. These findings may guide future research, including studies evaluating the value of screening and intervention for gastrointestinal-specific anxiety in managing ARFID. It was also identified that future longitudinal research would be valuable to further the understanding of ARFID symptoms in relation to the change in psychosocial and IBD-related factors over time.

Appendix V - Author guidelines for submission to the journal *Inflammatory Bowel Diseases*

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