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PSYCHOLOGICAL ASPECTS OF INFLAMMATORY BOWEL DISEASE

Section A: Which Psychological Constructs Are Associated with Quality of Life in People Living with Inflammatory Bowel Disease?
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Overview of Major Research Project (MRP)

This MRP examines psychological aspects of inflammatory bowel disease (IBD). Whilst both parts of the MRP focus on IBD, Part A covers a different topic to part B due to there being insufficient existing literature on Part B's topic to use for a literature review.

Part A is a systemic literature review exploring which psychological constructs have been reported as associated with quality of life (QOL) in IBD. Findings identify potentially modifiable factors in this relationship that may benefit from psychological intervention and indicate a rationale for improving the integration of physical and mental health care approaches within IBD services, towards achieving better systemic patient outcomes.

Part B develops a grounded theory of the interplay between IBD and unhelpful eating behaviours. Data and emergent theory identified aspects of participants eating experiences with scope to benefit from psychologically informed interventions, which may in turn support adaptive eating practices that better meet systemic health needs.

Overall, MRP findings tentatively suggest a rationale for increasing psychological support within IBD services, with a view to improving patient health outcomes.

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PART A

Which Psychological Constructs Are Associated with Quality of Life in People Living with Inflammatory Bowel Disease?

Contents

Abstract

Background: Patients with inflammatory bowel disease (IBD) are known to have a poorer quality of life (QoL). However, there has been little research into which psychological constructs are associated with QoL amongst people living with IBD. This is important, since psychological constructs may represent potentially modifiable factors for improving patient outcomes.

Methodology: A systematic search of Embase, Psychinfo, Cinahl and Assia was conducted to find studies that had tested the association between QoL and psychological constructs in IBD samples. Studies were screened according to inclusion criteria.

Results: 11 Studies were identified, all of cross-sectional design. Illness Perceptions (IPs), Maladaptive Coping, Meaning in life, Resilience, Self-efficacy, sense of coherence, body appreciation, neuroticism and defence mechanisms were reported to be significantly associated with quality of life. IPs and Coping were most widely investigated, whilst some constructs were only examined by one study. Limitations of respective studies are discussed.

Conclusions: The correlational design of studies reviewed prevented inferences from being drawn about causality. However, findings present a case for future research to further investigate the relationship between psychological constructs and QOL, with a view to exploring potentially targetable areas for intervention within IBD healthcare teams.

Introduction

Background

Inflammatory bowel disease (IBD) is a term representing two main autoimmune conditions which are characterised by chronic inflammation of the gastrointestinal tract – Crohn’s Disease and Ulcerative Colitis (Eliakim et al., 2015). 1 in 250 adults live with the disease (RGCP, 2019). IBD is progressive and people living with it are usually treated via specialist medical teams located in city hospitals, rather than local services. Main symptoms of IBD include persistent diarrhoea, abdominal pain, rectal bleeding, weight loss and fatigue, although there are several more (Bowel Research UK). IBD can be a debilitating condition resulting in the need for lifelong medications, prescriptive diets, fertility implications, emergency hospital admissions and surgical procedures and it can cause life threatening complications (IBD UK, 2021).

Unsurprisingly, there exists a plenitude of empirical research assessing Quality of Life (QOL) amongst people living with IBD. According to the World Health Organisation, “QoL is defined as individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation, 2012). As with other chronic health conditions, within the IBD population quality of life is often assessed using specific ‘health related quality of life’ (HRQOL) outcome measures. Although similar to the broader concept of quality of life, HRQOL tools focus specifically on the effects of illness and the impact of treatment, and is usually assessed across three main domains: psychological, physical and social functioning (Megari, 2013).

Existing Research

Studies examining QOL amongst IBD and other chronic health populations have tended to utilise quantitative methodologies towards examining and reporting prevalence of QOL (Knowles, Simon R. et al., 2018). Some might argue that this majority of quantitative, prevalence-focussed research is not synonymous with the original emphasis of the "individuals' perceptions" in the very definition of Quality of Life – the construct which we aim to better understand through clinical research. However, the historical critique of psychological research for its lack of empiricism is long established and has influenced a majority of objective, statistical and quantitative methodologies in the field (Toulmin & Leary, 1985).

Existing reviews of such studies report that QoL for individuals with IBD is poorer than for healthy individuals (Knowles, Simon R. et al., 2018). A large-scale review examining 466 studies found that this difference held for both mental and physically focussed QoL, and unsurprisingly, that QoL is also poorer during active disease (Knowles, Simon R. et al., 2018). Elsewhere however, a review and meta-analysis reported that only 37% of HRQOL was accounted for by disease activity itself, suggesting that there must be alternative determinants to be explored (van der Have, Mike et al., 2014). Further, they reported that psychological factors (including illness perceptions) were underrepresented amongst included articles and "warrant further research" (van der Have, Mike et al., 2014). The authors stressed the importance of identifying these potentially "modifiable" factors for developing psychological support interventions for this population.

Crucially for clinical psychology practice, whilst numerous studies have reported on the prevalence of QOL and/or psychological *distress* in the IBD population (Knowles, Simon R. et al., 2018), there is a dearth of qualitative information about the reasons, drivers and personal meaning behind trends of poor QOL in people living with IBD (van der Have, Mike et al., 2014).

Theory

Psychological theories present some possible perspectives when considering what might contribute to poor QOL in IBD populations. The Biopsychosocial model is increasingly referred to in physical health care (Knowles, Simon & Mikocka-Walus, 2014) and goes some way to addressing the dichotomy between the drive for objective, empirical data collection and experience, meaning rich information about individual experiences. A biopsychosocial perspective offers a framework from which to consider the individual in their entirety, integrating elements of the biological, psychological and social self (Irtelli & Durbano, 2020). This maps well onto the concept of HRQOL as both emphasise the psychological, physical and social functioning of the individual. This is a psychological approach well suited to integration of the differing perspectives of physical and mental health disciplines within health care (Knowles, Simon & Mikocka-Walus, 2014), such as when considering the interplay between a physical health condition like IBD, and QOL.

Cognitive theories offer a perspective on how the way people think about their experiences of chronic illnesses like IBD have wide reaching effects on their lives as a whole, as are represented by the different aspects of QOL. For example, Leventhal’s self-regulation theory offers a cognitive perspective on how individuals may try to make sense of and cope with chronic illness by forming “common sense beliefs” about their health condition (Petrie et al., 2008) The theory suggests that these beliefs fall into five categories: identity, cause, timeline, consequence and control.

Charmaz and Rosenfield (2010) take this further in their assertion that chronic illnesses like IBD alters sense of identity, including integration of cognitive constructions of the illness, and challenging previously held beliefs about the self. They propound that these changes affect a person's relationships, activity and plans for the future. Given the personal, often embarrassing symptoms arising from IBD and the considerable restrictions and changes these enforce upon individual's ability to function in their lives, it is easy to imagine how such shifts in beliefs about self and illness could influence Quality of Life. Indeed, the biopsychosocial model would remind us that each aspect of a person influences the others, and so a shift in cognition and sense of identity (psychological) would be theorised to impact the social and the physical aspects of the model as well.

Charmaz and Rosenfield (2016) consider how the extent of the disruption of chronic illness to people's daily lives forces changes to identity and sense of self without their choosing: "Learning that one has a chronic illness commonly becomes a pivotal point in a person's life, symbolising an assault on the self" (Charmaz, K., 2016). This perspective offers an insight into the overlap between quality of life and psychological factors like identity, and the importance of these effects in the way people see themselves and their shifting positions in life. These theories present important considerations for psychological therapists working into IBD healthcare teams.

Further, a recent expansion of research into bidirectional gut brain interactions has established links between the effects of inflammation in the gut, and psychological wellbeing (Gracie et al., 2018). Conditions involving chronic inflammation such as IBD are often associated with "…altered cognitive and emotional functions" (Knowles, Simon R. & Mikocka-Walus, 2015), demonstrating how this rapidly expanding field of research further emphasises links between physical conditions like IBD and emotional and cognitive factors as measured in QOL. To date however, most of this research has been positioned within a medical and prevalence-based focus.

Rationale

Whilst the aforementioned theories suggest some potential influencers of QOL in IBD, it is important to examine the empirical status of these theoretical ideas.

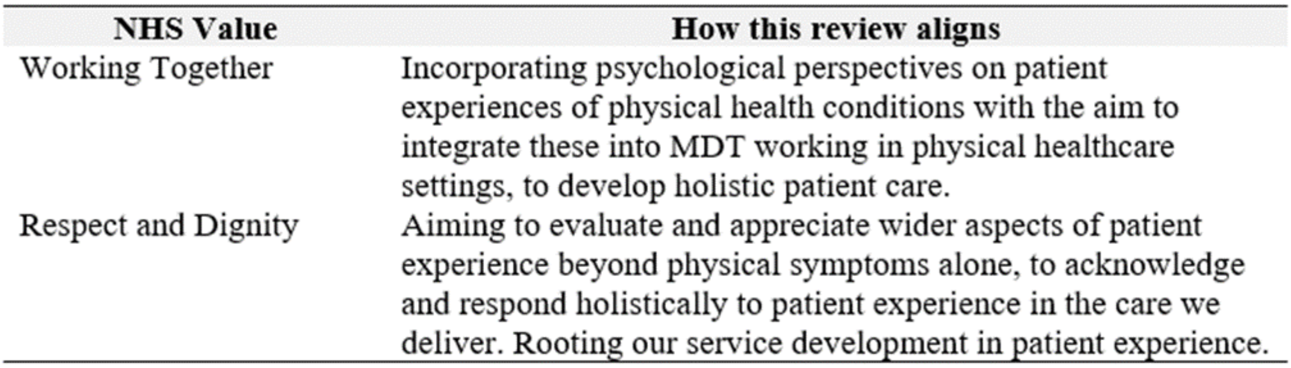
To date, existing literature examining psychological constructs associated with QOL in people living with IBD has not yet been reviewed. Therefore, this narrative review aimed to expand on the existing prevalence-based research base into QOL in IBD by addressing this gap. To do so, the current review investigated which psychological constructs have been identified and found to be associated with QOL amongst existing research studies. Whilst associations in and of themselves are insufficient to demonstrate causation, the current findings may represent a small step towards considering potential influencers of QOL amongst the IBD population.

The review holds the biopsychosocial model in mind, by adopting a holistic perspective on the psychological constructs and meanings experienced by people living with IBD and how these may be associated with their quality of life. As most previous literature has predominantly focussed on biological aspects and considering the finding that ‘potentially modifiable’ psychological aspects of QOL have been under investigated in the IBD population, the current review is specifically positioned within the psychological aspect of the biopsychosocial model. This review therefore offers a contribution to address this imbalance within the biopsychosocial perspective on QOL in individuals with IBD, that can be incorporated into consideration of holistic patient care. In the interests of keeping a clear focus, as well as acknowledging the scope of this review, the ‘social’ domain of the biopsychosocial model was not explored within the current review, but could be helpfully investigated in future research.

This review aligns with NHS' values of 'working together' and 'respect and dignity' (NHS Health Education England) as detailed in table 1, and provides a platform for future intervention research, which in turn may offer a valuable contribution to the development of psychological support services, a scarce but expanding resource amongst gastroenterology physical healthcare teams.

Table 1

How the review aligns with NHS Values



NHS Value	How this review aligns
Working Together	Incorporating psychological perspectives on patient experiences of physical health conditions with the aim to integrate these into MDT working in physical healthcare settings, to develop holistic patient care.
Respect and Dignity	Aiming to evaluate and appreciate wider aspects of patient experience beyond physical symptoms alone, to acknowledge and respond holistically to patient experience in the care we deliver. Rooting our service development in patient experience.

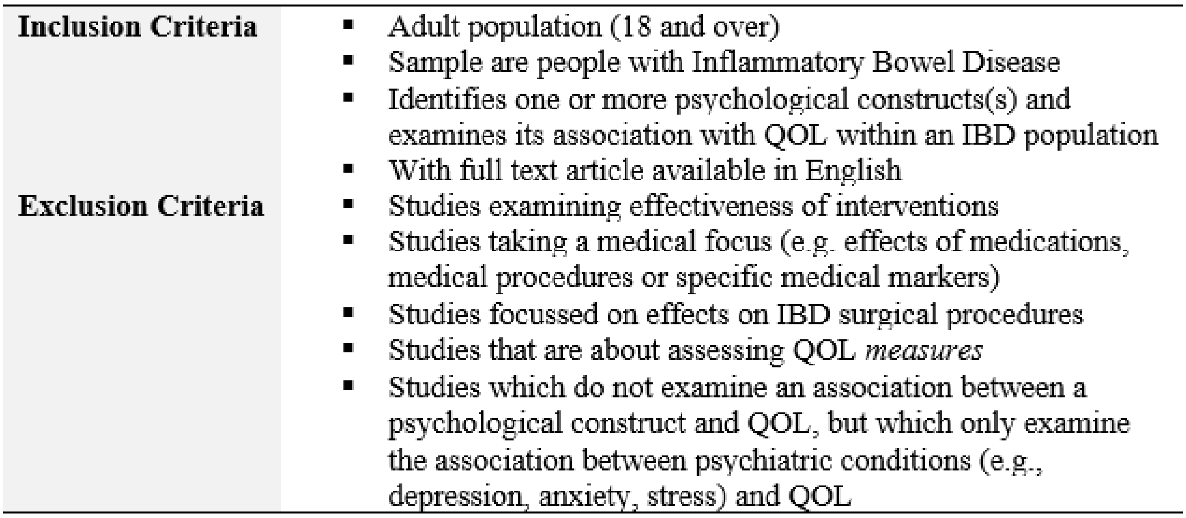
Method

Search Strategy

Preliminary scoping searches informed terms used for the literature search. These were: (("inflammatory bowel disease" or "IBD" or "crohn's disease" or "crohn's disease" OR "ulcerative colitis") and ("quality of life" or "QOL") and ("psychological" or "illness beliefs" or "illness perceptions" or "health beliefs" or "health perceptions" or "psychological construct*" or "psychological mediator*" or "psychological correlate*")).

Four databases were searched on 24/01/23: Embase, PsychINFO, Cinahl and ASSIA. No date limits were applied. Titles and abstracts were screened to determine whether studies were relevant, and inclusion/Exclusion Criteria were applied (Table 2).

Table 2
Inclusion and Exclusion criteria for studies included in the review



Inclusion Criteria	▪ Adult population (18 and over) ▪ Sample are people with Inflammatory Bowel Disease ▪ Identifies one or more psychological constructs(s) and examines its association with QOL within an IBD population ▪ With full text article available in English
Exclusion Criteria	▪ Studies examining effectiveness of interventions ▪ Studies taking a medical focus (e.g. effects of medications, medical procedures or specific medical markers) ▪ Studies focussed on effects on IBD surgical procedures ▪ Studies that are about assessing QOL *measures* ▪ Studies which do not examine an association between a psychological construct and QOL, but which only examine the association between psychiatric conditions (e.g., depression, anxiety, stress) and QOL

Screening

Figure 1 illustrates the number of papers found at each stage of the literature search screening process. As can be seen from figure 1, 11 studies met the inclusion criteria. Study characteristics are summarised in table 3.

Figure 1

PRISMA diagram of literature search stages

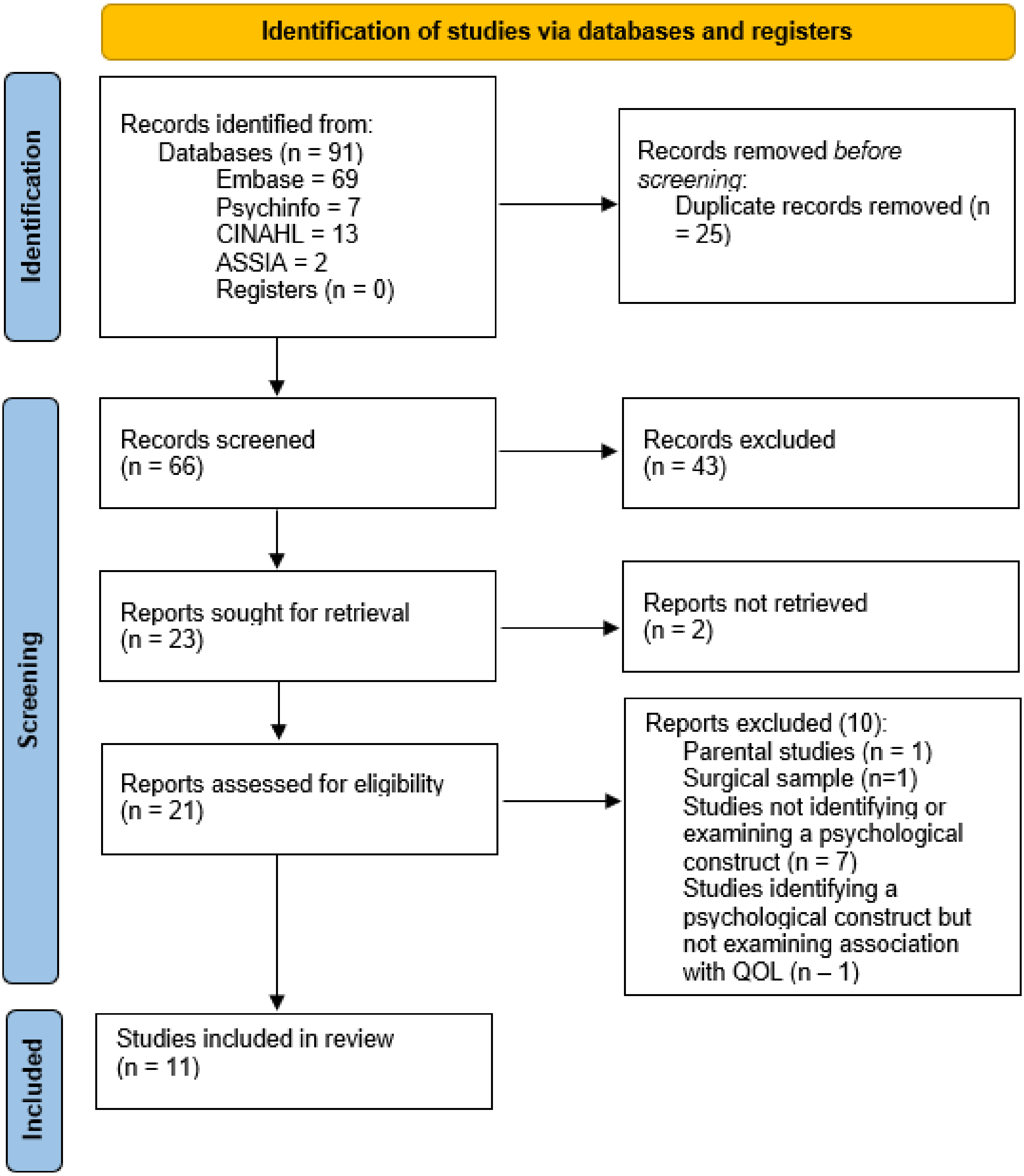


Table 3

Key study characteristics

Study	Study Design, and Location	Sample Description *(Sample size, mean age, gender, ethnicity, mean duration diagnosed with IBD, subtypes of IBD examined)*	Psychological Constructs Identified	Quality of Life (QOL) Outcome Measures	Psychological Construct Outcome Measures	Main Findings about associations with Quality of Life
1	Cross Sectional Melbourne	**261**, 37 years, 198 female, 62 male, 1 did not identify gender, 7.53 years (sd 8.53). Crohn's and Ulcerative Colitis.	Illness perceptions Self-efficacy Coping	Inflammatory Bowel Disease Questionnaire (IBDQ).	New General Self-Efficacy Scale, Carver Brief COPE Scale, Mindful Attention Awareness Scale, Brief Illness Perceptions Questionnaire	Illness Perceptions were significantly associated with QoL. Maladaptive coping and humour as coping were significantly associated with QoL. Self-efficacy was significantly associated with QoL. Adaptive coping was not associated with QOL.
2	Cross Sectional England	**102**, 41.9, (sd 16.57), 67 female, 35 male, 8.8 years (sd 8.68). Crohn's and UC	Illness perceptions	Inflammatory Bowel Disease Questionnaire (IBDQ).	The Revised Illness Perception Questionnaire (IPQR).	Illness perceptions were significantly associated with QoL. With the exception of personal control, which was found not to be associated.
3	Cross Sectional Portugal	**70**, 43.4 years (sd 12.81), 71.4% female, 164 months (sd 128.15) Crohn's and Ulcerative Colitis.	Body appreciation Meaning in life.	The WHO Quality of Life Scale Abbreviated Version.	Meaning in Life Scale. The Body Appreciation Scale-2. The Body Acceptance by Others Scale.	Meaning in life was significantly associated with QoL. Body Appreciation was significantly associated with QoL. *(Caution advised due to potential instability of measure).*

4	Cross Sectional China	**80**, 30% male in quiescent group 31% male in active group. Mean disease duration 2.90 years (active CD) and 4.36 years (inactive CD). Crohn's.	Neuroticism	Inflammatory Bowel Disease Questionnaire (IBDQ).	The Neuroticism subscales from the Eysenck personality inventory. The Buss-Perry aggression questionnaire.	Neuroticism was significantly associated with QoL.
5	Cross Sectional Melbourne	**81**, 35 years, 51.9% female 48.1% male, 13.46 years (SD= 6.35 years). Crohn's and Ulcerative Colitis.	Illness perceptions	World Health Organization QOL Questionnaire	Brief Illness Perceptions Questionnaire.	Illness perceptions were significantly associated with QoL.
6	Cross Sectional Greece	**185**, 47.9. 36.7% female 63.3% male. Median disease duration 8 years. Crohn's and Ulcerative Colitis.	Defence mechanisms	Inflammatory Bowel Disease Questionnaire (IBDQ).	General Health Questionnaire, the Hopkins' Symptoms Distress Checklist, the Defence Style Questionnaire, and the Lifestyle Index.	Defence mechanisms significantly correlated with QOL.
7	Cross Sectional Netherlands	**82**, 42 (sd 14), 63% female 37% male, 12 (median) Crohn's and Ulcerative Colitis.	Illness perceptions Coping styles Neuroticism	The Inflammatory Bowel Disease Questionnaire (IBDQ).	Crohn's disease activity index19 and the Crohn's disease endoscopic index of severity (CDEIS). The Revised Illness Perception Questionnaire (IPQ-R). The Medical Outcomes Survey Short Form 36. The Utrecht Coping List (UCL24).	Illness Perceptions were significantly associated with QoL, with the exception of 'control' related perceptions which were not associated. Maladaptive coping was significantly associated with QoL, but adaptive coping and avoidance were not associated. Neuroticism was significantly associated with QoL.
8	Cross Sectional Spain	**793**, 44.6, 52.8% female, 10.45 years (mean) Crohn's and Ulcerative Colitis.	Coping	Inflammatory Bowel Disease Questionnaire (IBDQ).	The short form 36, COPE	Coping was not associated with QoL.

9	Cross Sectional Brazil	**147**, 45.1, 57.1% female 42.9% male, 65.3% Latin/mixed race, 24.5% white, 6.1% Black, 3.4% Asian, 0.7 Indian, 80.5 months Crohn’s and Ulcerative Colitis.	Sense of coherence	HRQOL and WHOQOL-Brief.	Antoskvsky's SOC scale.	Sense of coherence construct was significantly associated with QoL.
10	Cross Sectional Shanghai	**159** Crohn’s.	Illness Perceptions Maladaptive coping	The inflammatory bowel disease questionnaire (IBDQ).	The Brief Illness Perceptions Questionnaire. The brief Coping Operations Preference Enquiry.	Illness perceptions were significantly associated with QoL. Maladaptive Coping was significantly associated with QoL, but problem and emotion focused coping were not.
11	Cross Sectional New York	**229**, (mean age unavailable) 53% female, 7.22 years Crohn’s and Ulcerative Colitis.	Psychological resilience	NIH PROMIS Global Health	The Connor Davidson Resilience Scale	Psychological resilience was significantly associated with QoL.

**Gender and ethnicity categories and proportions are reported exactly as stated within individual studies*

***Where demographic data is missing, this reflects an absence of data reported within individual studies*

Quality Rating

Included studies were individually assessed using the JBI critical appraisal tool for cross sectional studies assessment tool (appendix A), which assesses eight domains of research quality (table 4). This tool was chosen as an appropriate assessment tool for cross sectional studies that was straightforward to understand and apply, and because JBI is a well reputed provider of screening tools to effectively scrutinising research methods. The tool was applied by the author, and in cases where there was any ambiguity these were discussed with a second rater in supervision. Points of note arising from this analysis are discussed within relevant sections of the review.

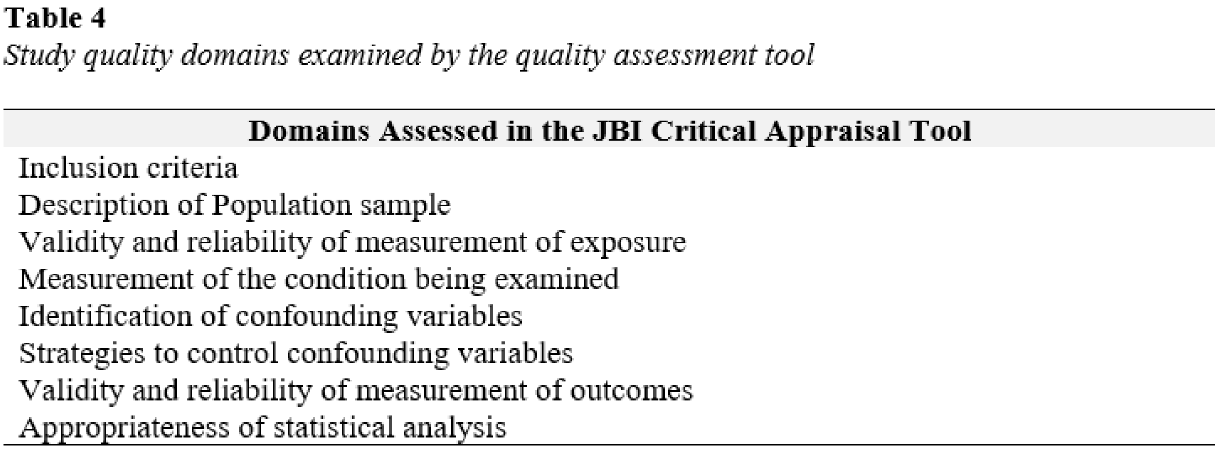


Table 4
Study quality domains examined by the quality assessment tool

Domains Assessed in the JBI Critical Appraisal Tool
Inclusion criteria
Description of Population sample
Validity and reliability of measurement of exposure
Measurement of the condition being examined
Identification of confounding variables
Strategies to control confounding variables
Validity and reliability of measurement of outcomes
Appropriateness of statistical analysis

Data Extraction

Data was extracted from the included articles by the author. Data extracted included the study characteristics (as detailed in Table 3) and all associations whether measured by single or multivariate analysis between the measures of psychological constructs and quality of life.

Review

Overview of Included Studies

Design

All studies were cross-sectional and therefore do not support causal conclusions.

Sample

Sample size ranged from 70 to 793 with a median of 147. Average duration since diagnosis ranged from 2.9 years to 13.7 years with a mean of 8.65 years. Average participant age ranged from 35 to 47.9. Samples were from a variety of countries (Australia, England, Portugal, China, Greece, Netherlands, Spain, Brazil, Shanghai, New York). All samples were patients living with a diagnosis of IBD.

In all but one of the ten studies that reported gender ratio, there were a greater proportion of female participants than other genders. Statistics reporting overall gender ratios of IBD prevalence vary widely amongst the literature (Lungaro et al., 2023; Rustgi et al., 2020), making it hard to evaluate the study sample's representation of the wider IBD population. Two studies (Liu et al., 2013 & Zhang et al., 2016) looked only at one sub type of IBD (Crohn's) whilst the remaining nine included both Crohn's and Ulcerative Colitis.

All but one of the studies (Matos et al., 2021) had sample sizes bigger than 75 and so, according to Cohen (Cohen, 1998) had sufficient statistical power to detect medium correlations of at least .4 (table 5). Study (Iglesias et al., 2014) was powered to detect even a small correlation of .2, whilst study (Matos et al., 2021) had a smaller sample of 70, giving power to detect large correlations of at least .5. Consideration of power is particularly relevant for cases where there are non-significant findings and will be returned to where relevant within the review.

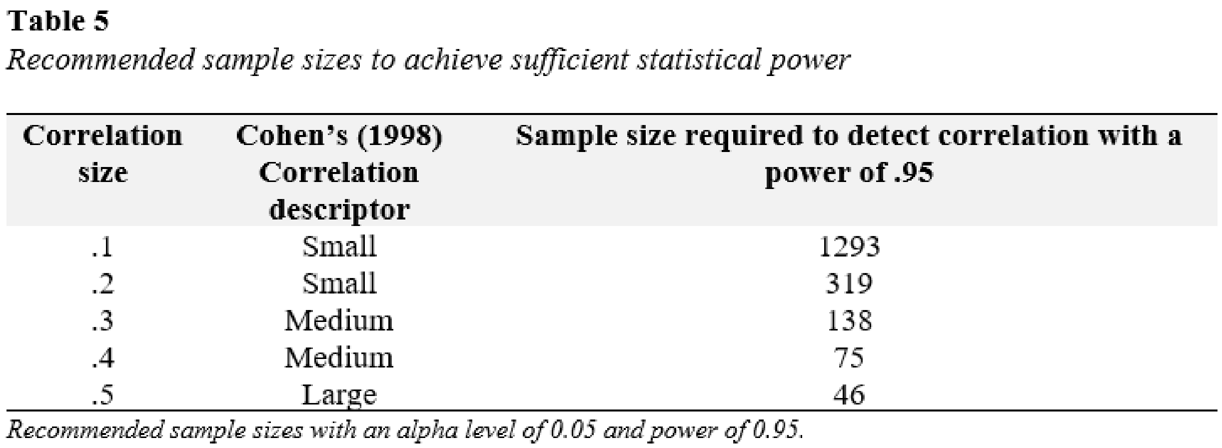


Table 5
Recommended sample sizes to achieve sufficient statistical power

Correlation size	Cohen's (1998) Correlation descriptor	Sample size required to detect correlation with a power of .95
.1	Small	1293
.2	Small	319
.3	Medium	138
.4	Medium	75
.5	Large	46

Recommended sample sizes with an alpha level of 0.05 and power of 0.95.

Outcome Measures

All studies utilised a measure of quality of life, each of which had good validity and reliability (table 6). Details of additional outcome measures concerning identified psychological constructs are included within the relevant subsequent sections. The average number of outcome measures utilised by studies was 5 and ranged between 4 and 9. Only those outcomes relevant to the current review topic are commented on here.

Analysis

All studies appropriately used multivariate analysis, with two studies using structural equation modelling, and nine using multiple regression.

Table 6

Quality of Life Outcome Measure Summary

Measure	Total number of studies using each measure in current review (see table 3 for full details)	Features
The Inflammatory Bowel Disease Questionnaire (IBDQ)	8	A 32-item questionnaire that measures disease related dysfunction specific to IBD across four domains (bowel symptoms, non-bowel related symptoms, social functioning and emotional functioning). Responses are collected via seven-point Likert scale. The questionnaire is available in different cultural variations. Found to be reliable and valid measure of HRQOL in IBD (Pallis et al., 2004)
WHO Quality of Life Scale Abbreviated Version	2	Employs 26 questions across four domains (physical, psychological, social and environmental). Utilises a five-point Likert scale measuring intensity, frequency, evaluation and capacity. The WHOQOL-Bref is a reliable and valid measure of HRQOL when applied in IBD samples (Cessaretti et al., 2010).
WHO Quality of Life Questionnaire	1	Employs eight questions across four domains (psychological, physiological, social and environmental). Participants respond using a five-point Likert scale. Shown to have good psychometric properties and satisfactory convergent and discriminant validity (Schmidt et al., 2006).
NIH PROMIS Global Health Questionnaire	1	A 10-item questionnaire that measures general health related QoL and has been normed for the general population. Good reliability and construct validity. (Cella et al., 2010)

Study Findings

Nine psychological constructs were identified within reviewed studies (table 16) and are now considered in turn. Evaluation of study quality is addressed later in the review.

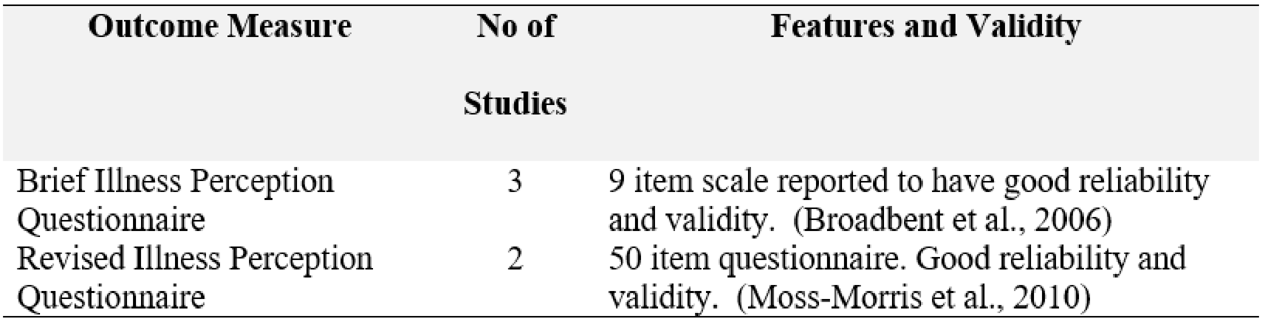
Illness Perceptions

The construct ‘Illness perceptions’ (IP) refers to a person’s cognitive and emotional representations of their illness and has been linked to QOL outcomes. In a 2003 meta review of 45 studies, five cognitive dimensions of illness perceptions were identified: cause, consequences, identity, timeline and controllability (Hagger & Orbell, 2003). The nine item Brief Illness Perceptions Questionnaire (IPQ) is a measure shown to have good validity for measuring IP (Broadbent et al., 2006) which assesses these five cognitive dimensions, as well as emotional representations.

In our current review, five studies (Kantidakis et al., 2021; Rochelle & Fidler, 2013; Tribbick et al., 2017; Van der Have, M. et al., 2013; Zhang et al., 2016) examined IPs and all reported significant associations between IPs and QOL. All studies utilised valid and reliable measures of IPs (table 7). Study sample sizes ranged from 81 to 261 with a mean of 137.

Table 7

Illness Perception Outcome Measures Used



Outcome Measure	No of Studies	Features and Validity
Brief Illness Perception Questionnaire	3	9 item scale reported to have good reliability and validity. (Broadbent et al., 2006)
Revised Illness Perception Questionnaire	2	50 item questionnaire. Good reliability and validity. (Moss-Morris et al., 2010)

Findings concerning the different aspects of IPs examined within individual studies are discussed in turn below.

'Control' – a cognitive dimension of IPs. Four studies in the review examined control related illness perceptions. Of those, two (Tribbick et al., 2017; Zhang et al., 2016) reported significant associations between both *personal* and *treatment* control, and QOL (Tribbick et al., 2017; Zhang et al., 2016). Patients who perceived themselves to have little *personal* control (higher scores) over their IBD had poorer QOL. In terms of *treatment* control, those with stronger beliefs in the efficacy of medication for controlling illness (higher scores) had better QOL. Another study (Rochelle & Fidler, 2013) corroborated this association between treatment control and QOL, but found no association for personal control, despite being sufficiently powered to detect a correlation had one existed (table 5).

Conversely, one study (Van der Have, M. et al., 2013) reported that perceptions around control were not significantly associated with HRQOL. Like all other (but one) of the studies, this study was sufficiently powered to detect medium correlations of at least .4 (table 5), and so it appears unlikely that this could have been a type two error. Authors speculate that reasons for this finding may be because of a difference in baseline characteristics (i.e. studies using samples that include ileostomy/colostomy patients may be likely to have stronger IPs) and that the IPQ-R has not been validated for use with IBD samples specifically. However, the IPQ-R is a valid and widely used measure in a number of studies examining other chronic illnesses.

In summary, three of four studies reported associations between treatment control and QOL and two of four studies reported associations between personal control and QOL.

Other cognitive dimensions of IPs. Four studies (Rochelle & Fidler, 2013; Tribbick et al., 2017; Van der Have, M. et al., 2013; Zhang et al., 2016) also examined IP domains of 'consequences', 'identity' and 'timeline'. Findings indicated that patients who believed their disease symptoms would last a shorter time (Tribbick et al., 2017) and who had less strong thoughts about its cyclical nature (Van der Have, M. et al., 2013) had higher QOL scores. Patients with poorer IPs around identity and consequences of their illness also had lower QOL.

In summary, all of the studies reported significant associations between the domains of consequences, identity and timeline, and QOL.

Self-Perceived Health. One study (Van der Have, M. et al., 2013) also utilised an additional measure of self-perceived health and found a significant strong association, indicating that those with more positive perceptions about their health experienced better QOL.

Summary of IP findings. Five overall dimensions of IPs were examined (controllability – treatment and personal, consequences, identity, timeline and self-perceived health), all of which were significantly associated with QOL with the exception of *personal* control, which was more ambiguous given that half the studies reported associations and half did not.

Coping

Coping refers to a person’s efforts and approaches to dealing with difficult situations. There are a variety of classifications of coping styles, but the most commonly used groupings are problem focussed (adaptive), emotion focussed (adaptive), and avoidant (maladaptive) coping. Four of our reviewed studies tested associations between coping as a psychological construct and QOL (Iglesias et al., 2014; Kantidakis et al., 2021; Van der Have, M. et al., 2013; Zhang et al., 2016). All utilised validated measures of coping (table 8). Study sample sizes ranged from 82 to 793.

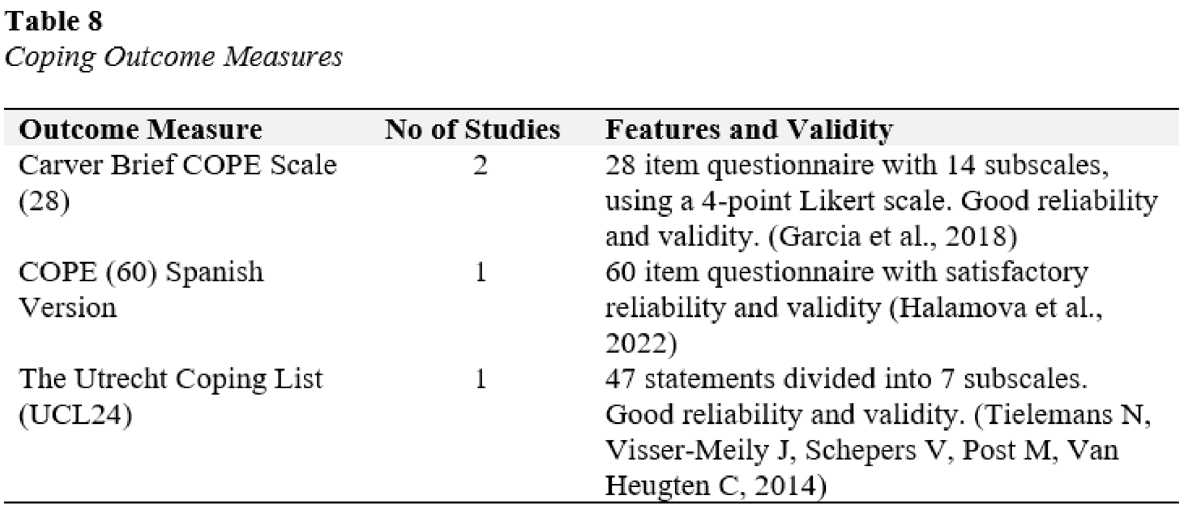


Table 8
Coping Outcome Measures

Outcome Measure	No of Studies	Features and Validity
Carver Brief COPE Scale (28)	2	28 item questionnaire with 14 subscales, using a 4-point Likert scale. Good reliability and validity. (Garcia et al., 2018)
COPE (60) Spanish Version	1	60 item questionnaire with satisfactory reliability and validity (Halamova et al., 2022)
The Utrecht Coping List (UCL24)	1	47 statements divided into 7 subscales. Good reliability and validity. (Tielemans N, Visser-Meily J, Schepers V, Post M, Van Heugten C, 2014)

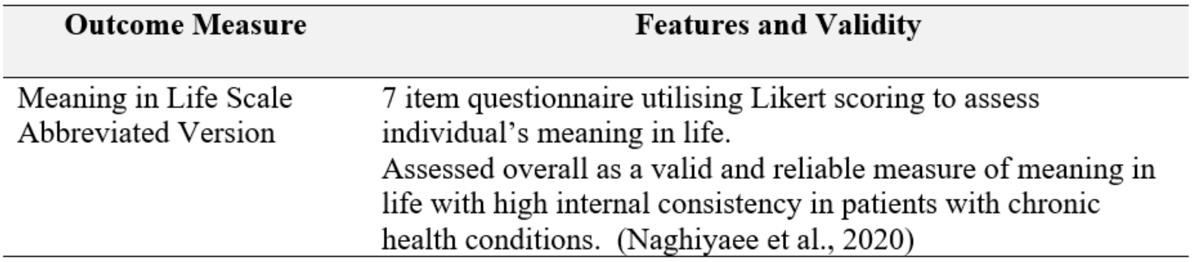
Three of the four studies reported significant negative associations between *maladaptive* coping styles and QOL (Kantidakis et al., 2021; Van der Have, M. et al., 2013; Zhang et al., 2016). However, no associations were found between *adaptive* coping and QOL in any of the studies. As each of these studies were sufficiently powered to detect medium correlations (Table 5) it is unlikely that these were due to type two errors.

One study (Iglesias et al., 2014) found no association with QOL and acknowledged this as an unusual result. Sample size indicated sufficient statistical power to detect even a small correlation within this study (Table 5), indicating it unlikely that the finding resulted from a type two error. Authors suggest that a possible reason for finding no direct association between coping and HRQOL could be the use of non IBD specific measures such as the Brief COPE. None of the studies utilised the more recently created IBD-COPE measure. However, all four studies utilised non-specific coping measures and in the researcher’s opinion this is unlikely to influence a type two error. Further, evaluation of the IBD-COPE’s efficacy is reported as ambiguous (McCombie et al, 2016).

Meaning in Life (ML)

Meaning in life (ML) is described by Guerra, Lancastre, Silva and Teixeira (2017) as the perception of having goals in life and the mission to pursue and develop one's own potentials.

Table 9
Meaning in Life Outcome Measures



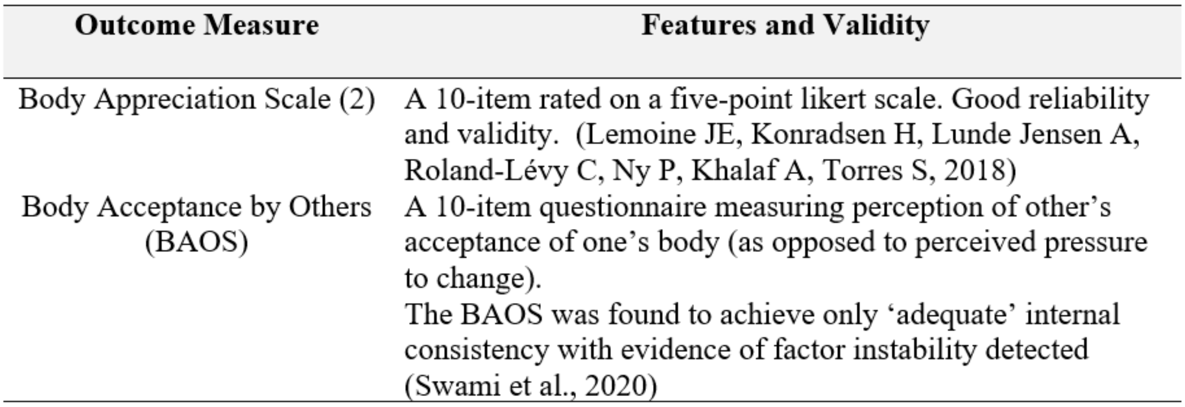
Outcome Measure	Features and Validity
Meaning in Life Scale Abbreviated Version	7 item questionnaire utilising Likert scoring to assess individual's meaning in life. Assessed overall as a valid and reliable measure of meaning in life with high internal consistency in patients with chronic health conditions. (Naghiyaee et al., 2020)

One study (Matos et al., 2021) measured this construct using the valid Meaning in Life Scale, and in support of these findings found a significant positive correlation between meaning in life and all QOL domains. In particular, regression models revealed ML to be a significant predictor of psychological and social domains of QOL. It is possible therefore that having a stronger sense of ML serves as a protective factor against deteriorating QOL. However, this is a purely speculative consideration since correlational studies cannot inform on the direction of the relationship between these two variables.

Body Image

Authors (Matos et al., 2021) outline that their study aimed to measure facets of body image through utilisation of the two scales outlined in table 10, which examine participants self-perceptions of body appreciation and also their perceptions of other's acceptance of the participants' body. The concept of 'body appreciation' represents the ability to maintain positive opinions of and respectful regard of self regardless of changes and unrealistic media ideals, including adopting healthy behaviours and care for one’s body (Matos et al., 2021). Of note, the BAOS was reported to be a less robust measure (table 10). Authors note that negative body image has been associated with low QOL in patients with IBD (Matos et al., 2021).

Table 10
Body Appreciation Outcome Measure



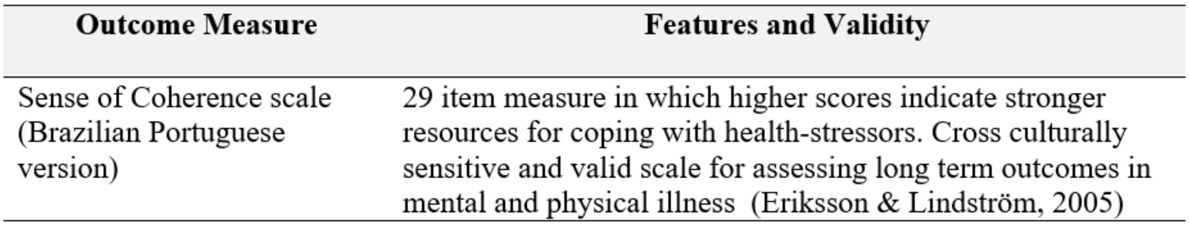
Outcome Measure	Features and Validity
Body Appreciation Scale (2)	A 10-item rated on a five-point likert scale. Good reliability and validity. (Lemoine JE, Konradsen H, Lunde Jensen A, Roland-Lévy C, Ny P, Khalaf A, Torres S, 2018)
Body Acceptance by Others (BAOS)	A 10-item questionnaire measuring perception of other’s acceptance of one’s body (as opposed to perceived pressure to change). The BAOS was found to achieve only ‘adequate’ internal consistency with evidence of factor instability detected (Swami et al., 2020)

Matos et al (2021) found body appreciation to be significantly positively correlated with all QoL domains. Perceived body acceptance by *others* was also positively correlated with physical, social and environmental QoL. Further, regression analysis revealed that body appreciation and body acceptance by others were significant predictors of psychological QOL. Study authors speculate that these results could suggest that acceptance of body changes is an essential factor for developing a healthy post disease identity. This process may involve adaptation and acceptance of parts of the physical self which had not been chosen or may not have been present before diagnosis of IBD.

Sense of Coherence (SOC)

SOC is a theoretical construct concerned with explaining why some people develop psychological illness when others do not, following stressful and distressing life events. Antonovsky's theory of SOC (Unni & Moksnes, 2021) hypothesizes than an individual with a strong SOC maintains and enhances health through effective and flexible coping with stressors, by adopting health enhancing behaviours and avoiding unhealthy behaviours.

Table 11
Sense of Coherence Construct Outcome Measure



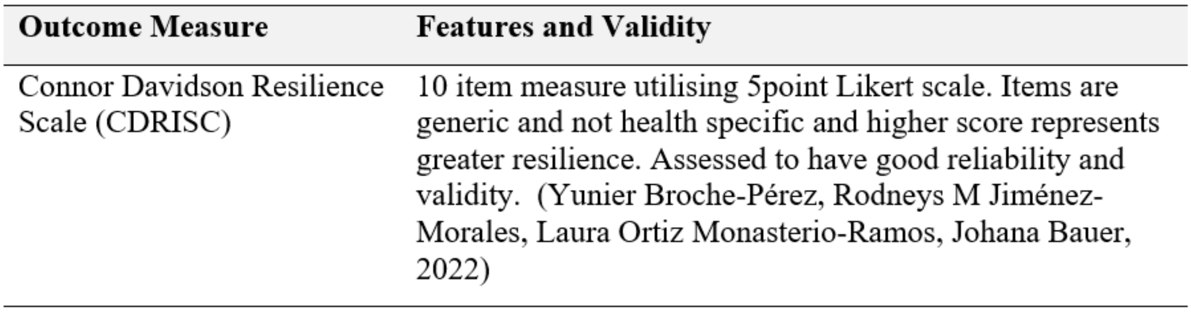
Outcome Measure	Features and Validity
Sense of Coherence scale (Brazilian Portuguese version)	29 item measure in which higher scores indicate stronger resources for coping with health-stressors. Cross culturally sensitive and valid scale for assessing long term outcomes in mental and physical illness (Eriksson & Lindström, 2005)

One study (Freitas et al., 2015) examined this and reported SOC to be significantly correlated with all domains of QOL in patients living with IBD, showing that people with a stronger sense of coherence also had higher QOL.

Psychological Resilience

Resilience is defined as the inherent and modifiable capacity of an individual to cope or recover from adversity (Iacoviello & Charney, 2014). Resilience is regarded as a modifiable trait that is shown to respond to behavioural interventions (Sehgal et al., 2021).

Table 12
Psychological Resilience Outcome Measure Used



Outcome Measure	Features and Validity
Connor Davidson Resilience Scale (CDRISC)	10 item measure utilising 5point Likert scale. Items are generic and not health specific and higher score represents greater resilience. Assessed to have good reliability and validity. (Yunier Broche-Pérez, Rodneys M Jiménez-Morales, Laura Ortiz Monasterio-Ramos, Johana Bauer, 2022)

One study in this review examined resilience in an IBD population (Sehgal et al., 2021) and found a significant and positive association between high resilience and better QoL for all patients with IBD. Authors note that whilst this was the first study to examine resilience in an IBD population specifically, their findings were consistent with existing literature examining resilience and QOL (Taylor et al., 2018).

Neuroticism

Neuroticism is a term used to refer to a trait disposition towards experiencing negative effects (Widiger & Oltmanns, 2017) and previous research indicates that neurotic patients are more prone to lower QOL (Van der Have, M. et al., 2013).

Supporting these findings, two studies (Liu et al., 2013; Van der Have, M. et al., 2013a) examining neuroticism within IBD both found that neuroticism (Van der Have, M. et al., 2013) was strongly inversely associated with QOL, which was true in both active and quiescent disease (Liu et al., 2013). Each study utilised a different measure (table 13).

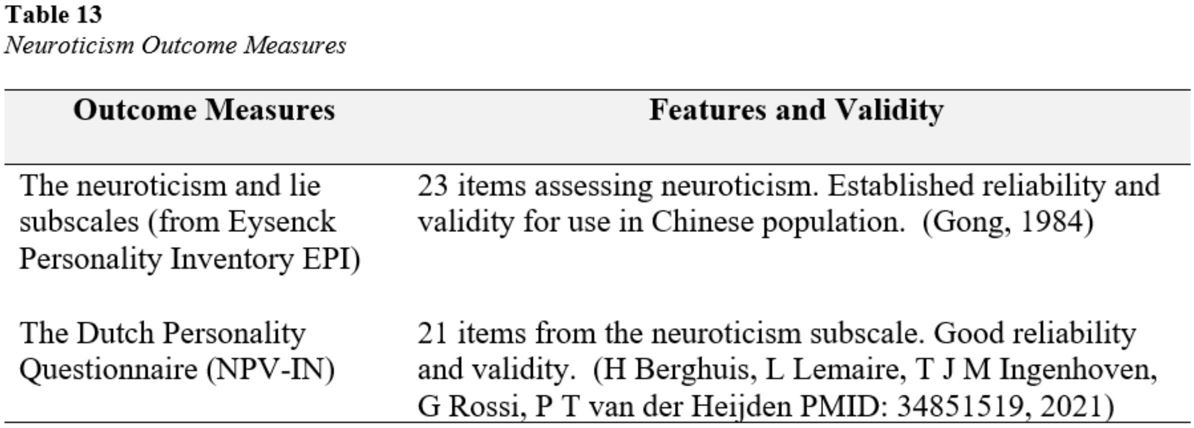


Table 13
Neuroticism Outcome Measures

Outcome Measures	Features and Validity
The neuroticism and lie subscales (from Eysenck Personality Inventory EPI)	23 items assessing neuroticism. Established reliability and validity for use in Chinese population. (Gong, 1984)
The Dutch Personality Questionnaire (NPV-IN)	21 items from the neuroticism subscale. Good reliability and validity. (H Berghuis, L Lemaire, T J M Ingenhoven, G Rossi, P T van der Heijden PMID: 34851519, 2021)

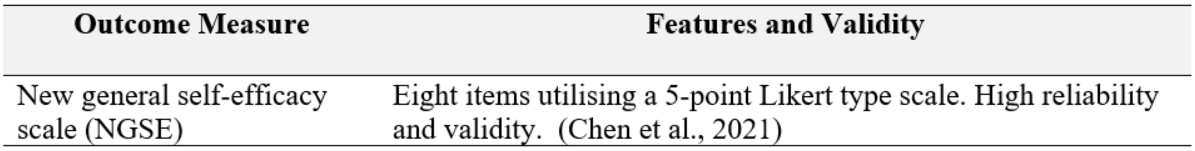
Self-Efficacy

Self-efficacy refers to beliefs in one's capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands

(Kantidakis et al., 2021). Previous research has established self-efficacy to be a strong predictor of health outcomes in chronic illnesses, but not IBD specifically.

One study in the review examined self-efficacy (Kantidakis et al., 2021) and reported it to be significantly positively correlated with QOL.

Table 14
Self-Efficacy Outcome Measure



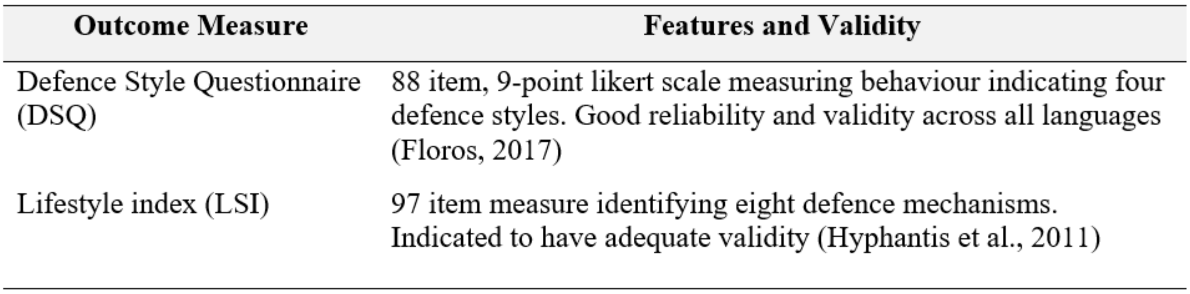
Outcome Measure	Features and Validity
New general self-efficacy scale (NGSE)	Eight items utilising a 5-point Likert type scale. High reliability and validity. (Chen et al., 2021)

Defence mechanisms

Defence mechanisms are defined as unconscious psychological processes implemented to manage internal conflicts and preserve functioning from the interference of disturbing, painful and unacceptable thoughts, feelings and experiences (Perrotta, 2020). Defence mechanisms are generally regarded as stable aspects of personality (Hyphantis et al., 2010).

One study (Hyphantis et al., 2010) utilised two outcome measures (table 15) to examine eleven facets of defence mechanisms, and reported that five of them (maladaptive action, regression, compensation, displacement and reaction formation) were significantly correlated with QoL in an IBD population.

Table 15
Defence mechanisms Outcome



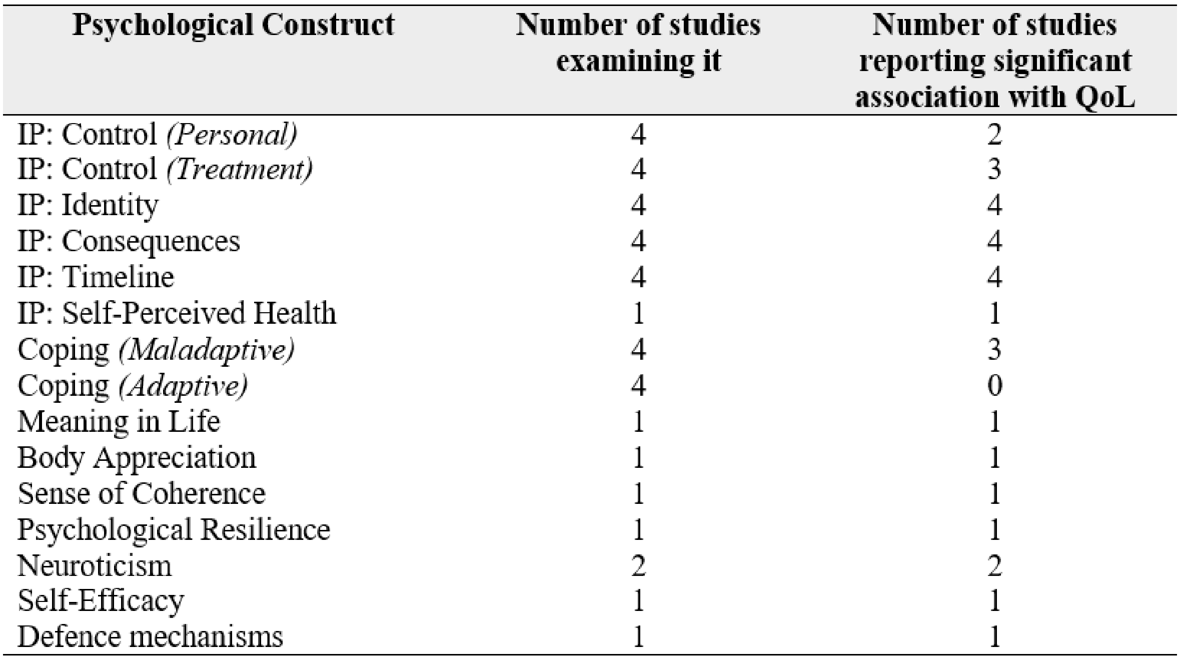
Outcome Measure	Features and Validity
Defence Style Questionnaire (DSQ)	88 item, 9-point likert scale measuring behaviour indicating four defence styles. Good reliability and validity across all languages (Floros, 2017)
Lifestyle index (LSI)	97 item measure identifying eight defence mechanisms. Indicated to have adequate validity (Hyphantis et al., 2011)

Summary

As summarised in table 16, there was evidence of an association between all of the psychological constructs and QOL, with the following exceptions. Associations with personal control were only reported in half of the studies which examined it. For treatment control, one study reported no association. For maladaptive coping, one study reported no association and for adaptive coping, no studies reported an association. It is important to acknowledge that these findings are subject to publication bias, given that studies reporting significant findings are more likely to be available through publishing than any without (Montori et al, 2000). If additional unpublished studies exist reporting no association for these constructs, this could bring the integrity of the current findings into question, given the overall very small number of studies identified.

Table 16

Number of studies examining each psychological construct and reporting an association between construct and QoL



Psychological Construct	Number of studies examining it	Number of studies reporting significant association with QoL
IP: Control *(Personal)*	4	2
IP: Control *(Treatment)*	4	3
IP: Identity	4	4
IP: Consequences	4	4
IP: Timeline	4	4
IP: Self-Perceived Health	1	1
Coping *(Maladaptive)*	4	3
Coping *(Adaptive)*	4	0
Meaning in Life	1	1
Body Appreciation	1	1
Sense of Coherence	1	1
Psychological Resilience	1	1
Neuroticism	2	2
Self-Efficacy	1	1
Defence mechanisms	1	1

Overview of Study Quality

Study quality was assessed using the JBI quality framework for cross sectional studies (Joanna Briggs Institute, 2017). Key critiques are outlined below.

Sample

Considering sample characteristics, most studies reported sample size, mean age, gender ratios and duration of illness. However, notable exceptions were Zhang et al (2016), which reported sample size only, Sehgal et al (2020) which did not report mean participant age and Liu et al (2013) which was missing mean age and gender information. None of the studies reported ethnicity data, which would be helpful in considering relevant cultural factors in relation to the psychological constructs and QOL being examined, and also differences between studies. Gender information was presented in binary categories, suggesting people may not have been offered a full range of options that represent their identity. Further, regarding the female gender bias amongst the studies in this review, consultation of wider literature reporting gender-based prevalence of IBD presents a very mixed and sometimes contrasting picture. A recent review of epidemiology by Crohn's and Colitis UK summarised that "…prevalence only marginally differed between genders." (Crohns and Colitis,), a finding that has been echoed in other reports. However, some studies have reported a higher ratio of females to males in CD samples but no difference in UC samples (Blumenstein & Sonnenberg, 2023), whilst some studies report that in UC gender bias appears after age 45 when men appear to have a higher incidence than women (Rustgi et al., 2020b). Variability between findings makes it difficult to ascertain whether the female bias amongst studies in the current review could be a product of study design or not. However, each of these points outlined here impact on the generalisability of the sample and study findings.

Although the JBI quality assessment tool does not address sample size, incidents of insignificant findings were also evaluated against a consideration of sample size and power sufficiency (table 3). All studies within the review were adequately powered to detect correlations should they exist, minimising the likelihood of type two errors.

Sampling bias is likely to be present in all studies, if we entertain the assumption that patients consenting to participate in research are likely to have a stronger rationale for wanting to engage with the research topic than those who chose not to participate, which may inadvertently influence a bias in baseline characteristics.

Design

A key limitation of each of the studies reviewed was that as they all used a cross-sectional design, we cannot make any inferences about causality from their findings. Further, all studies utilised self-report measures, increasing risk of subjective bias and common method variance.

Considering potential confounding factors that may be relevant to this particular population and topic of interest, variability in disease activity appears salient. It would be reasonable to assume that samples containing a higher proportion of people in IBD remission may represent a healthier cohort and different experiences to a sample with a greater proportion of people facing the burden of active disease. Of the eight studies that measured disease activity (Freitas et al., 2015; Iglesias et al., 2014; Kantidakis et al., 2021; Liu et al., 2013; Tribbick et al., 2017; Van der Have, M. et al., 2013; Zhang et al., 2016), Liu et al (2013) was the only study which divided its participants according to disease activity by assigning to one of two categories – quiescent or active disease. However, regardless of whether or not this distinction was built into the study and although all studies included multivariate analysis and so attempted to control for confounds including illness severity to a degree, this does not eradicate the possibility that there may be other confounding variables present that weren’t controlled for.

Similarly, eight studies examined both Crohn’s and Ulcerative Colitis, whilst three examined only one of the two conditions. Although both are conditions of Inflammatory Bowel Disease and share a lot of commonalities in disease symptoms, there are also differences between them, which may also affect baseline characteristics. This is a consideration to hold in mind when comparing different results found across studies and may be particularly pertinent if the topic were to be investigated using a design allowing for exploration of causality.

Of note, all studies identified within this review were of a quantitative methodology. Through crafting objective, quantitative outcome measures with forced, closed questions, it could be said that we are constructing our own knowledge, rather than collecting and centring the meaning rich and experiential knowledge of the people we aim to support through research. Some may argue that this privileging of empiricism introduces an inevitable bias into the research findings presented here, potentially bypassing primary sources of information in our quest to understand the human psyche. Conversely, most reliable outcome measures are developed from consideration of people’s experiences, and so the two approaches might be viewed as complementary contributors to the evidence base. It is anticipated therefore that the contribution of a qualitative investigation into this topic may complement the quantitative majority of findings in the existing research base.

Outcomes

In relation to measures used for psychological constructs, the Body Acceptance by Others scale (Swami et al., 2020) was found to be less robust as a reliable measure, achieving ‘adequate’ internal consistency with evidence of factor structure instability. Of note, despite being sufficiently powered, this study (Matos et al., 2021) also had the smallest sample size (70) of all studies reviewed. As instability of measures carries the potential to increase risk of a type two error, this suggests that findings of Matos et al (2021) that Body acceptance by others was a predictor of physical QOL may need to be regarded with caution.

All other measures had good validity and reliability. However, The IPQ-R and The Brief COPE have not been validated for use specifically with IBD populations.

Kantidakis et al (2021) noted a significant limitation in identifying an error in its illness perception coding, making it unsuitable for comparison to studies which used the correct full scale.

Data Analysis

The use of multivariate analysis in all studies suitably addresses the possibility of collinearity when testing associations between multiple variables. However, a limitation of multivariate analysis can be the risk of type 1 errors, in which the null hypothesis is rejected when a significant effect is not actually present. Risk of type 1 error may be more relevant for study Kantidakis et al (2021), which analysed 9 different outcome measures.

Rochelle & Fidler (2013) did not report on any study limitations at all, which seems a significant omission given, that all studies carry limitations.

Discussion

In interpreting the findings of the current review, it is important to hold in mind that we cannot infer causality from correlational findings or rule out the presence of extraneous variables within the association. However, the studies reviewed have, as aimed, identified psychological and potentially modifiable constructs shown to be associated with QoL amongst IBD populations.

The most widely investigated construct was illness perceptions (IPs), and the finding that IPs were associated with QoL appeared robust since it was replicated in all five studies that examined it. Results seemed to support Leventhal's self-regulation theory, with all five cognitive dimensions of illness perceptions being associated with QoL. Of note, the categorisation of these findings reflects the level and method of measurement within the outcome measures implemented, which themselves align with Leventhal's theory by breaking IPs down into control, consequences, identity, timeline and cause.

Compared to IPs, there were slightly fewer studies examining the construct of coping styles (table 16), and a greater number of different outcome measures used to measure it. A particularly interesting outcome was the lack of association between *adaptive* coping and QOL, as anecdotally, one might expect more adaptive coping to associate with better QOL. It is possible that differences in measurement or categorisation of the construct across a small number of studies (four) could have influenced these findings, and so the findings may benefit from repeated testing with more commonality of outcomes. Nonetheless, the maladaptive coping styles represent a construct that could be appropriately targeted in psychological intervention, and thus pose a consideration for clinical implications of this research.

The constructs of meaning in life, sense of coherence, resilience and self-efficacy were each positively associated with QoL and appear to represent a 'positive psychology' group of traits. From this perspective, it would be reasonable to hypothesise that such constructs could hold protective value in helping individuals to withstand the "assault on the self" and shifts in cognition and identity brought about by living with a condition like IBD (Charmaz, K., 2016). Again, these psychological concepts represent common and appropriate areas for psychological intervention and may present a rationale for positive, resilience focussed support for people with IBD, in addition to more common problem focussed interventions.

As noted, findings in relation to the construct of body appreciation are to be regarded with caution in light of potential outcome measure instability, especially as it was only examined in one study. Anecdotally however, it would appear reasonable to consider that in the context of a challenging and sometimes embarrassing condition like IBD, to maintain a positive body appreciation may also demand a degree of psychological resilience. Given that relationships to our bodies and image are inherently incorporated into our sense of self concept, Charmaz and Rosenfield’s (2010) ideas about chronic illness’ challenging sense of identity and beliefs about the self appear salient again here.

The consideration of neuroticism as a psychological construct and its negative association with QoL is interesting to consider against research around the gut-brain axis, which considers links between psychological distress and physical inflammatory responses, both of which are known to impact QoL. Further, given that neuroticism is also considered to be a domain of personality, it appears relevant to consider this construct against theory concerning challenges to self-identity in IBD. Personality domains are generally considered relatively stable and enduring across time (Bleidorn et al., 2022; Damian et al., 2019), whilst self-identity is recognised to be continually influenced and challenged by events across the lifespan (Shu-fang, 2000). In the case of living with chronic health conditions like IBD and the extra changes this enforces on people’s behaviours, relationships and perspectives, it is easy to conceptualise how this tension between enduring traits and identity reformation may give rise to a sense of dissonance between the established, taken for granted sense of self and the new, adapting parts of self. Conceivably, navigating these tensions could exacerbate neurotic tendencies, and impact QoL in terms of psychological and social functioning. However, the relationship between neuroticism and QoL is likely to be complex and multifactorial and these speculations are beyond the scope of this review, but may represent considerations for future research and clinical implications.

Limitations

The review is limited by the features of the studies it examines. Main limitations regarding design and quality are that all studies were correlational and cannot prove causation, and all utilised self-report measures. In the case of body image, quality of measure was a further limitation. There are also questions around generalisability of samples, particularly concerning gender and lack of ethnicity monitoring, which would be important to explore.

Studies were based across a variety of countries (table 3). Whilst it is positive that findings were not restricted to one country, in most cases there was only one study per country, making it difficult to infer any patterns or differences in associations that may be particular to certain cultures.

A further limitation of the design of the review itself is that only one person quality rated and extracted data from the studies, due to resourcing limitations of the review forming part of a Clinical Psychology Doctorate. This increases the risk of a subjectivity bias.

Clinical and Research Implications

Research Implications

Overall, significantly more research is needed to replicate the findings of this review and in order to establish the associations reported within it. Several constructs were only tested by one study. Whilst IPs have received relatively more attention amongst existing studies than some other psychological constructs, there is an overall shortfall of research into psychological constructs associated with QOL within the IBD population. This provides a rationale for future studies to investigate the relationship between QOL and psychological constructs further, and studies with designs allowing for investigation of causality would be beneficial.

Considering limitations of the studies reviewed here, future studies would benefit from reporting the ethnic diversity of their samples in order to assess and improve diversity of the populations that research represents. Studies employing longitudinal designs could also usefully capture information about how psychological constructs develop with time since diagnosis, which if relevant, could contribute to a rationale for early intervention within IBD services. Finally, conducting a meta-analysis could contribute a valuable next step in our understanding of quantitative research on this topic.

Further, the addition of qualitative research would add holistic and nuanced perspectives to our current prevalence-based understanding of the psychological constructs identified here. For example, in exploring what may have led patients to develop the types of illness perceptions and coping styles identified, and exploring whether or not there may be scope for services to influence these positively for patients in future. This would also contribute to the current prioritisation for integrating of physical and mental healthcare in NHS services (PPN, 2020).

Lastly, whilst one might hypothesise about the potential influence of illness perceptions upon self-concept, our review did not identify many inquiries into identity specifically. Therefore, there may be scope for future research into how identity challenges arising from living with IBD may or may not intersect with QOL.

Clinical Implications

Patient care in IBD services takes a primarily medical perspective, prioritising disease symptom management and reporting on people's collective experiences in terms of prevalence statistics. This reflects the origins of such services having developed within physical health care settings, and the later (and continued) integration of psychological perspectives into physical health care services. Clinically, the findings in this review could contribute to promoting a more biopsychosocial approach to IBD patient support, in addressing the variety of factors contributing to quality of life, besides disease activity. The findings presented here might be helpfully incorporated into psychologically informed case formulations within physical health multidisciplinary teams when considering patient QOL, contributing to more holistic biopsychosocial perspectives on patient care.

Addressing some of the psychological constructs identified here with a view to improving Quality of Life and supporting patients towards embodying greater self-empowerment, positivity and resilience could conceivably facilitate improved adherence to IBD friendly life choices and adherence to dietary and medical regimes, thereby improving physical health outcomes. For example, supporting self-efficacy, resilience and cognitive beliefs relating to perceived personal control over one's illness *could* facilitate improved empowerment and confidence in adhering to IBD friendly advice. For example, Whelan (2021) previously discussed links between QoL, modifiable psychological factors and nutrient intake.

Beyond implications for psychological therapists alone, dissemination of these findings within the wider MDT with an emphasis on early intervention could facilitate a broader dialogue between patients and non-psychological health professionals about how they are *coping* with their illness, besides consideration of disease markers. Findings from this review present a case for developing assessment of coping methods and illness perceptions by *all* staff during clinic visits. Consideration of how psychological factors might be recognised and addressed within routine clinic appointments would be a step towards improving integrated health care. In considering a useful outcome of this review's findings, it may be that development of specific screening pathway for use by non-psychological clinicians within IBD teams could assist in increasing detection and response to some of the potentially modifiable psychological constructs (such as maladaptive coping) identified here.

Each of the psychological constructs identified within this review could be regarded as potentially modifiable targets for psychological therapy, a scant but expanding resource within gastroenterology teams. Whilst further research is required to establish the relationships reported in this review, these findings could contribute to decisions around development and provision of evidence-based psychological treatment pathways for patients in IBD services.

Several of the findings in this review support existing and well-established psychological theories previously referenced such as Leventhal's self-regulation theory and Charmaz and Rosenfield's work on cognitive constructions of illness. In practice, in considering less helpful illness perceptions which may be impacting on patient's QOL, cognitive behavioural therapy is an evidence based psychological approach widely used within the NHS to support re-evaluation and re-framing of biased thoughts.

Findings also suggested the value of positive psychology perspectives around building resilience and meaning in life (Matos et al., 2021). The finding that Meaning in Life positively correlates with QOL (Matos et al., 2021) presents a rationale for third wave CBT approach, such as Acceptance and Commitment Therapy (ACT), which uses values directed living to help people reconnect with meaningful living, whilst supporting adjustment to (or acceptance of) uninvited events such as diagnosis of a chronic illness such as IBD (Prevedini et al., 2014). From a capacity perspective, if further research were to support the efficacy for ACT in this population, then these kinds of psychological interventions would also be compatible with the time limited therapy models offered within NHS services, and are evidence based for supporting with the psychological difficulties faced by people living with chronic health conditions such as IBD.

Finally, the activation of specific defence mechanisms and their relationship with QoL presents an interesting point for reflection, given that defence mechanisms are largely regarded as relatively stable and unconscious aspects of personality. However, it is not uncommon for psychotherapy to spotlight defences through use of therapeutic interpretations and invite conscious awareness of their potential impact on a person's life. If this finding were replicated in subsequent research then it may represent an additional potential target for therapeutic intervention in striving to improve QoL in the IBD population.

Conclusion

This review investigated which psychological constructs have previously been identified as associated with QOL in people living with Inflammatory Bowel Disease. Findings have been presented within the context of limitations presented by issues around study design and sample characteristics. The review found that of all the psychological constructs identified here, illness perceptions were most commonly examined. Overall, Illness Perceptions, Meaning in Life, Body Appreciation, Sense of coherence, psychological resilience, Neuroticism, self-efficacy and defence mechanisms were shown to be significantly associated with QOL amongst people living with IBD.

Information synthesised in this review offers a contribution to current understanding of this topic and presents a potential platform for further research, which could usefully inform service development plans for psychological support pathways within gastroenterology teams. Future research could helpfully replicate the findings of this review in larger and more diverse samples and perhaps utilising longitudinal designs, to provide further evidence for the constructs identified here. Qualitative investigation would be particularly valuable to expand upon potential nuances implicated in the relationship between psychological constructs and QOL in people living with IBD.

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PART B

A GROUNDED THEORY OF THE INTERPLAY BETWEEN INFLAMMATORY BOWEL DISEASE AND UNHELPFUL EATING BEHAVIOURS

Intended journal for publication: Appetite or Journal of Crohns and Colitis

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Abstract

Background: The prevalence of disordered eating (DE) amongst IBD populations poses implications for disease management and systemic health outcomes. Statistics suggest a prevalence of anxiety and depression in the development of DE in IBD, and psychological theory has implicated identity challenges of chronic illnesses in the development of DE. However, there exists little research exploring motivations and function in the development of DE, and previous studies have highlighted the need to explore potentially modifiable psychological aspects of the interplay between IBD and DE.

Aims: The study aimed to explore the interplay between IBD and DE behaviours.

Methodology: A modified version of social constructivist grounded theory methodology was utilised in qualitative exploration of the topic through individual interviews. Twelve participants who had IBD and self-identified as experiencing unhelpful eating behaviours were recruited from within an NHS Trust site and via social media. Recruitment continued until theoretical saturation was reached. Interviews were analysed and identified themes synthesised to reveal emergent theory.

Results: For people with IBD, a process of navigating control of eating occurs within the contexts of shifting identity and eating as a social practice.

Conclusions: The model extends existing literature and identifies potentially modifiable psychological aspects in the relationship between IBD and DE behaviours. Limitations are discussed and suggestions presented for clinical and research implications.

Introduction

Background

This study relates to Inflammatory bowel disease (IBD), which is a term representing conditions characterised by chronic inflammation of the gastrointestinal tract such as Crohn’s Disease and Ulcerative Colitis. 1 in 250 adults live with this progressive disease (RGCP, 2019) which is also associated with poorer quality of life and wellbeing (Knowles et al., 2018).

There is growing evidence of a link between IBD and disordered eating (DE) (Satherley et al., 2015), but currently no definition or administrable measure of ‘DE behaviours’ as opposed to ‘Eating *Disorders*’ (ED). Anecdotally, DE behaviours in IBD populations manifest broadly and include restrictive eating, binging and purging. However, despite the impact these difficulties can have on this group of patient’s lives and health, because they do not meet diagnostic criteria for an ED, their difficulties are far less researched and they do not have access to the same sources of psychological or practical support for their eating. Some evidence suggests that people following a prescribed diet are more susceptible to developing DE behaviours (Satherley et al., 2015), which is significant given that all patients with IBD are advised to follow some dietary advice. Although common disease management diet therapies are based on principles of short-term exclusion of food groups, research shows that for many people with IBD this translates to long term avoidance of particular foods (Day et al., 2021), with risks of contributing to their existing vulnerability to nutritional deficiencies and exacerbating fatigue (Whelan et al., 2021). Further, it has been reported that less than 20% of patients receive formal dietary advice after diagnosis (Limdi, 2018), and so sources of dietary advice accessed by people looking to manage their IBD varies considerably. As yet there exists no optimal ‘one size fits all’ diet for IBD, leading to lengthy processes of trial and error and unpredictability for people striving to find effective and individualised dietary adaptations. Meanwhile, prolonged periods of symptom flares continue to profoundly impact people's ability to function in their everyday work, leisure and family environments, with potential reactions to food consumption posing a consistent and volatile threat.

Unsurprisingly, food anxiety relating to gastrointestinal symptoms is a considerable factor in the development of unhelpful eating behaviours amongst IBD populations (Day et al., 2021), yet this is a relatively underexplored area in IBD research (Day et al., 2021). Whilst it is known that people with gastrointestinal disorders do generally consume less food than healthy norms, it remains unclear whether food restriction results purely from symptom management, or whether it serves additional purposes such as weight loss or reclaiming control (Satherley et al., 2015). The area of psychogastroenterology is a relatively recent and expanding field of research into how mental health and cognition are linked to gut health (Ganci et al., 2019 & Liang et al, 2018), and is highly relevant to work undertaken within IBD services. Greater understanding of the interplay between IBD and DE is important, since a delayed diagnosis of either condition is likely to lead to worsened prognosis (Ilzarbe et al., 2017).

There is some evidence that depression and anxiety may be key factors in the development of DE in IBD patients (Satherley et al., 2015). It is widely accepted that depression and anxiety trigger symptom relapses amongst IBD patients, and both depression and IBD are impacted by inflammation (Moulton et al., 2019). The direction of this relationship is unclear, though some research suggests that depression is a stronger predictor of ulcerative colitis than in reverse (Gaines et al., 2020). Reported links between IBD, DE, depression and body image (Wabich et al., 2020 & Cushman et al., 2020) raise further questions around possible motivations for DE practices in people living with IBD.

Amongst psychological theory, the role of identity has been implicated in both chronic health condition populations such as IBD (Kelly & Field, 1996) and DE populations (Cruwys et al., 2016; Stein & Corte, 2007). The 'Negotiation Model' (Gerhardt, 1989) is a theoretical model representing a process of identity challenges in less visible chronic illnesses (Kelly^ & Fieldû, 1996) like IBD. It highlights the significance of daily disease management rituals in altering self-identity, are also a feature of DE practices. These theoretical findings raise speculative considerations of a potential impact of identity in the relationship between IBD and DE.

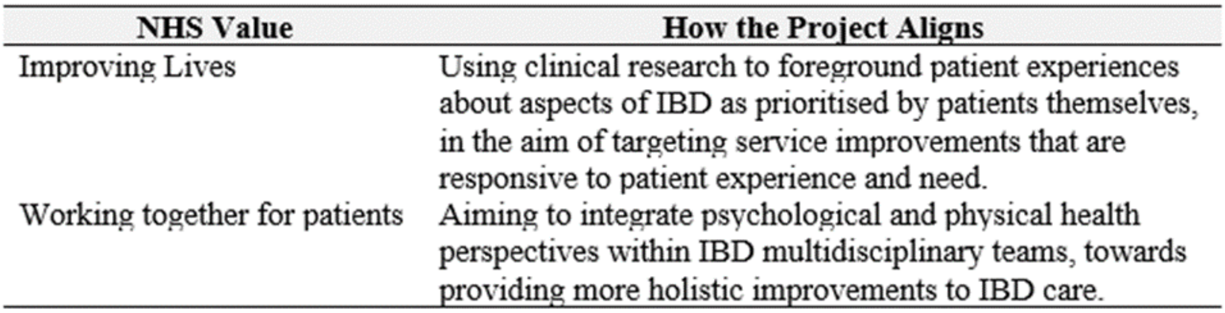
A second theoretical perspective is offered by Polyvagal Theory, which proposes an intersection between mental health and gastrointestinal disorders as mediated by the effects of trauma or distress on the autonomic nervous system (Porges, 2017). Vagus nerve stimulation has been empirically shown to reduce inflammation and thus improve symptoms of both IBD, and anxiety and depression. Considering previously mentioned research around depression and anxiety triggering IBD symptoms and contributing to the development of DE, Polyvagal Theory appears directly relevant to consideration of the interplay between IBD and DE. Overall however, theoretical perspectives *directly* addressing the relationship between IBD and DE prove very hard to come by.

Contribution of the study

Amongst existing literature on the topic of IBD and eating behaviours there are a plethora of quantitative reports around the prevalence of comorbidities between IBD and DE, yet minimal qualitative exploration or psychological theory directly addressing drivers of DE for people with IBD. The need to further explore the role of potentially modifiable psychological factors in the development of eating behaviours that contribute to poorer health outcomes in IBD populations has been previously highlighted (Whelan et al., 2021). Further, in acknowledgement of the already extensive literature base and associated clinical resources dedicated to diagnosable EDs, this study will instead focus on the under researched group of patients living with IBD who also experience DE but do not meet diagnostic criteria for an ED. Therefore, a qualitative exploration and grounded theory (GT) of the nuances between IBD and DE offers a valuable contribution to the literature and for health professionals working within GI teams, aligning with NHS Values (table 1) (NHS Constitution, 2023).

Table 1

NHS Values aligned with the study



NHS Value	How the Project Aligns
Improving Lives	Using clinical research to foreground patient experiences about aspects of IBD as prioritised by patients themselves, in the aim of targeting service improvements that are responsive to patient experience and need.
Working together for patients	Aiming to integrate psychological and physical health perspectives within IBD multidisciplinary teams, towards providing more holistic improvements to IBD care.

Research Aim and Questions

The study aims to develop a GT of the interplay between Inflammatory Bowel Disease and Unhelpful Eating behaviours through exploration of participant experience. The interview schedule (appendix E) addresses research questions to this end, as outlined in table 2.

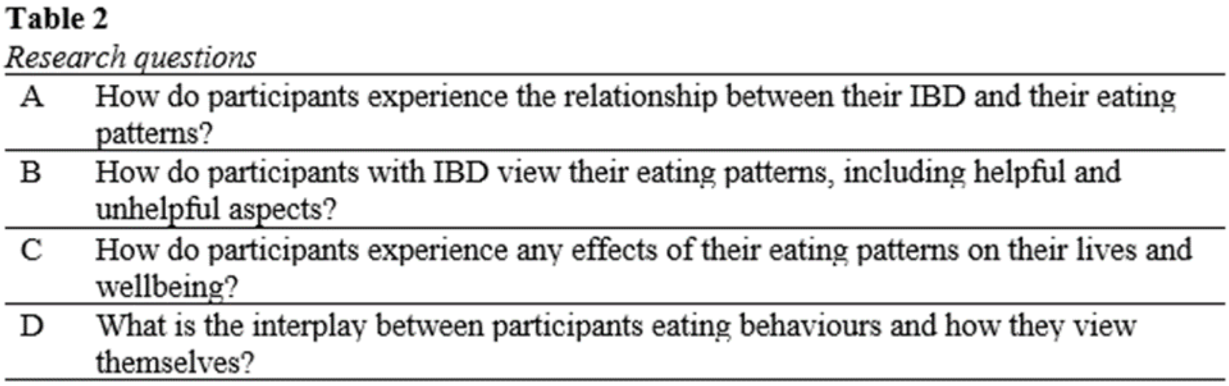


Table 2

Research questions

A	How do participants experience the relationship between their IBD and their eating patterns?
B	How do participants with IBD view their eating patterns, including helpful and unhelpful aspects?
C	How do participants experience any effects of their eating patterns on their lives and wellbeing?
D	What is the interplay between participants eating behaviours and how they view themselves?

Method

Design

The study utilises a modified version of Charmaz's social constructivist GT (Charmaz, 2008). Given the lack of existing theory in this area, the inductive approach of GT was used to generate information from the data and progress beyond identifying themes and towards exploring *how* construction of individual experiences and meaning are formed through interplay between multiple factors involved in living with IBD. Constructivist GT's epistemology lends itself to this research aim in its appreciation of the social construction of phenomena, facilitating a degree of heterogeneity in the exploration of the examined phenomena. Constructivist GT fits with the researchers philosophical positioning by foregrounding process and construction of participants' experiences rather than positioning the researcher as an observer of fixed realities.

Theoretical sampling was applied to the interview schedule and one to one semi-structured interviews were used.

As there is no existing administrable measure of ‘DE (DE) behaviours’ (as opposed to ‘eating *disorders’*) any definition and application of the term ‘DE behaviours’ is not evidence based. For the purpose of this study, the term ‘DE’ refers to experiences of eating which participants identified as being unhelpful for them, and which did not meet DSM5 criteria for eating disorders. The concept of unhelpful eating behaviours was deliberately kept broad, in order to capture a ‘bottom-up’ representation of the issues as participants experienced them, rather than dictating which behaviours should and shouldn’t be included.

The term ‘unhelpful eating behaviours’ was chosen as the most likely option to ground the data in participant experience, using accessible language to invite discussion of which aspects of eating behaviours felt unhelpful to *them*. Possible alternative terms such as ‘detrimental’ or ‘disordered’ eating were discounted in efforts to minimise potentially pathologizing or stigmatizing language, and to avoid confusion with diagnosable ED.

Ethical Considerations

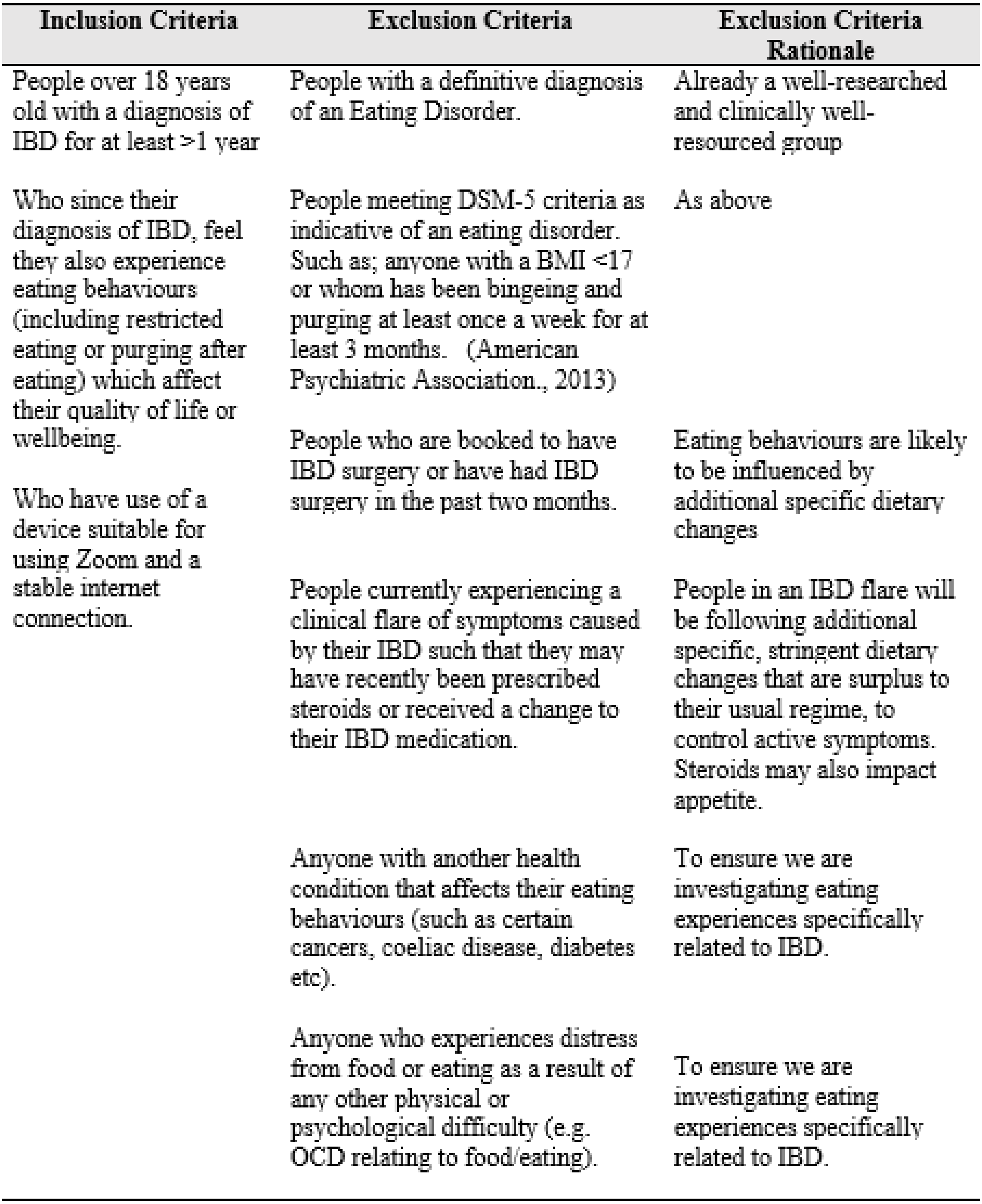
Prior to data collection ethical approval were obtained from the NHS Research ethics committee (Appendix C) and the participating NHS Trust (appendix D). Written informed consent including advice on withdrawal rights and data confidentiality (Appendix J&L) was obtained from participants prior to data collection. The subject matter was not expected to elicit considerable distress. However, care was taken to outline the distinction between the study’s focus on unhelpful eating behaviours and eating *disorders* in the eligibility criteria, to alleviate any potential confusion for participants. After interview participants received a support signposting information sheet and were offered a debrief in which to raise questions or concerns. A summary of study findings was emailed to participants upon study completion (appendix I).

Participant Recruitment

Inclusion and exclusion criteria were applied at the recruitment stage (table 3) and purposive sampling was employed. Purposive sampling is a non-randomised method used to recruit participants with characteristics relevant to the investigated phenomenon (Coolican., 2019). Whilst the study intended to apply theoretical sampling at subsequent recruitment stages, significant delays in recruitment meant this was not possible due to the additional delays that would have occurred in seeking ethical approval for changes to recruitment criteria. This is discussed further within limitations.

Table 3

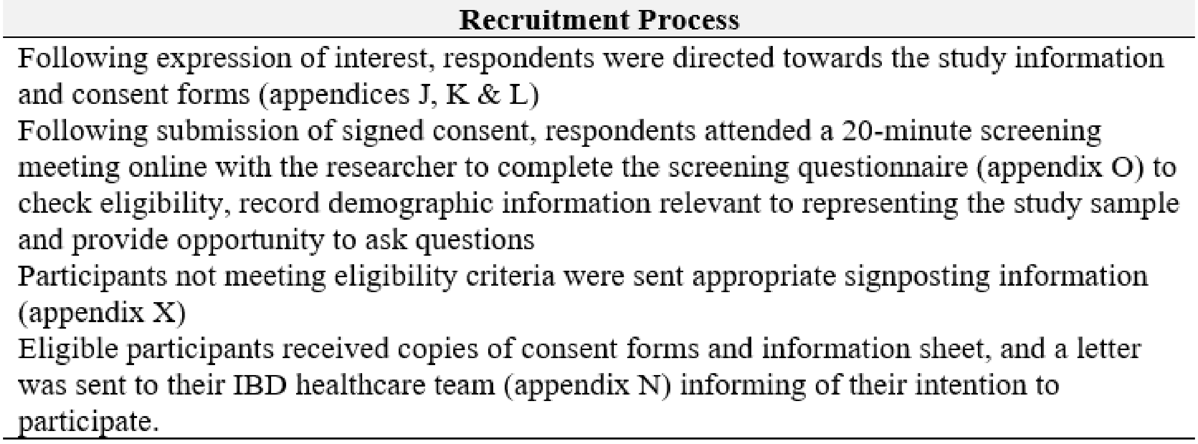
Recruitment criteria



Inclusion Criteria	Exclusion Criteria	Exclusion Criteria Rationale
People over 18 years old with a diagnosis of IBD for at least >1 year	People with a definitive diagnosis of an Eating Disorder.	Already a well-researched and clinically well-resourced group
Who since their diagnosis of IBD, feel they also experience eating behaviours (including restricted eating or purging after eating) which affect their quality of life or wellbeing.	People meeting DSM-5 criteria as indicative of an eating disorder. Such as; anyone with a BMI <17 or whom has been bingeing and purging at least once a week for at least 3 months. (American Psychiatric Association., 2013)	As above
Who have use of a device suitable for using Zoom and a stable internet connection.	People who are booked to have IBD surgery or have had IBD surgery in the past two months.	Eating behaviours are likely to be influenced by additional specific dietary changes
	People currently experiencing a clinical flare of symptoms caused by their IBD such that they may have recently been prescribed steroids or received a change to their IBD medication.	People in an IBD flare will be following additional specific, stringent dietary changes that are surplus to their usual regime, to control active symptoms. Steroids may also impact appetite.
	Anyone with another health condition that affects their eating behaviours (such as certain cancers, coeliac disease, diabetes etc).	To ensure we are investigating eating experiences specifically related to IBD.
	Anyone who experiences distress from food or eating as a result of any other physical or psychological difficulty (e.g. OCD relating to food/eating).	To ensure we are investigating eating experiences specifically related to IBD.

Participants were initially recruited from a gastroenterology clinic within an NHS hospital trust, via posters and leaflets and with clinic staff directing eligible patients towards these materials. There were estimated to be approximately 1,150 patients in the service presenting with unhelpful eating behaviours. However, recruitment progressed slower than expected so ethical approval was gained to broaden recruitment to include social media platforms. Recruitment steps are outlined in Table 4. All participants self-selected for the study and were offered an optional £10 Amazon voucher in thanks.

Table 4
Recruitment steps



Recruitment Process
Following expression of interest, respondents were directed towards the study information and consent forms (appendices J, K & L)
Following submission of signed consent, respondents attended a 20-minute screening meeting online with the researcher to complete the screening questionnaire (appendix O) to check eligibility, record demographic information relevant to representing the study sample and provide opportunity to ask questions
Participants not meeting eligibility criteria were sent appropriate signposting information (appendix X)
Eligible participants received copies of consent forms and information sheet, and a letter was sent to their IBD healthcare team (appendix N) informing of their intention to participate.

From the sample recruited from the NHS, thirteen people expressed an interest. Of those, two were ineligible and five did not respond beyond first contact. Six people proceeded to participation. Of the sample recruited via social media, seventeen people expressed an interest. Of those, five did not respond beyond first contact. Six people proceeded to participation. The remaining six people expressed an interest after recruitment had closed. Nobody dropped out of the study after completing their screening appointment or withdrew their data following participation. Theoretical saturation of the main categories appeared to have been reached by recruitment closing, but is discussed within limitations.

Participant Characteristics

In accordance with GT, recruitment continued until interviews ceased to produce novel information, and data themes became repetitive. Of the twelve participants, half were recruited from NHS clinic and half via social media. All identified as female, aged between 20 and 57. Years since diagnosis ranged between 2 and 33. Overall, participants recruited from social media had longer diagnose duration than those recruited from the NHS. Sexuality and ethnicity were recorded to monitor sample representation. Full participant characteristics are displayed in table 5.

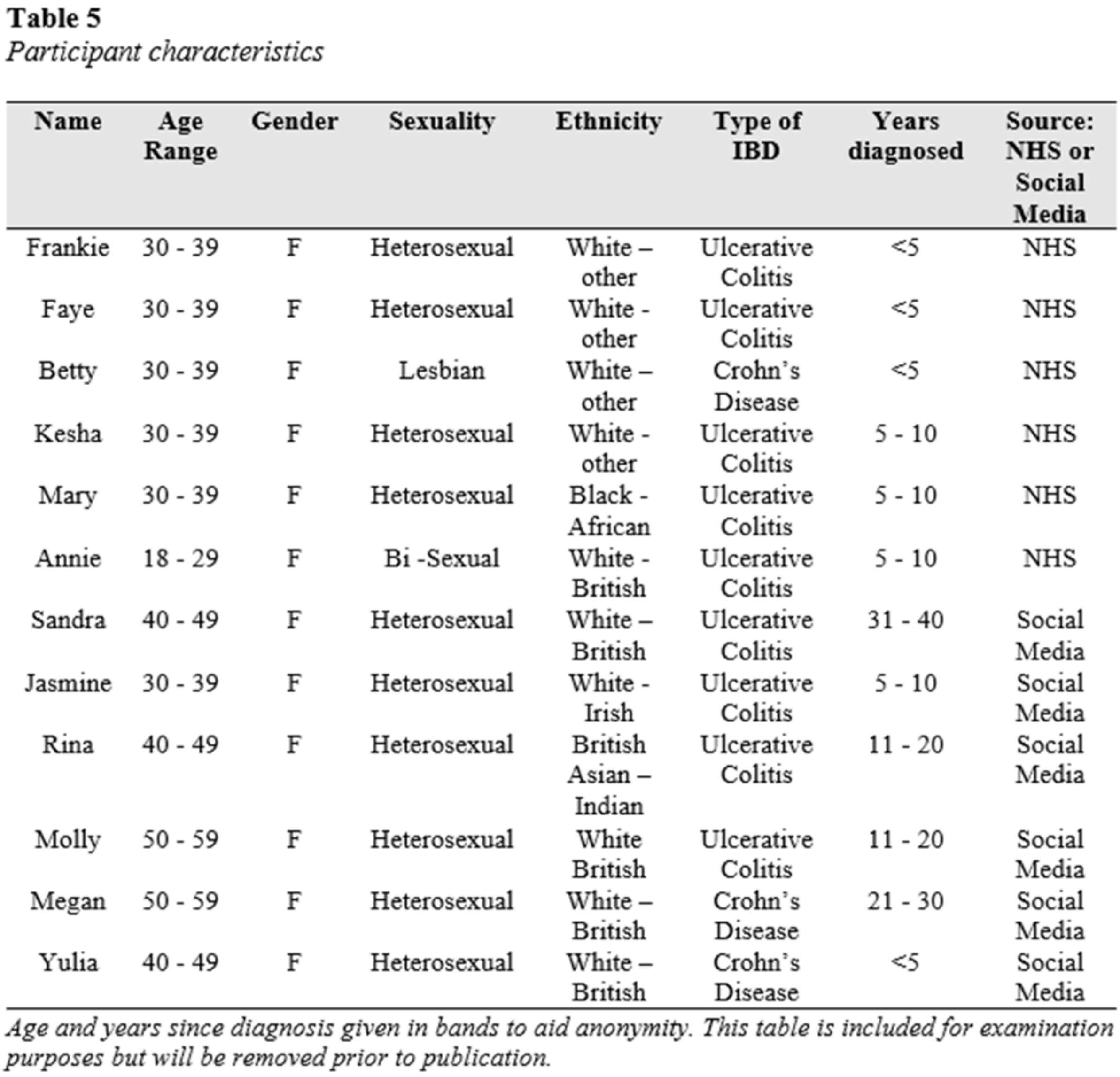


Table 5

Participant characteristics

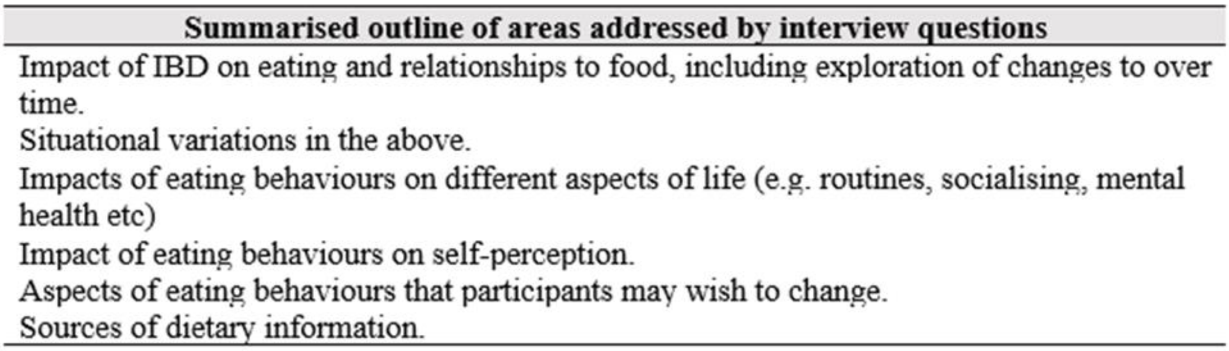
Name	Age Range	Gender	Sexuality	Ethnicity	Type of IBD	Years diagnosed	Source: NHS or Social Media
Frankie	30 - 39	F	Heterosexual	White – other	Ulcerative Colitis	<5	NHS
Faye	30 - 39	F	Heterosexual	White - other	Ulcerative Colitis	<5	NHS
Betty	30 - 39	F	Lesbian	White – other	Crohn's Disease	<5	NHS
Kesha	30 - 39	F	Heterosexual	White - other	Ulcerative Colitis	5 - 10	NHS
Mary	30 - 39	F	Heterosexual	Black - African	Ulcerative Colitis	5 - 10	NHS
Annie	18 - 29	F	Bi -Sexual	White - British	Ulcerative Colitis	5 - 10	NHS
Sandra	40 - 49	F	Heterosexual	White – British	Ulcerative Colitis	31 - 40	Social Media
Jasmine	30 - 39	F	Heterosexual	White - Irish	Ulcerative Colitis	5 - 10	Social Media
Rina	40 - 49	F	Heterosexual	British Asian – Indian	Ulcerative Colitis	11 - 20	Social Media
Molly	50 - 59	F	Heterosexual	White British	Ulcerative Colitis	11 - 20	Social Media
Megan	50 - 59	F	Heterosexual	White – British	Crohn's Disease	21 - 30	Social Media
Yulia	40 - 49	F	Heterosexual	White – British	Crohn's Disease	<5	Social Media

Age and years since diagnosis given in bands to aid anonymity. This table is included for examination purposes but will be removed prior to publication.

Interview

Participants were invited to attend a 60–90 minute online interview to discuss their experiences of the topic. A semi-structured interview schedule using open questions was developed (Appendix E) to explore relevant areas (table 6). The schedule was used flexibly to follow participants' conversational leads, with the order of questions changing in response to the flow of emergent information. Follow-up questions prompted further discussion around areas of relevance. In accordance with GT theoretical sampling principles, the interview schedule was adapted in three phases by adding questions related to data arising in the research process (Appendix E), in order to follow the thread of emerging theory and facilitate 'bottom up' analysis of the research topic.

Table 6
Areas covered by interview schedule



Summarised outline of areas addressed by interview questions
Impact of IBD on eating and relationships to food, including exploration of changes to over time.
Situational variations in the above.
Impacts of eating behaviours on different aspects of life (e.g. routines, socialising, mental health etc)
Impact of eating behaviours on self-perception.
Aspects of eating behaviours that participants may wish to change.
Sources of dietary information.

Data Analysis

Interviews were listened to in full and transcribed, preserving an appreciation of the context and construction of interviews between participant and researcher (Charmaz, 2014). Data was analysed concurrently with interviews in increments of three, adhering to the principles of GT by facilitating immersion in the data and ongoing adaptation of question design in response to emergent theory (Charmaz, 2014). Transcripts were analysed via application of open and focussed codes and conceptual categories. Theoretical memoing was conducted simultaneously to capture researcher reflections and ideas (Urquhart, 2013), retaining a critical awareness of the researcher's influence in the analytical process, and as a means of tracking emergent theory (Charmaz, 2014). The analytical process aimed to stay close the data (Charmaz, 2014). Codes and categories were synthesised to establish the emergent theory (appendix F&S).

Researcher Reflectivity

Contrary to classical GT which suggests the researcher should proceed as a "tabula rasa" (Mills et al., 2006), constructivist GT recognises the influence of researcher knowledge and experience on the research process and outcomes (Charmaz, 2014; Urquhart, 2013) and stresses the need to remain aware of the researcher's theoretical sensitivity (Mills et al., 2006). As such researcher reflexivity was considered throughout the study (appendix G*)*.

Throughout data collection and analysis, the researcher sought to remain perceptive to differences and nuances between individual accounts of living with IBD, to avoid assuming common experiences. This felt particularly pertinent when approaching theoretical saturation. Considering researcher positioning, the researcher was aware of the possibility that their own experience of having irritable bowel syndrome may lead to certain assumptions about the experiences of people living with IBD. In response, particular diligence was paid to checking that the analysis was grounded in the data and using supervision to reflect on this.

Results

Overview

This conceptual model (figure 1) represents a GT of the interplay between IBD and unhelpful eating behaviours. This study found that for people with IBD, a process of navigating control of eating (the core category) occurs within the contexts of shifting identity and eating as a social practice. The context of navigating control is characterised by movement between experiences of loss of control and actions serving to reclaim control. The context of shifting identity relates to identity changes in response to living and eating with IBD. The context of eating as a social practice was present in all aspects of the model. Each of the conceptual categories (table 8) of the model will now be explored in turn.

Figure 1

Conceptual model of the interplay between unhelpful eating and Inflammatory Bowel Disease

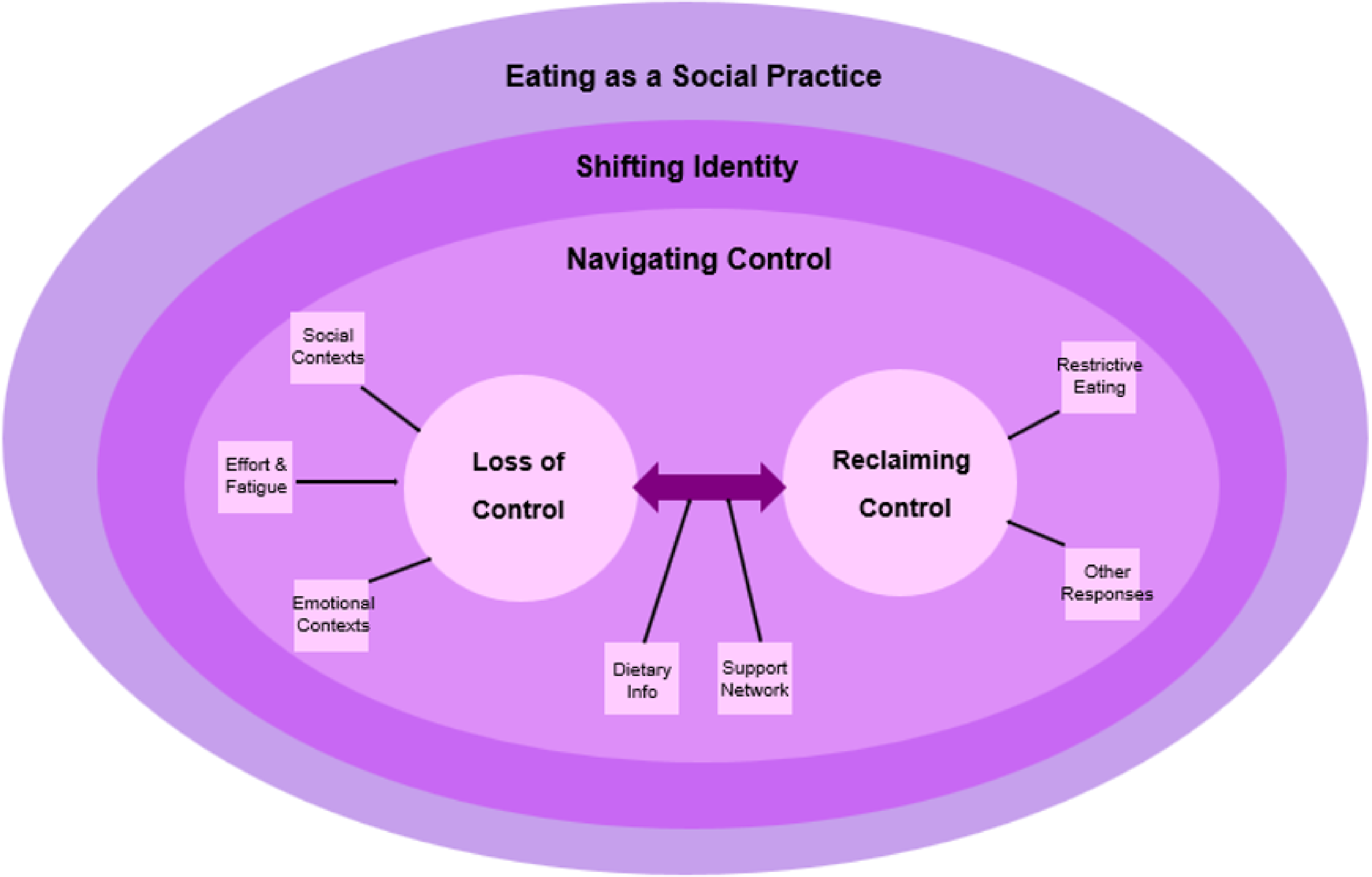
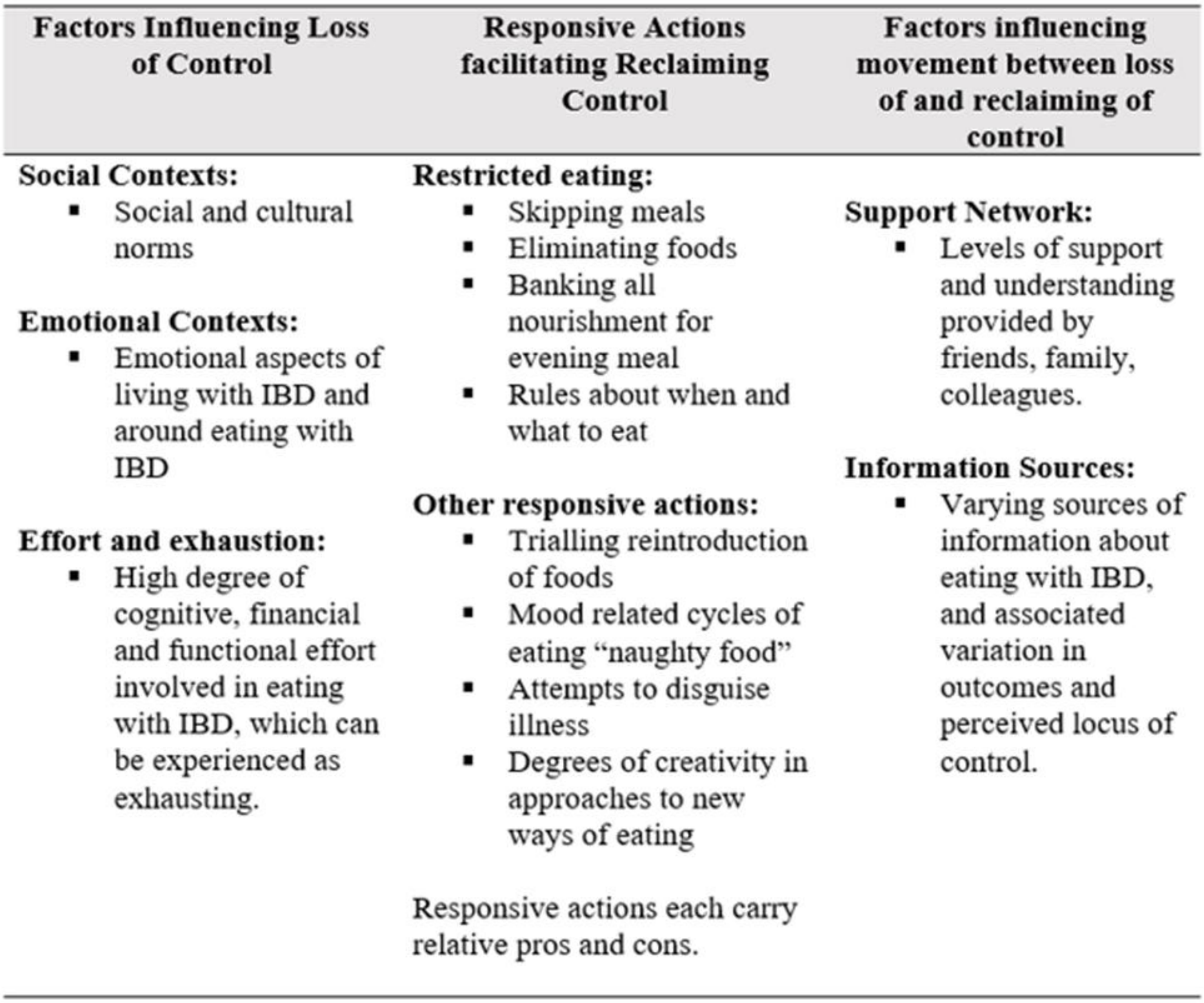


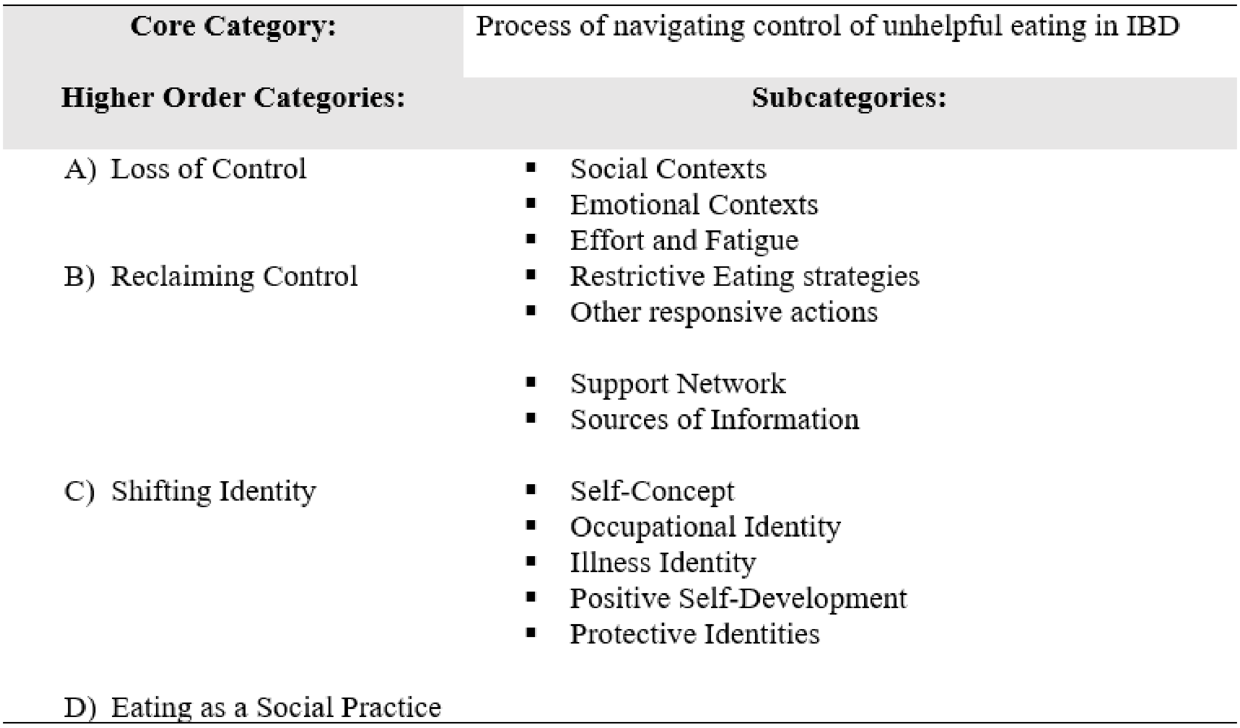
Table 7

Elaboration of subcategories in the process of Navigating Control



Factors Influencing Loss of Control	Responsive Actions facilitating Reclaiming Control	Factors influencing movement between loss of and reclaiming of control
Social Contexts: ▪ Social and cultural norms **Emotional Contexts:** ▪ Emotional aspects of living with IBD and around eating with IBD **Effort and exhaustion:** ▪ High degree of cognitive, financial and functional effort involved in eating with IBD, which can be experienced as exhausting.	**Restricted eating:** ▪ Skipping meals ▪ Eliminating foods ▪ Banking all nourishment for evening meal ▪ Rules about when and what to eat **Other responsive actions:** ▪ Trialling reintroduction of foods ▪ Mood related cycles of eating "naughty food" ▪ Attempts to disguise illness ▪ Degrees of creativity in approaches to new ways of eating Responsive actions each carry relative pros and cons.	**Support Network:** ▪ Levels of support and understanding provided by friends, family, colleagues. **Information Sources:** ▪ Varying sources of information about eating with IBD, and associated variation in outcomes and perceived locus of control.

Table 8
Hierarchy of conceptual categories



Core Category:	Process of navigating control of unhelpful eating in IBD
Higher Order Categories:	**Subcategories:**
A) Loss of Control	Social Contexts Emotional Contexts Effort and Fatigue
B) Reclaiming Control	Restrictive Eating strategies Other responsive actions Support Network Sources of Information
C) Shifting Identity	Self-Concept Occupational Identity Illness Identity Positive Self-Development Protective Identities
D) Eating as a Social Practice	

A. Navigating Control - Loss of control

The theme of ‘loss of control’ whilst eating often attuned to the embodied self: Faye: *“…there is something wrong with me like that I that I don't have a full control over my body.”*. Living with IBD causes unpredictable symptoms and necessitates changes to people’s familiar functioning, thereby impacting on choice and autonomy in everyday life:

> Mary: *“I just didn't feel like I had any control and I just constantly felt like my life was like under threat or like in danger…… It's just like seeing everybody living their lives and I'm struggling to like, make sense of my own and, like, reconcile with like, yeah, I can't, like actively participate in those things anymore.”*

Social contexts. Loss of control was evident in a range of social contexts. Due to difficulties with eating, people's decisions and abilities to take exercise, attend work and social events were restricted. Mary: *"I can't go about my day".* When planning exercise, significant diligence was paid to establishing a "safe time to eat" and preparing IBD friendly snacks. Often these measures made activities feel impractical, and people opted to miss out: Betty: *"I just can't be bothered……It's another thing for me to do, another thing to pay attention to".* Day to day planning and preparation of food was a source of physical, economical and mental fatigue, reducing the element of control people felt they had to make plans with the ease they would have done before. Sometimes, the weight of this effort became a barrier to regular eating: Mary: "*…I feel like I probably just eat like once a day now".* Further, whilst increased working from home made symptom management easier, it also further isolated people from social environments.

Travel and holidaying were discussed as having become less accessible with the need for excessive planning around availability of "safe foods" and toilets. Prior to trips away, extensive pre-planning was given to monitoring and restricting nutritional intake, to minimise the chances of experiencing symptoms whilst away: Betty: *"I'm hyperaware".* Even localised travel involved risk and discomfort, and long-haul travel was often not an option, with some people feeling unable to travel at all. Frankie: *"There's logistical obstacles like time or let's say I wanna travel somewhere and like I have to think. OK, you know what, am I gonna eat? Will I be able to eat?"*

The social contexts people inhabited thereby changed, moving them farther away from pre-established identities. In extreme cases, prolonged bouts of active disease left people isolated and socially deprived, unable to leave home for long periods of time. However, whilst all participants discussed significant difficulties faced around eating out socially, one participant raised the perspective that sometimes, eating in an environment where she was distracted by others and had less control over what and how to eat was actually helpful, as it prevented overthinking, and thereby reduced her physical symptoms:

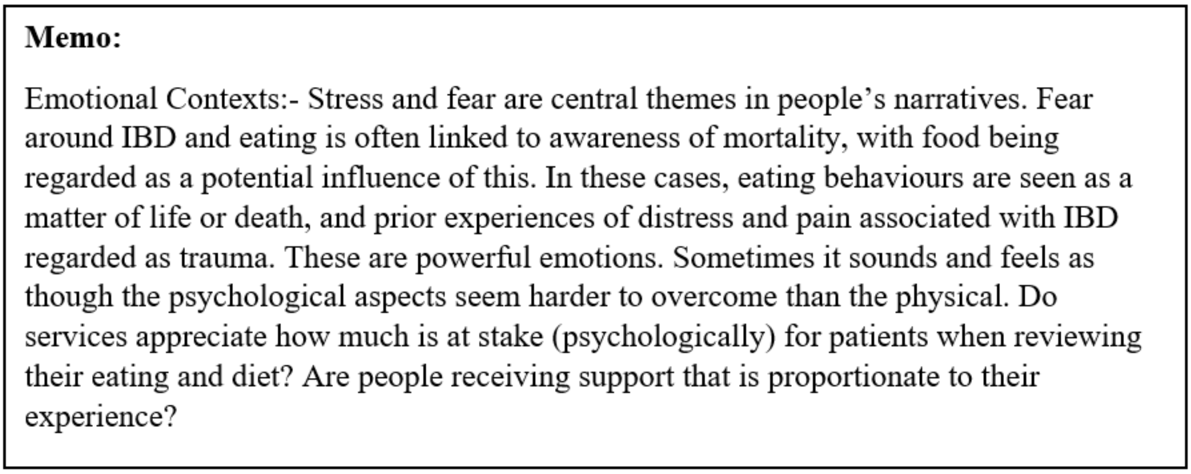
> Rina: *“...sometimes if I end up not having as much control that that can be actually a good thing, because sometimes it is more the mind that's affecting than actually what I'm eating……if I don't pay that much attention, I can eat a lot more variety.”*

Emotional contexts. The emotional impact of IBD upon eating behaviours and disease symptoms was widely discussed. Unwelcome emotional experiences associated with eating appeared to be characterised by a loss of control, due to uncertainty around repercussions of eating, and levels of emotional distress elicited by eating. Stress was identified as a common trigger for gastric symptoms alongside anxiety, panic and depression, and participants observed changes to their self-esteem: Annie: *“I just feel like not good about myself, that I can't really eat properly”.* Loss of control was evident in the sense of IBD enforcing changes to eating, emotions and self-concept. Several participants expressed awareness of links between their physical and mental health, feeling that psychological factors sometimes caused their somatic symptoms rather than food itself: Yulia: *“I know that the food doesn't trigger any problems with it in me, but I do feel effects and I think that's probably due to a certain amount of anxiety”.* Further, a number of participants specifically linked fear and distress with the act of eating: Mary: “*you have had like debilitating anxiety. The intensified fear of like eating and how that's going to impact your symptoms……even like having to eat where I'm like crying because……it's a fear of what's going to happen after I eat”.* There was an acknowledgement of not having struggled with these emotional experiences as their ‘previous’ selves but that eating and living with IBD had enforced these emotional effects and contributed to a sense of loss of control, as day to day emotional resilience significantly impacted how able they felt to go about their daily functioning.

One participant discussed variability in their ability to tolerate foods depending upon their mood whilst consuming it:

Rina: "*…if I don't pay that much attention, I can eat a lot more variety. Whereas…… it's something that you're focusing on and then you can work yourself into a bit of a overthinking kind of situation where you just don't feel like trying too much too quickly.*"

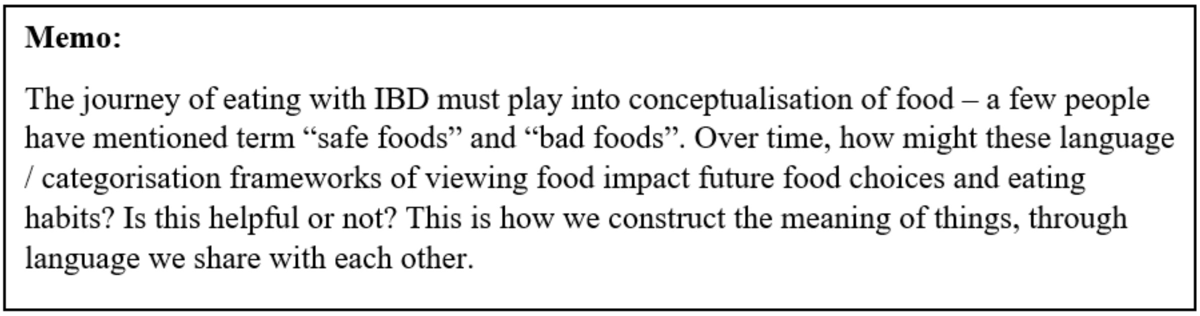
Several people acknowledged a tendency for vicious cycles of eating conceptually "naughty" foods which was usually triggered either by experiencing emotional difficulty, or extended periods of symptom remission bringing a false sense of security: Betty: *"I go into the resentment stage and then I go into self-punishment……So I eat stuff that I know it's just not gonna be OK……I do still eat my feelings".* There appeared to be a mirroring of conceptually uncontrollable somatic symptoms causing uncontrollable emotions, leading to uncontrollable eating patterns. In some cases, people became despondent of the constant effort of adhering to IBD friendly diets but still experiencing flares anyway, leading to a further sense of loss of control.



Memo:

Emotional Contexts:- Stress and fear are central themes in people's narratives. Fear around IBD and eating is often linked to awareness of mortality, with food being regarded as a potential influence of this. In these cases, eating behaviours are seen as a matter of life or death, and prior experiences of distress and pain associated with IBD regarded as trauma. These are powerful emotions. Sometimes it sounds and feels as though the psychological aspects seem harder to overcome than the physical. Do services appreciate how much is at stake (psychologically) for patients when reviewing their eating and diet? Are people receiving support that is proportionate to their experience?

Effort and exhaustion. A common aspect of living with IBD discussed amongst participants was the high level of cognitive and functional effort involved in coping with the disease. Betty: *"why do I have to think three million thoughts before I eat, which is something I need to survive……it's exhausting."*. People spoke of a constant need to be highly organised, with excessive planning required before outings or plans. Sandra: *"…my body's almost trained to be overanalysing and over thinking about what, what, what goes in"*. For example, mealtimes were dictated by meticulous planning around what time of the day one might have access to a toilet. Sometimes, this led to food restriction and/or avoidance.



Memo:

The journey of eating with IBD must play into conceptualisation of food – a few people have mentioned term "safe foods" and "bad foods". Over time, how might these language / categorisation frameworks of viewing food impact future food choices and eating habits? Is this helpful or not? This is how we construct the meaning of things, through language we share with each other.

B. Navigating Control - Reclaiming Control

All participants developed responsive actions to manage eating since developing IBD. Whether adaptive or maladaptive, these responses assisted them in reclaiming some control over their everyday lives, by controlling when and how they ate. All responsive actions involved different forms of boundaried eating, (table 7) most of which were characterised by restrictive eating.

Restrictive eating. Amongst participants, skipping meals was the most commonly reported action used to reclaim daily control. Participants disclosed saving up their daily nutritional intake until the evening meal, since this took place whilst safely at home and without fear of experiencing gastric symptoms in social contexts: Mary: *"But I still like need* *to work to support myself, so I just wouldn't eat. Just kind of trying to eat food in the evening……I essentially I feel like I probably just like once a day now."* One participant also evidenced cognitive strategies that had become somewhat automatic in her daily approach to eating, as she relayed how she'd learnt to coach herself to restrict meals to very small portions and deny extra courses:

Sandra: *"I will then say to myself, well, I'm not actually that hungry and I and I'll eat a small amount and then I'll be like, no, I'm really full. I'm stuffed. I can't eat anymore, which isn't true…… It's a really it's a very sort of in ingrained behaviour. It's so ingrained that it kind of almost happens without thought."*

Elimination of food groups was another common response. Reasons for eliminating particular foods varied, from following NHS dietary advice, trialling advice offered by IBD community forums and responding to reactions to suspected trigger foods particular to the individual.

> Jasmine: *"I think it may be taken that to the extreme, where like there's lots of things I cut out of my diet……there's lots of fruits and vegetables you would have to avoid as well, but I've never actually reached the point where I've put brown bread back on my diet……Again, I cut out like nuts and seeds and never really put them back in, and there's lots of groups and vegetables that sort of fall into that category as well."*

Whilst short term elimination of some foods is commonly advised during periods of disease flare ups, some participants recognised that they were restricting their diet to fewer foods than needed and over prolonged periods due to fear of repercussions of reintroduction.

Megan: *"I'm sure that if I started reintroducing things back into my diet again, it would be better. But psychologically I can't get there, so I avoid it."*. Participants voiced suspicions that their food restrictions were driven more by psychological fear and uncertainty than of actual reactions to foods. However, due to uncertainty, it was difficult to switch between periodic responsive dietary changes and back to a more balanced diet according to disease activity: *Annie: "...I'm allowed to eat them now. But like, I think I still have like a block in my head about all the stuff that I've kind of been restricted on before."*. A cost of restricting foods cited by several participants was reduced enjoyment of food. One participant discussed how the restriction and planning of an IBD friendly diet put her off of eating, and lead her to replace meals with favourite snacks: Rina: *"...if it's all planned, I feel really restricted and usually don't want to eat what I've prepared."*

Several participants used nutritional shakes to varying degrees, with one discussing a long-term meal-replacement regime in which their sole nutritional intake was consumed by Huel drinks. There were strong themes of trial and error as people implemented a variety of different diets, medications and trials, as well as in the phased reintroduction of previously eliminated foods. Kesha: "*I've tried to implement breakfast multiple times and perhaps not in the right moment, so it doesn't work……. I did go vegan for six months and it didn't work for me"*. For some, this process had been repeated over such long periods of time such that it became difficult to establish what the individual's 'norm' was. Frankie: *"...what would it take for this food to be a food I could eat?"*. Reintroduction of previously eliminated foods was a common anxiety trigger, due to variability in dietary advice and unpredictability of consequences. In a situation where disease unpredictability brought so much uncertainty to people's lives, it seemed that reclaiming control by holding on to responsive actions in the longer term posed an attractive prospect.

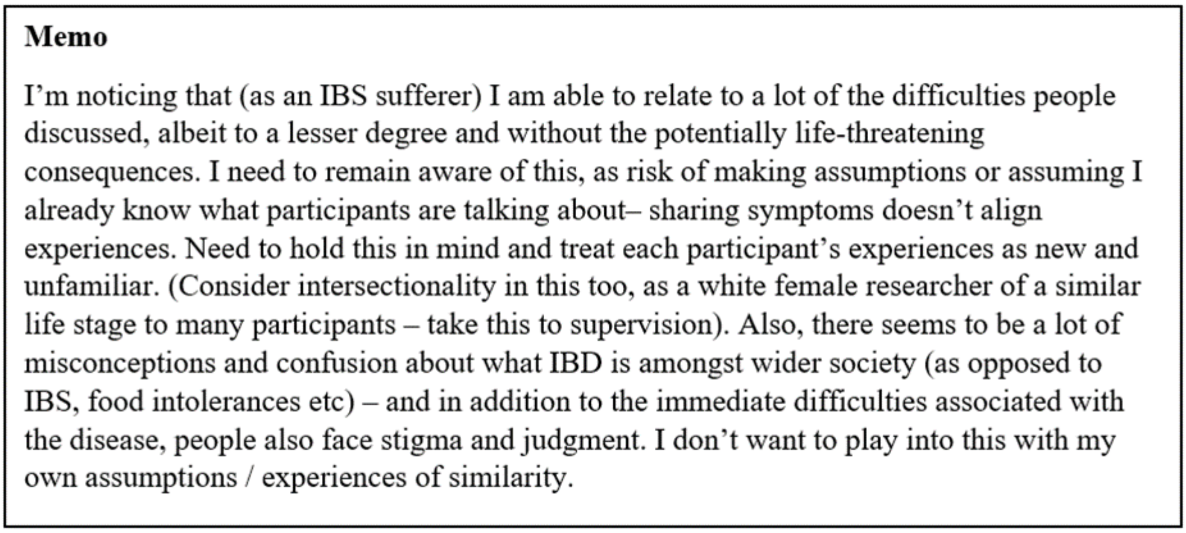
> *Frankie: "…don't know if that'll be months or years that I still always carry huel with me because I don't wanna be hungry and have the like. I don't wanna have the choice between eating something I'm concerned that will make me sick and not eating."*

Consideration of time was influential in the food choices people made. For example, having multiple 'safe' sandwiches in a day was more convenient for work than time intensive preparation of fresh meals. Removing food as a symptom trigger enabled people to attend work, socialise, exercise and take part in family activities with reduced fear of being unwell whilst there. For all participants, this involved constant navigation between the relative costs and gains of responsive actions. Common costs of this strategy were exacerbated fatigue and lethargy (contributing an additional reason to decline activities and invitations), experiencing other's judgements (for example, colleagues suspecting an eating disorder), and the risk of causing unhelpful cyclical patterns of eating (being so hungry by the evening that one overeats or make unhelpful food choices). Despite these unintended consequences, most people felt that restrictive strategies ability to help them reclaim control and pursue 'normal' daily activity outweighed the costs. Betty: "*If not eating equals no pain, I would rather go with not eating.*"

Memo:

Restrictive eating:- There seems to be a bit of a dichotomous relationship to food. Food as pleasure vs food as punishment (pain). A treat vs fuel. How might the ways we conceptualise food and our relationship with it influence our eating practices? Do the additional parameters and rules involved in eating with IBD play into this? What part does language play in constructing meaning around this?

Other responsive actions. In efforts to fit in with social norms, hold on to pre-existing identities, and to avoid being identified as different or 'ill', people sometimes attempted to disguise or deny their disease: Annie: *"I don't want to look like I am like, I'm not fine."*. This manifested in a variety of ways. Some people risked eating potentially provocative foods when in social settings in favour of not drawing attention to themselves or inconveniencing others. Others avoided disclosure of their illness, which sometimes caused food elimination or isolation in efforts to avoid others detecting symptoms or difficulties, for example by passing judgement about why somebody kept rushing to the toilet at work. Jasmine: *"I'm maybe a bit of a people pleaser and I just like to go with the flow. And no, I don't want to be the person that's causing a fuss having people change things for me."*.



Memo

I'm noticing that (as an IBS sufferer) I am able to relate to a lot of the difficulties people discussed, albeit to a lesser degree and without the potentially life-threatening consequences. I need to remain aware of this, as risk of making assumptions or assuming I already know what participants are talking about– sharing symptoms doesn't align experiences. Need to hold this in mind and treat each participant's experiences as new and unfamiliar. (Consider intersectionality in this too, as a white female researcher of a similar life stage to many participants – take this to supervision). Also, there seems to be a lot of misconceptions and confusion about what IBD is amongst wider society (as opposed to IBS, food intolerances etc) – and in addition to the immediate difficulties associated with the disease, people also face stigma and judgment. I don't want to play into this with my own assumptions / experiences of similarity.

Navigating Control - Support networks.

Availability and quality of support networks appeared influential in participants navigation between loss of and reclaiming of control. When available, supportive networks carried the potential to facilitate social integration and to convey acceptance of participants' new eating practices and developing identities, thus facilitating a movement towards reclaiming control over their lives and networks. When less available however, participants' experiences of eating were expressed as more challenging, isolating and more characterised by a loss of control, with fewer examples of reclaiming control.

Availability of support seemed to provide encouragement for participants to make healthy choices even whilst burdened by the extra effort involved. Rina: "*…there's people around me who will keep me in check". *There was a unanimous appreciation of dynamics in which participants did not need to explain or justify eating behaviours. Betty: *"… when I go back [home]…… I don't even have to ask. Everything is super clean. And yeah, there is no even asking. Can you eat this? Can you not eat this? It's just so simple. It it's not a battle".* Support networks also appeared valuable in counteracting some of the more stigmatising reactions that participants sometimes encountered from people with less understanding of their disease associated eating choices. People valued loved one's practical efforts to provide appropriate foods and sharing the load of day-to-day preparations. Kesha: *"But the girls, they understood my condition. I think it's important that I socialize with people that are aware of my condition……they've been super, they've been super supportive……She will always make sure she's got a grilled fish for me".*

To some degree therefore, support networks appeared to serve a protective function against fear of eating and supported ongoing social engagement, thus helping to preserve wellbeing and guard against burnout from daily disease management rituals. In this way, availability of support networks appeared to facilitate a stronger sense of reclaiming control for participants in their journeys of living and eating with IBD.

Navigating Control - Dietary information sources.

Availability of reliable, quality dietary advice also had an influential impact on people's navigation between loss of and reclaiming of control. All participants expressed dissatisfaction at the dietary advice received from NHS healthcare teams. Several said they had never had contact with a dietician or nutritionist but had been handed a generic leaflet on healthy eating during routine clinic appointments instead. All people felt that advice provided was too generic and did not fit with their individual experiences.

> Frankie: *"…my medical team referred like the gastric saw referred me to the Crohn's and colitis website. And for me it was kind of in the back of my head was like well if this is a big deal, I would expect you to tell me myself…… my adventure with eating and what I eat has come outside of the NHS."*

Most people expressed confusion and anxiety about what they should and should not eat, situating them within loss of control. Faye: "*I find working out what I'm supposed to eat quite overwhelming".* Consequently, every participant had travelled a journey of self-education, in efforts to find ways to reclaim control over eating for IBD. Social media forums hosted by organisations such as IBD UK were a common information source, and most of what people had implemented was learnt from speaking with other people who had IBD, and lots of trial and error. IBD is a relatively idiosyncratic disease in itself and additional variations in the sources of advice accessed about eating with IBD inevitably translate to variation in the experiences and outcomes of people living with the disease. On going processes and outcomes of dietary trial and error shifted participants back and forth between loss of and reclaiming of control. Of note, those who had been able to pay for private nutritional advice reported to have found this helpful, and had particularly valued the ability to seek advice in response to specific questions and/or symptoms. For others, financial resources were a barrier to accessing such support.

C. Shifting Identity

Shifting identity was a key context. People navigated the journey between trying to maintain aspects of pre-existing identities whilst negotiating changes to self- identity and associated functioning within various social contexts: Kesha: *"I still try to keep up with the group"*. The role of food and eating in highlighting difference between self and others was universally present as an area of difficulty, and often lead to avoidance of eating around other people: *Mary: "…it makes me feel different and makes me kind of stick out".*

Memo:

I am feeling a sense of isolation and loneliness from people.

Self-Concept: Self-conceptualised reflections were suggestive of the impact that difficulties of living and eating with IBD had had on self-identity: Faye: *"…there is something wrong with me."* and how it shaped self-esteem: Jasmine: *"It feels like, failure.".* Whilst these statements reflect self-conceptions, they were also inherently embedded within social contexts and identities since participants were benchmarking themselves against perceived social norms. Changes to sense of self raised questions for people about where they fit in, since restrictions around eating had somewhat disconnected them from familiar social contexts. Mary: *"And like I said, not being able to eat and having to like, perform……there's things that I can't do and I think I just feel perpetually like left out…… it's just like a complete loss of self.".*

Pre-diagnosis identities were often defined in terms of activity and occupation. Participants reflected on previous relationships to self with a sense of loss, discussing how self-concept had changed with the changes that eating with IBD had enforced upon their lives. Frankie discussed her pre-existing identity as somebody recognised by others as widely travelled and spontaneous in eating a range of cuisines. Since having IBD however, this became impractical due to inability to tolerate foods:

> Frankie: *"…that was kind of part of my identity of, like, easy-going. Go wherever you want, eat whatever you want. And so that was a big part of my identity of, like, I'll go wherever I want and it'll be fine. And now I know that that's not always gonna be true."*

Occupational Identity: There were clear links between occupational identities and self-worth: *Jasmine: "…my like idea of self-worth was sort of attached to my productivity and being able to go to work……but then all of a sudden when you can't, it's like, right. Well, what, what is the point?".* Several participants reflected on the significant impact of IBD related restrictions on eating and functioning on professional identities:

> Mary: *"… fashion in terms of the images that are promoted and circulated within the industry and within society are very quite like pristine and quite clean…….There's nothing in, IBD itself is a really, I guess you could say a grotesque kind of disease. There's nothing glamorous about it……my place in fashion is having to perform this like perfectionist image hiding, kind of the reality of like what's going on with within me …It's still challenging though, because I was, the illness is very much intertwined to my identity…".*

Illness Identity: People discussed the sense of difference engendered by developing chronic illness at a young age and how this challenged socially expected ‘norms’ about youth identity. Adjusting to new daily rituals and gradually incorporating IBD into one’s identity was a process that occurred over time. For all participants, there was navigation between fusion or rejection of illness identities: Jasmine: *“I don't see myself as someone who's sick, but the reality is a lot of the time I am”.* Participants also reflected on the additional adjustment of having to consider society’s conceptualisation of them in relation to “disabled” identities, in a variety of personal and professional contexts:

> Frankie: *“I guess yeah, it's a form of disability. I guess check the box that says I have a disability. I think for a long time I continued to shy away from that. And so I think in my identity, it definitely has affected that because I know I can't. I no longer can do whatever I want.”*

Memo:

Identity and Social contexts: - There seems to be a sense of IBD being too personal a condition to discuss with others, yet there’s also a simultaneous sense of feeling misunderstood around eating with IBD. IBD often regarded as an invisible illness, and people living with it fear other’s judgements about their food and eating choices. Does this misunderstanding and barriers to communicating contribute to the sense of feeling different, and effects on identity? There is a disparity between feeling like the illness effects every aspect of a person’s life, but also that IBD is an invisible illness misunderstood by others, and not relating to the assigned ‘disabled’ identity label. This sounds confusing and potentially difficult to integrate into developing personal and social identities. Can I actually understand this as a researcher without living it myself? Very complex.

Positive aspects of self-development: Several participants acknowledged positive ways in which eating with IBD had lead to development of fresh perspectives in general Yulia: *“I've had to become lot more chilled out, a lot more relaxed.”* and also in their eating practices: Faye: *“So in the past, I probably wouldn't always have breakfast…… so that that is* *actually a positive thing from having IBD".* There was acknowledgement of a shift away from the struggle of being forced by IBD to make food and lifestyle choices that were different from others, towards a new position of empowerment engendered by the realisation that they still held choice, and now occupied more informed positions to approach this from: Frankie: *"…now I know that the choices that I've made are very clear, powerful, conscious choices.".* Participants recognised a distinction between this new conscious choice, and previous ways of just eating what was available or dictated by culture. It appeared that people's journeys through eating with IBD lead them to gain confidence and skills in recognising and asserting personal needs and boundaries, which in turn could be useful to them in managing their IBD:

> Rina: *"I feel a lot more confident because I have understood how I can use food to actually, you know, control and manage my digestion…… It's also just a shift in my life generally and how you know how I operate; what I value I think is important."*

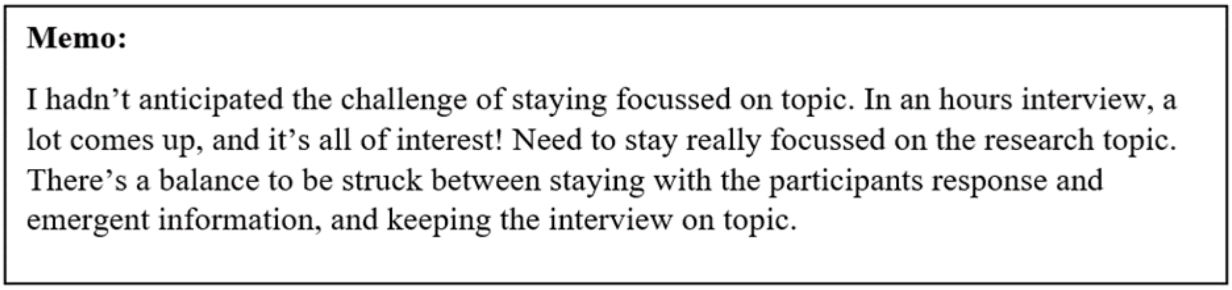
Protective identities: A couple of participants discussed pre-disposing identities as culinary creatives and self-identified "foodies", which served as a protective factor in facilitating curious and enthusiastic approaches towards experimentation with new ways of eating IBD-friendly recipes:

> Kesha: "*…I like to experiment actually……I love to try a variety of things…… we travel a lot and I have friends that are from different countries. And then they they talk about different food……I order variety of the things that I could eat, and I was perfectly fine."*

In summary, it seemed that in the process of reclaiming control, responsive actions functioned to facilitate both moves *towards* new, adaptive identities, as well as to gravitate *back* towards pre-existing ones, with continual flux between the two. Whilst this journey was different for each individual, there was evidence of gradual acceptance and integration of IBD into sense of self over time for all participants.

D. Eating as a social practice

As evidenced throughout preceding sections, the context of eating as a social practice was evident in all parts of the model, relating to friendships, family, dating, work, leisure and travel in participant narratives. Participants discussed the roles of eating in forming community and relationships, and associated difficulties in achieving these social functions when their own dietary needs and eating behaviours did not align with the social and cultural norms observed in others. Mary: "*All like life socializations revolves around food. Umm, like in our society and like lots of cultures, not just like the Western society*". These difficulties were experienced within a variety of types of relationships: Frankie: "*my worry is that like there's this societal norm that, you know, first dates are drinks or dinner……and that's a no go for me. So like, how do I conform to this like social norm of dating?*". The role of eating in positioning people within shared cultural contexts was also referenced: Kesha *"…anytime I go to [home country], my father will bring out the BBQ and he will buy racks of ribs and pork shoulders. So some people never get used to the idea that I I don't I don't have the meat*".



Memo:

I hadn't anticipated the challenge of staying focussed on topic. In an hours interview, a lot comes up, and it's all of interest! Need to stay really focussed on the research topic. There's a balance to be struck between staying with the participants response and emergent information, and keeping the interview on topic.

Discussion

This study aimed to develop an understanding of the interplay between IBD and unhelpful eating behaviours. The resulting theoretical model suggests that processes of navigating control through eating behaviours occur within wider contexts of shifting identity and eating as a social practice. As such, it proposes an insight into the meaning and function of unhelpful eating behaviours for people living with IBD, addressing identified gaps in the existing literature (Whelan et al., 2021) with a novel contribution that links identity, social contexts and control mechanisms as a theoretical concept specific to IBD. Although there is no existing theory specifically addressing this phenomena, the current findings align with (previously cited) accounts offered by self-regulation theory and the negotiation model. Despite known idiosyncrasies of both disease activity and disease management in IBD, participants nonetheless shared many of the experiences and responsive actions identified within the model (figure 1), suggesting some evidence of commonality within the proposed theory.

Psychological distress associated with eating was experienced by all participants, which is consistent with Satherley's (2015) assertion that mental health is implicated in the development of DE in IBD. The arrival of these emotional aspects as part of the new landscape eating with IBD appeared to contribute to participants' sense of loss of control. Participants' views echoed the uncertainty amongst literature about the direction of this relationship between mental health, cognition and gut health (Gaines 2020). However, some participants recognised stress and anxiety as triggers for worsening IBD symptoms, acknowledging variations in their tolerance of potentially aggravating foods depending upon the mood they were in when they ate it. This maps onto polyvagal theory which spotlights the link between mental health and gut inflammation (Moulton, 2019; Porges, 2017). Participant reflections on the involvement of mental health in somatic reactions to food, and it's influence on the adoption of restricted eating behaviours present an important insight into the interplay between unhelpful eating behaviours and IBD, and go some way to addressing the shortfall of research into food related anxiety in IBD highlighted by (Day et al., 2021).

Beliefs about food consumption and meal planning developed from prior experiences appeared to influence participants' eating practices, leading to restriction of meals and foods eaten. Theoretically, findings echoed self-regulation theory (Leventhal et al., 1997), which speaks to the development of beliefs about cause and control in people's experiences of chronic illness. Participant data suggested that beliefs did not always adapt with changes in experience due to high levels of uncertainty and fears of pain, embarrassment, and incapacitation. Whilst some participants demonstrated insight into this sense of feeling stuck they also expressed difficulty in changing eating practices, understandably regarding it safer to stick to strategies that had previously helped them regain some control and certainty over their daily lives. These findings were consistent with Day et al (2021) who reported that restricted eating practices that started as short term symptom control often became more permanent, even when they had become maladaptive, as unpredictability of the disease made it hard for people to contemplate reintroduction of foods and meals. Further, the unavailability of helpful dietary advice and resulting journeys of self-education contributed to wide variations in approaches to eating between individuals. Whilst this manifested in varying lengths of trial and error of attempted diets, restrictions, medical trials and meal replacements, the wider theme of restricted eating consistently featured as a long-term strategy for all participants. This corroborates previous literature stating that restricted eating was common amongst IBD populations (Satherley, 2015).

A further theme evident in each of the interviews was that of shifting identity in the face of eating with IBD. Gerdhart (1989) highlighted the significance of disease management rituals such as eating behaviours in IBD in altering self-identity and cited such 'rituals' as features of DE. The very nature of experiencing self in relation to disease and other's reactions to it appeared to give rise to changes in the way participants conceptualised themselves and their roles within interpersonal contexts. The function of food and eating behaviours appeared central to this shift in self-conceptualisation, since eating practices were discussed as influential upon all interpersonal and functional contexts, echoing the aforementioned Negotiation Theory's account of identity challenges in chronic illness (Gerdhart, 1989). Previous research suggests that identity difficulties are implicated in the development of DE (Cruwys et al., 2016; Stein & Corte, 2007). Whilst the current study cannot infer causality, data tentatively suggests that the relationship between identity challenges and unhelpful eating behaviours may be bi-directional. Participant experiences suggested the presence of an ongoing process of navigation between pre-existing and developing identities, as people explored which 'new' aspects of self they were willing to embrace and which they preferred to reject. Availability of support networks and helpful dietary advice also appeared to exert influence upon whether people felt empowered and supported to incorporate positive aspects of self-growth and travel *towards* new IBD related identities, or whether they felt more misunderstood and hopeless, attempting to find ways to 'fit in' with social norms and pre-existing identities. This process of negotiation between old and new aspects of self appeared inherently linked with the journey between experiencing loss of control and reclaiming control through eating behaviour change.

In summary, findings here go some way to answering the earlier question posed by Satherley et al (2015) about *why* people with IBD engage in food restriction, as it would appear that whilst the strategy *is* aimed at symptom management; the relationship is much more nuanced, with restrictive eating also functioning to facilitate reclaiming of control, and interpersonal and occupational activity. Emergent theory from the current study aligns with social constructivist theory (Vygotsky, 1978) as its findings suggest that eating behaviours in

IBD are not driven by body image or nutrition conscious concerns but by individual's desires to function in relation to their social contexts, facilitate social connections and fuse with preferred identities.

Limitations

Whilst core principles of social constructivist GT were followed as closely as feasible within the context of a DClinPsych project, the methodology nonetheless took more of a 'modified' GT approach. Whilst theoretical sampling was carried out via adaptations to interview questions, slower than expected recruitment made it impractical to modify recruitment criteria within the resources available for a DClinPsych doctorate. It is therefore unlikely that theoretical saturation was achieved for *every* possible category. The achieved sample size was within the usual range of published GT studies of this type (Smith et al., 2015).

There was a female gender bias in the findings. Of the few men who expressed interest, one was ineligible and others were non-responders beyond initial contact. Reported gender ratios of IBD vary amongst the literature (Lungaro et al., 2023; Rustgi et al., 2020) and cannot account for the bias in this sample. However, female sufferers reportedly value dietary therapy and engage in food restriction more compared to men (de Vrie et al, 2019) and there is also a strong female bias amongst eating disorder populations (Eating Disorders Victoria, 2021 & National Eating Disorder Association, 2018). It is therefore possible that the sample's gender ratio is not as biased as first glance suggests. Nonetheless, a further possibility is that different genders may have felt more or less comfortable discussing the personal nature of IBD with a female researcher.

The use of a dual source sample (from both the NHS and from social media) could have introduced bias. For example, some research reports that people have stronger faith in online advice following active disease whereas people in remission have stronger faith in NHS advice (Marsh et al, 2019). Whilst symptoms of active disease were an exclusion criteria for the current study, it is therefore *possible* that the social media sample may have represented a cohort of people for whom IBD symptoms have historically been more active or severe than those amongst the NHS sample.

Inclusion criteria relating to the definition of ‘unhelpful eating behaviours’ was kept deliberately broad, but during recruitment some participants expressed uncertainty about what this captured. This could have contributed to slower than expected recruitment if some people avoided volunteering due to uncertainty around ‘qualifying’ eating behaviours. However, during interview participants identified eating behaviours that they regarded as problematic with minimal prompting.

Clinical Implications

The study’s findings present a rationale for psychological interventions in IBD, supporting patients to explore and manage emotional aspects of eating. Fears associated with food and aversive emotional experiences during eating are likely to reinforce avoidance of eating and contribute to nutritional deficiencies, which are a concern for physical health outcomes in IBD (Whelan et al., 2021). Whilst partly due to difficulties with gut absorption and digestion, prolonged elimination of foods also contributes to deficiencies (Whelan et al., 2021). Therefore, addressing psychological motivations for restricted eating could be advantageous for supporting patients to consume diets that better meet systemic dietary needs and support resilience against perpetuating factors such as hopelessness and despondency.

Provision of psychoeducational groups co-facilitated by dieticians and psychologists could improve provision of dietary advice and support psychological aspects of eating, within NHS capacity and resources. Such groups may also provide opportunity for peer support;

important given that availability of support networks was cited as a strength in assisting adherence to dietary needs.

Specifically, supportive intervention could influence whether ‘reclaiming control’ through eating behaviours is characterised by adaptive or maladaptive strategies. Other areas with scope for interventional benefit include perceptions of eating within social contexts, emotional aspects of eating, emotionally motivated cycles of unhelpful eating and identity dilemmas. Specifically, drawing on relational frame theory (Barnes-Holmes et al, 2004) through Acceptance and Commitment Therapy (ACT) based interventions could promote psychological flexibility and committed action towards adaptive eating behaviours. Relational frame theory spotlights our ability to alter thinking and language patterns that contribute to secondary, non-organic suffering (Barnes-Holmes et al, 2004). Increasing people’s understanding and sense of empowerment around living and eating with IBD from a values-near approach such as ACT may support adaptive approaches to eating well. Opportunities to explore the gut-brain connection could also address the confusion expressed about links between emotions and physical symptoms when eating.

Research Implications

Further evaluation of the proposed model could be usefully operationalised by qualitative and quantitative methodologies.

Repeating the current design with increased resources allowing for theoretical sampling would be an important step in testing these findings. For example, increasing recruitment of males and people from a range of ethnicities, sexualities and socioeconomic backgrounds may improve sample diversity and transferability of findings. Providing a choice of researcher genders might also increase accessibility of the study.

Further, hypothesised relationships emerging from the current model could be quantitively tested using longitudinal designs. For example, to explore the interplay between emotional and somatic aspects of eating, and whether support networks and eating control strategies might influence identity. Quantitative methods could usefully interrogate a range of psychological phenomena identified in the current model in this way, and would be valuable in their ability to test causality and measure the strength of associations between the factors identified.

Pilot studies would be essential in evaluating the efficacy of potential clinical interventions aimed at supporting development of adaptive eating behaviours that promote good systemic and emotional health, and positive identity development.

Conclusion

As far as the researcher is aware this study is the first to propose a theoretical conceptualisation of the interplay between IBD and unhelpful eating behaviours. The model explores the functions and meanings attached to eating behaviours for people living with IBD, within the broad contexts of their lives. The model indicates processes and contexts relevant to the development of unhelpful eating behaviours in IBD and identified potentially modifiable psychological and behavioural aspects in this relationship. Therefore, combined with existing literature, findings of the current study contribute to an argument for psychological support for IBD patients exhibiting unhelpful eating behaviours (Wardle et al., 2018) and reflect the wider push for integration of clinical psychology into physical health services for better patient outcomes (PPN, 2020).

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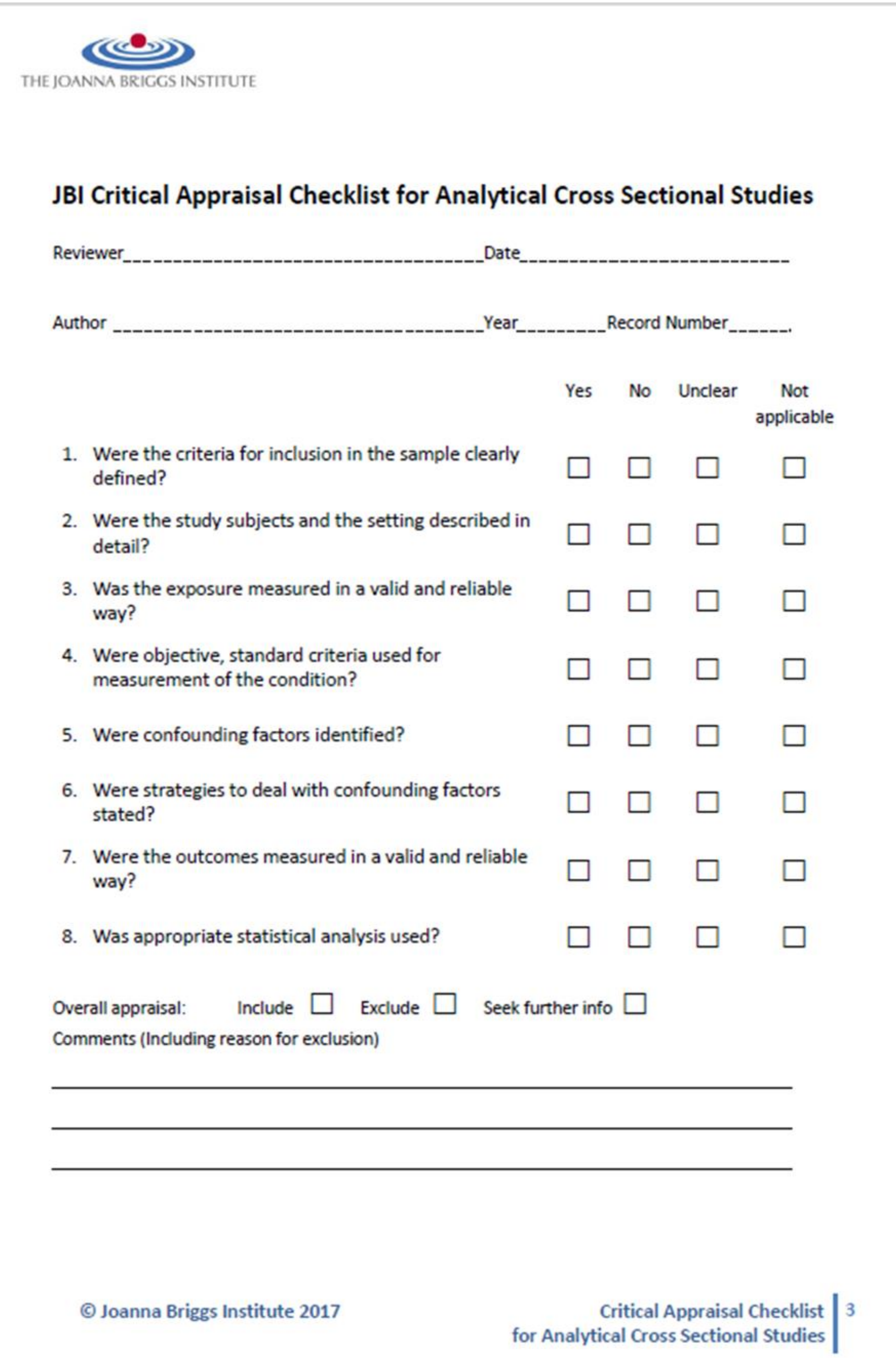
APPENDICES

Appendix Label	Description
A	JBI Critical Appraisal Tool
B	Recruitment Poster / Leaflet
C	NHS Health Research Authority Ethical Approval
D	Local Capacity and Capability Assessment Approval
E	Interview Schedule
F	Analytical Codes
G	Research Diary Excerpts
H	Post Research Summary for ethics panel
I	Post Research Summary for participants
J	Participant information sheet
K	Participant Eligibility Information
L	Participant Consent Form
M	Participant debrief sheet
N	Letter notifying IBD healthcare team of intent to participate
O	Participant screening questionnaire
P	Clinical measure 1
Q	Clinical measure 2
R	Development of Grounded Theory Conceptual Model
S	Full Coded Transcript

A. Critical Appraisal Tool (Part A)



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JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer___________________________________Date___________________________

Author _____________________________________Year_________Record Number______.

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	☐	☐	☐	☐
2. Were the study subjects and the setting described in detail?	☐	☐	☐	☐
3. Was the exposure measured in a valid and reliable way?	☐	☐	☐	☐
4. Were objective, standard criteria used for measurement of the condition?	☐	☐	☐	☐
5. Were confounding factors identified?	☐	☐	☐	☐
6. Were strategies to deal with confounding factors stated?	☐	☐	☐	☐
7. Were the outcomes measured in a valid and reliable way?	☐	☐	☐	☐
8. Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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Critical Appraisal Checklist
for Analytical Cross Sectional Studies | 3

B. Recruitment Poster and Leaflet

Canterbury Christ Church University

[redacted]

Do you have **Inflammatory Bowel Disease**? And have you developed **eating behaviours that feel unhelpful** to you?

If so, I'm interested to hear from you!

People from all walks of life live with Inflammatory Bowel Disease. 1 in every 250 people in fact.

But some people also develop changes to their usual eating behaviours, which may become unhelpful for them or start to have a negative impact on their lives in some way. Such behaviours vary in type but often exceed the usual dietary advice prescribed for managing IBD symptoms. Is this you?

Research

My name is [redacted] I'm a Clinical Psychologist Trainee working in the NHS. I am conducting a small, confidential research study aiming to develop our understanding of this topic so that our services can get better at supporting people living with these experiences. Can you help?

If you choose to take part you will be invited to meet with me via video call to discuss these experiences confidentially. If you are eligible and participate in interview, you will be offered a £10 voucher in thanks, recieved after your interview.

[redacted]

To find out more, scan the code on the left or contact [redacted] to receive information

C. NHS Health Research Authority Ethical Approval

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D. Local Capacity and Capability Assessment Approval (Emails)

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E. Interview Schedule

This is a selection of questions that may be used - not all questions will be used in every interview, and they may be adapted according to emergent theory. The broad areas outlined here serve as a guide for the interview process.

Area	Questions
How did behaviours/ changes start?	Can you tell me about whether you think living with IBD has changed your relationship with food or eating habits? What eating behaviours have you developed that you feel are unhelpful? (If relevant) Can you tell me more about these changes you've observed in your eating patterns since receiving your diagnosis of IBD? (Including type, and frequency etc) Are there any particular times or situations when you notice the way you eat more than others? What is your understanding of why these changes may have come about? (if relevant)
Have they evolved?	Can you tell me about any positive and negative aspects of your eating behaviours? How do they help, and how do they get in the way? Can you tell me whether you've noticed any links between your eating behaviours and your mental health? (If yes) What can you tell me about that? How do you feel about your relationship with food and/or your eating style?
How do they impact / how are they problematic?	What impact do your eating behaviours have on different parts of your life? (consider routine, social, emotions etc) Do you feel that any of your eating behaviours can be problematic for you and your life and if so, how? Can you tell me about how helpful or unhelpful you think your eating behaviours might be for your IBD? How do you think your eating behaviours influence the way you see yourself, or feel about yourself? Have others around you noticed anything about your eating behaviours?
About Change	Is there anything about your eating behaviours that you would like to change?

	Can you tell me about any ways in which you might already have tried to change the eating behaviours that have developed since living with IBD?
Other possible areas I may expand on if they seem relevant to emergent theory (as guided by the background literature):	▪ Identity – self and social ▪ Reclaiming control via eating behaviours ▪ Self-esteem ▪ Body image ▪ Anxiety around disease symptoms ▪ Brief enquiry about inflammation issues elsewhere in the body - relates to Polyvagal theory ▪ Pre-existing mental health - relates to polyvagal theory on links between distress and inflammation. *This would not be any in depth questioning but may include a brief outline of difficulties occurred and any effects of this, if it is raised first by the participant*

Questions added in response to emergent theory.

Phase of updates	**Possible additional questions to ask and/or emerging themes to look out for and respond to**
One	What are the costs and benefits of the changes that you've made to the way that you eat? Why do you think your eating behaviours are unhelpful? Do you think any of the costs are more a result of changes made than of the IBD itself? What have been your main sources of dietary information? What have your IBD healthcare team and your social network said about the changes you've mad to your eating?
Two	Does greater focus/preoccupation with eating exacerbate intolerance? Do you experience fewer symptoms when you're less aware of food and eating? Do you think your relationship with your body has changed at all in response to the challenges it faces with eating since having IBD? If yes, how has this changed over time? Do you feel that your sense of 'fight' with IBD and eating changes has lessened or settled over time?
Three	▪ Attunement to or disassociation from body ▪ Loss of control ▪ Positive aspects

F. Analytical Codes

Following initial 'open' line by line coding of the transcripts whereby descriptive codes were first applied to the data, these were then organised into the following focussed codes. At this point, re-coding of transcripts became incident by incident, with a smaller number of codes that represented meaning containing larger amounts of data.

Focussed Codes:

Attunement to body
Boundaries
Confusion over food and bodily responses
Covid
Cycles of Eating Behaviours
Eating as a Social Practice
Emotional Aspects of Eating and Food Tolerance
Fatigue
Fears of eating in restaurants and exercise
Food as a loss
Food highlighting difference
High effort involved in dietary adherence
Identity
Impact on travel, work and holidays
Importance of Support Network for Eating
Lack of control
Living with Crohn's is a fight
Perfectionism
Positive aspects of eating with IBD
Radical dietary changes
Revelation in having choice of eating
Sense of blame from others
Sources of dietary advice
Trauma
Trial and error

Following revisitation of transcripts and recording and synthesising selective codes, the following theoretical codes were applied to the emerging theory within the data:

Theoretical Codes:

- Eating as a social practice
- Shifting Identity
- Sense of loss of control
  - Social contexts
  - Emotional contexts
  - Effort and fatigue
- Actions that facilitate reclaiming of control
- Role of support networks
- Sources of dietary information

G. Abridged Research Diary (Excerpts)

Researcher's personal reflections on the interview process:

I am feeling a sense of isolation and loneliness from people.

The experience of living with IBD feels very limiting for people. It impacts so much more of their lives than I'd appreciated.

I'm quite shocked to think that people are managing to go through entire days of their lives without any nutritional sustenance until the evening meal. This must have wider health implications? Makes me wonder about access to disable toilet facilities in workplaces etc. Is this harder for women? I can't know as not spoken to any men yet.

Misunderstanding – seem to be a lot of misconceptions and confusion about what IBD is – as opposed to IBS, food intolerances etc – and in addition to the immediate difficulties associated with the disease, people also face stigma and judgment.

There is a sense of personal embarrassment attached to IBD due to the personal nature of its symptoms. Managing overactive bowel activity whilst in work and social settings is difficult for people to manage. Combination of the personal nature of IBD, and other's judgements makes it a real catch 22 for people in terms of whether explaining and discussing would help or hinder.

I noticed that (as an IBS sufferer) I am able to relate to a lot of the difficulties people discussed, albeit to a lesser degree and without the potentially life-threatening consequences. Need to remain aware of this, as risk of making assumptions or assuming I already know what they're talking about or going to say – sharing symptoms doesn't align experiences – need to continue to hold this in mind and treat each participant as a fresh individual and regard their account of experiences as new and unfamiliar. Consider intersectionality. LISTEN. – Take to supervision.

There is much more implicated in people's relationship to food and eating than 'just' symptom control. Mention of trauma, fear, identity, perceptions of difference, social bonding, cognitive and time resources, financial implications, food as a barrier to travel, exercise, socialising, work, dating etc. I can already see how food and eating in the context of IBD could have a big impact on mental health.

Associations with food and eating appear to spiral and become something much bigger than the initially obvious issue.

Some positive outcomes and learning points raised by participants too, important to acknowledge as part of their entire experience. Research too focussed on the problems, because that is always what we want to find/ understand / solve as scientist practitioners.

People saying they feel unrepresented in society.

Shift from a sense of fight with the body over processing food and towards a more harmonious 'working with the body'. Appears to come with a bit of time and adjustment to the condition as a long-term presence in their lives.

People are voicing their own awareness of links between psychological factors and experiencing physical symptoms/tolerance of food. (*This is interesting, but I need to* *approach this sensitively as I don't want to mistakenly suggest any implication that it's 'all in your head' or contribute to feelings of blame and/or misunderstanding.*)

The journey of eating with IBD must play into conceptualisation of food – a few people have mentioned term "safe foods" and "bad foods". Over time, how might these frameworks of viewing food impact future food choices and eating habits? Is this helpful or not?

Could the seemingly protective factor of being creative with food be utilised / promoted via Ots in future for people with IBD to support a healthier approach to food, cooking and diet and encourage exploration and creativity? Currently, cooking is viewed in society as an optional 'hobby or interest' rather than drawn upon as a potential skill for adaptive living or tool of empowerment.

On a general note, I hadn't anticipated the challenge of staying focussed on topic. In an hours interview, a lot comes up, and it's all of interest! Need to stay really focussed on the research topic. There's a balance to be struck between staying with the participants response and emergent information, and keeping the interview on topic. But I can already see how there is scope for so much more research in this area, even after only my first few interviews.

- Living with a sense of body as saboteur – could flare at any moment
- Establishing new norms and standing firm: process/journey away from loss.
- Links with health anxiety? Signs of hypervigilance, anxiety and trauma
- Bidirectional relationship between gut symptoms and emotional wellbeing
- Intersection between identity and food restriction – doing so allows people a greater chance of functioning in everyday society as they did before, and thus to distance themselves from illness/disability identities. (Denying parts of self to 'fit in' with social identities).
- There appears to be some flux in identity embracing or rejection, and in relationship to bodily self: greater bodily attunement, understanding an re-established respect for body. But also, rejection of body's needs (nourishment, fuel) and splitting off of this part, in order to "fit in" to social identities.
- Continual process of identity re-adjustment in relation to social norms – distance from cultural eating practices, dating practices, exercise norms, family traditions etc.
- Is there a cultural element to predisposing attitudes towards cooking and food? Would need wider sample to measure this.
- Eating as a social practice seems to intersect with everything – unavoidable context that bears influence in all domains of life. (reduced friendship circles, more selective in seeking relationships, food highlighting differences, quality of support network bears influence on whether people embrace adaptive strategies or choose maladaptive ones in order to deny being seen as different, cultural identities.)
- Support networks seem influential

Reflections on theoretical sampling amendments to interview schedule:

- Need to be a bit more specific in asking people to name the pros and cons of eating strategies and why/how they find them unhelpful/helpful
- Participants are raising links between somatic and emotional symptoms – pick this up as a thread and add some questions around this
- Participants discussing poor dietary information as influential part of their journeys – pick this up in questioning.
- Relationship to body through eating – has been some mention of being closely attune, hypervigilance and also dissociation. Has relationship to body changed at all since eating with IBD?
- Positive aspects of eating with IBD have been mentioned – invite consideration of this for more balanced view?

Reflections during coding:

Reducing open codes to selective codes is really hard!! There seem to be so many levels of detail I could go into. For example with identity, there seem to be themes around illness identity, disablement, mourning of previous identities, forming of new identity, social identities, “foodie” identities…but this is too much and too descriptive to form selective and theoretical codes. What is the process here??? Take to supervision. There seems to be a theme of *shifting* identity – identity is fluid and affected by eating with IBD in a number of ways. Where does this fit with all the other emerging themes? Are/how are these codes linked?

I need to keep stepping back outside of the codes and back into the interviews and transcripts to hold in mind the meaning and tone conveyed in individual participants’ responses. What did their words mean to them? The context, tone and feeling of the interviews may be conveying information about how these codes are or are not linked, in a way that abstract codes cannot tell me in isolation.

Examples of Theoretical Memos

Relevant Area of Analysis	Reflective Memo
Identity	Women discuss their ‘pre IBD’ selves in terms of ability to travel, exercise, cook, work, reliably and productively and socialise. Then comes the sense of IBD’s arrival as a gradual and persistent challenge to all that was taken for granted about a one’s identity. There follows a process of re-evaluation limits and abilities, of increased self-awareness – how do others see me? More boundaries and rules come into life. Start looking at self in context of “illness” and comparing to peer group – do others around seem to have the same struggles? What does it means for self-identity if not? Unable to participate in social eating in the same way as others might: differences emerge. See self differently Implications for family, intimate relationships and friendships too.

Emotional Contexts	Stress and fear are central themes in people’s narratives. Fear around IBD and eating is often linked to awareness of mortality, with food being regarded as a potential influence of this. In these cases, eating behaviours are seen as a matter of life or death, and prior experiences of distress and pain associated with IBD regarded as trauma. These are powerful emotions. Sometimes it sounds and feels as though the psychological aspects seem harder to overcome than the physical. Do services appreciate how much is at stake (psychologically) for patients when reviewing their eating and diet? Are people receiving support that is proportionate to their experience?
Restrictive eating	There seems to be a bit of a dichotomous relationship to food. Food as pleasure vs food as punishment (pain). A treat vs fuel. How might the ways we conceptualise food and our relationship with it influence our eating practices? Do the additional parameters and rules involved in eating with IBD play into this?
Identity and Social contexts of loss of control	There seems to be a sense of IBD being too personal a condition to discuss with others, yet there’s also a simultaneous sense of feeling misunderstood around eating with IBD. IBD often regarded as an invisible illness, and people living with it fear other’s judgements about their food and eating choices. Does this misunderstanding and barriers to communicating contribute to the sense of feeling different, and effects on identity? There is a disparity between feeling like the illness effects every aspect of a person’s life, but also that IBD is an invisible illness misunderstood by others, and not relating to the assigned ‘disabled’ identity label. This sounds confusing and potentially difficult to integrate into developing personal and social identities.
Dietary Information	Feeling unsupported around their eating by NHS…… what choice do people have but to do their own research, and trial and error? (This in itself could be seen as a marker of resilience and independence – people being proactive in their own healthcare).

Reflections on conceptualising the theoretical model:

It feels like the key elements of the theory are relatively clear in my mind as the data seemed to speak loudly, which is good. But I have no idea how to conceptualise this in a way that will make sense to other people. I want to really understand my thinking here, and will need to keep referring it back to the data to make sure I am representing something that is as close as possible to what is actually there. I want to do my participants justice in trying to stay as closely attuned to their conveyance of the topic as I can. It feels a challenging task, as no theory can be “right”, but I want it to be as accurate as I feel it can be in demonstrating the themes that arose in people’s responses.

Depicting all of this is a diagram is really challenging. Without explicit reference to all of the codes, it feels a bit reductionist. But I understand from supervision that the components of the model need to be abstract and as reflective of processes as possible. This is just an unfamiliar process. Got to remain patient and just keep revising it. Trying not to pay too much attention to the ‘types’ of diagram or model that other grounded theory models have used, as I’d rather mine stays truly grounded in the data than changes it’s meaning to fit with a prescribed graphic.

H. Post - Research Summary for Ethics Panel

Background: The prevalence of disordered eating behaviours amongst IBD populations poses implications for systemic physical health outcomes and disease management. Statistics suggest a prevalence of anxiety and depression in development of disordered eating in IBD, and psychological theory has implicated identity challenges in chronic illness in the development of disordered eating. However, there exists little research exploring motivations and function in the development of such eating behaviours, and previous studies have highlighted the need to explore potentially modifiable psychological aspects of the interplay between IBD and disordered eating behaviours.

Aims: The study aimed to explore the interplay between IBD and disordered eating behaviours by addressing the following research questions:

a. How do participants experience the relationship between their IBD and their eating patterns?

b. How do participants with IBD view their eating patterns, including helpful and unhelpful aspects?

c. How do participants experience any effects of their eating patterns on their lives and wellbeing?

d. What is the interplay between participants eating behaviours and how they view themselves?

Methodology: Twelve participants who self-identified as having an IBD diagnosis and experiencing unhelpful eating behaviours were recruited from within an NHS Trust and via social media. A modified version of social constructivist grounded theory was utilised in qualitative exploration of the topic through semi-structured interview.

Results: The emergent conceptual model indicated that people with IBD experience a process of control navigation in their eating experiences. This process is characterised by movement between a sense of loss of control resulting from IBD related eating challenges, and reclaiming control via employment of responsive eating strategies. Each of these eating strategies carried relative pros and cons, and as such brought unhelpful elements to participants lives on occasion. The process of control navigation occurred within the wider contexts of shifting identity and eating as a social practice.

Conclusions: The conceptual model presented extends existing literature, and suggests the presence of potentially modifiable psychological and behavioural aspects in the relationship between IBD and disordered eating behaviours. Suggestions are made in terms of clinical and research implications, and study limitations noted.

I. Post Research Summary for Participants.

A Grounded Theory of the Interplay between Inflammatory Bowel Disease (IBD) and Unhelpful Eating Behaviours: Study Summary

Dear Participant,

Thank you again for your valued participation in the above research study, which is now complete. As expected, I am today providing a summary of the study findings for your interest.

The study interviewed twelve participants about their experiences of unhelpful eating in the context of living with IBD. The following main themes emerged from the data:

- A sense of **loss of control** arising from the changes to people's ways of eating imposed by IBD. This was discussed in terms of its impact across a range of aspects of people's daily lives, including ability to work, travel, socialise, date and carry out leisure pursuits.
- A sense of **reclaiming of control** via implementation of new eating strategies. Restricted eating (skipping meals, avoiding food groups, banking all nutritional intake for the evening meal etc) was a particularly common strategy featured. There was a sense that strategies carried their own pros and cons that needed to be weighed up in considering whether to stick with or discard the strategy, and whether participants regarded them as helpful or unhelpful.
- A sense of **shifting identity** since living and eating with IBD. People discussed how their sense of self had changed since experiencing IBD related eating changes. This was discussed in relation to self-concept, occupational identities, illness identities (and "disablement"), protective identities and also positive aspects of self-development.
- Eating around other people (**"Eating as a social practice")** was a theme present in all other aspects discussed, which seemed to have a big impact on participants experiences.

Following analysis of interviews a theoretical diagram was designed to represent participant experiences, which was based upon the main themes outlined above, and their subcategories.

As a result of the findings, recommendations for future research are made within the report. Importantly, suggestions for clinical service developments are also proposed, which focus on improving integration of and increasing provision of support for psychological aspects of eating with IBD, as well as addressing the shortfalls in practical, dietary advice and support in NHS IBD services.

The full (anonymised) study report including detailed explanation of the model and associated recommendations will be made publicly available at Canterbury Christ University's online research repository at some point from spring 2024 onwards. If you wish, you will be able to view this by visiting: https://repository.canterbury.ac.uk/research-institute/847x6/salomons-institute-of-applied-psychology

J. Participant Information Sheet

Canterbury
Christ Church
University

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

Information about the research

A Grounded Theory of the Interplay between Inflammatory Bowel Disease (IBD) and Unhelpful Eating Behaviours

Hello. My name is [name], and I am a trainee clinical psychologist at Canterbury Christ Church University. You are reading this as you have expressed an interest in an advertisement about a research study.

I would like to invite you to participate in the study, but before you decide whether to take part it is important that you understand why the research is being done and what it would involve for you.

You can keep this form for your reference, and if you consent to participate you will also be given a copy of your signed consent form to keep.

What is the purpose of the study?
This study aims to develop a better understanding of the experiences of people living with Inflammatory Bowel Disease (IBD), who have developed eating behaviours that they feel negatively impact on their lives or wellbeing, since living with IBD.

Such eating behaviours are likely to be beyond the dietary changes advised by your IBD healthcare team for symptom management. Examples *might* include overly restricting your diet, binge eating or deliberately vomiting after eating.

The study is not aimed at people with a diagnosis of an eating disorder such as anorexia nervosa or bulimia, which are specific conditions. This study does not aim to diagnose eating disorders.

It is intended that the study will contribute to research, so that patient care in IBD services can be improved in a way that is informed by the lived experiences of people who are actually living with the condition. It is recognised that approaches to eating and nutrition can become difficult after a diagnosis of IBD for a variety of reasons, and so it is important for our NHS services to develop more awareness of how this effects people, in order to deliver appropriate care and support.

Who is eligible to take part?
People who have a diagnosis of IBD and also experience eating behaviours which they feel affect their quality of life or wellbeing. Full eligibility criteria were published in advert for the study which you have responded to, and is also provided in the document accompanying the consent form, which has been sent to you with this information sheet.
Approximately 10 - 20 people will be individually interviewed for the study.

Do I have to take part?

It is up to you to decide whether to join the study. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw from the interview at any time, without giving a reason, and this would not affect the standard of care you receive. You can withdraw your data from the study up to one week after your interview.

What will happen to me if I take part?

Initially I will offer you a short online appointment with me (about 20 minutes) to introduce myself and answer any questions you might have about the study after reading this information. During this appointment I will need to ask you to confirm whether or not you confirm your consent to take part in the study, and if so I'll need you to complete and return the consent form that I've sent with this information. We will both keep a copy of your consent form.

If you consent to take part, then I will ask you to complete some short screening questions during that first appointment via an online programme called Gorilla, so that I can be sure that you are eligible to take part in the study (such as age, and some general questions about your health). At the end of this appointment I will confirm whether or not you are eligible to take part in the study.

If you are not eligible to take part, then I will explain this and you will have the opportunity to ask any questions, and for me to provide you with a list of helpful resources you may wish to access. No further contact will be planned after this.

If you are eligible, then I will send a general letter to your IBD health care team to let them know that you intend to participate in a research study. They will not receive any further information from me or about what we discuss during your participation, unless something you tell me causes significant concern for your safety such that I have a duty of care to share this information.

If you are eligible, then you will be invited to attend an online video interview with me. You will need to be in a quiet place free of distraction where you have privacy to speak freely and without interruption. Interviews will be audio and video recorded, so you will be asked to consent to this in order to be able to proceed with participation. You are within your rights to decline to be audio and video recorded, and if so, you will not be interviewed and will be withdrawn from the study, with thanks for your interest.

The interview will be up to 90 minutes long, and we can take a break if needed. Very occasionally, we may choose to extend the interview or meet for a short second interview if further information is required. At the start of the interview I will explain to you about NHS confidentiality procedures.

The interview is informal and relaxed. During the interview, I will ask you some questions about IBD and your eating. The interview completes your participation in the study.

The study is estimated to be complete by September 2023, although there may be a short extension. Towards the end of the study, I will contact you to provide a written summary of the research findings for your information.

Payments

You will be offered the option to submit your email address to receive a £10 voucher (for Amazon or VEX multiplay) as a thank you for taking part. If you opt in to this, your email address will be shared with Canterbury Christ Church University who will issue the voucher after your participation is complete. You do not have to submit your email address and receive a voucher if you would prefer not to.

What are the possible benefits of taking part?

It is important to highlight that your participation in the study will not offer you any immediate clinical benefit, as you are not receiving a treatment.

However, your contribution to the study will increase our understanding of these issues and so assist in the improvement of IBD care in future, benefitting future patients of IBD services. For this reason your participation is greatly valued and appreciated.

What are the possible disadvantages and risks of taking part?

If you feel that discussing your eating or IBD is likely to cause you distress, we would advise you not to participate in this study.

However, we know discussing personal topics can feel difficult and may naturally raise some anxiety. You are welcome to decline any question during the interview.

After your interview we will have a short debrief to discuss how you found the interview and discuss any needs you may have. You are also welcome to contact me with any questions or concerns relating to the study afterwards.

How will we use Information about you?

We will need to use information from you for this research project. This information will include your:

- Name
- Contact Details
- Date of birth

People will use this information to do the research and to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

After interviews have been anonymised and typed up (‘transcribed’), which will be no longer than one month after interview, interview recordings will be securely deleted.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Data will be used for the purposes of the current study only.

The study will be published within my Clinical Psychology Doctoral thesis, which will be available online in the University repository. The study may also be published in a professional journal. Anonymised quotes from your interview may be included in any published report.

The only time when I would be obliged to pass on information from you to a third party would be if, as a result of something you told me, I were concerned about your safety or the safety of someone else, or if you disclosed a serious crime.

For further information about data protection, you can access 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.

Who is sponsoring and funding the research?
Salomons Institute for Applied Psychology at Canterbury Christ Church University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Stanmore Research Ethics Committee.

What are your choices about how your information is used?

You can stop being a part of the study without giving a reason up until one week after your interview date. After this point, information about you that we already have will remain in the research study.

We need to manage your information in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

1. To read more about how the NHS looks after your information visit https://www.hra.nhs.uk/information-about-patients/ and http://www.hra.nhs.uk/patientdataandresearch

2. You email me on [email] or alternatively leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [name] and leave a contact number so that I can get back to you.

3. **For Advice on whether you should participate:** Please feel free to discuss this with your friends, family or healthcare team.

4. **Who to approach if you are dissatisfied with the study and want to complain:** If you are dissatisfied and wish to formally complain, you can do this by contacting Professor Margie Callanan, Director of Salomons Institute for Applied Psychology on margie.callanan@canterbury.ac.uk

K. Participant Eligibility Sheet

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

A Grounded Theory of the Interplay between Inflammatory Bowel Disease (IBD) and Unhelpful Eating Behaviours

Name of Researcher: [Name]

PARTICIPANT ELIGIBILITY

To see if you are eligible to participate in this study, please check that the following criteria apply to you:

I am:-

- Aged over 18
- Living with a diagnosis of Inflammatory Bowel Disease (Ulcerative Colitis or Crohn's Disease) for at least 1 year
- Since my diagnosis of Inflammatory Bowel Disease, I feel I have developed changes to my eating behaviours/patterns which impact on my life and /or wellbeing in some way. (Examples may include very restricted eating, or purging after eating for example)
- I have access to a device with a camera and a stable internet connection that I could use to take part in an online interview.
- I am able to participate in an English-speaking interview without the need for an interpreter.

I also:

- Have NOT ever received a diagnosis of an Eating Disorder (such as anorexia or bulimia)
- I do not have a Body Mass Index (BMI) of 17 or less. *(If you are unsure, you can easily check this by entering your height and weight at https://www.nhs.uk/live-well/healthy-weight/bmi-calculator/ or you can ask the researcher)*
- Am NOT booked to have surgery for my IBD and I have NOT had IBD surgery in the past six months
- Am NOT currently experiencing a flare up of my IBD that has result in medication changes or a prescription of steroids
- Do NOT experience difficulty or distress from food or eating as a result of any other physical health condition or psychological difficulty

If you have any questions about the eligibility criteria, please speak to the researcher.

L. Participant Consent Form

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Participant Identification number for this study:

CONSENT FORM

A Grounded Theory of the Interplay between Inflammatory Bowel Disease (IBD) and Unhelpful Eating Behaviours

Name of Researcher: [Name]

Please initial box for each 9 points to indicate agreement

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I confirm that I have read and understand the eligibility criteria for this study and believe to the best of my knowledge that I am eligible for this study. ☐

3. I understand that my participation is voluntary and that I am free to withdraw from the interview at any time without giving any reason, without my medical care or legal rights being affected. ☐

4. I understand that I can withdraw my data from the study up to one week after the date of my interview.

5. I understand that in addition to the researchers involved in the study, staff within the NHS and Salomons Institute for Psychology who monitor the standard of research may have access to my data for these purposes ☐

6. I agree to the researcher audio <u>and</u> video recording my interview for research purposes ☐

7. I agree that anonymous quotes from my interview and other anonymous data may be used in published reports of the study findings ☐

8. I consent to my IBD healthcare team being notified of my intention to participate in a research study.

9. I agree to take part in the above study. ☐

Please insert a digital signature if you have one, or else type your name to indicate consent:

Name of Participant____________________ **Date________________**

Signature ___________________

Name of Person taking consent: [Name] **Date_____________**

Signature ____________________

*One copy of signed consent form to be provided to participant, one retained for the research file, and one to be provided to [Hospital name] gastroenterology clinic for inclusion in patient notes. * Highlighted sentence removed for participants not recruited from within the NHS.*

M. Participant Debrief Sheet

*(*Highlighted text indicates approved adaptations for version provided to participants recruited via social media rather than via the NHS Trust)*

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Information and Support After Participation

Thank you for taking part in this study and contributing to our understanding of how living with IBD interacts with eating behaviours.

You have been made aware that if participation in the study has raised any concerns for you, you have the option of contacting the researcher to arrange a short debrief appointment to discuss these concerns. You can request this appointment by emailing: [email] or by telephoning 01227 927070.

However, whether or not you choose to request a debrief appointment, we'd like to make you aware of the following information.

Concerns About Inflammatory Bowel Disease (IBD)

If you feel that your IBD is flaring or have questions about changes in your symptoms, please contact the IBD helpline: [email] This is not an urgent response system, so if you are acutely unwell, please attend A&E. If you feel that your IBD is flaring or have questions about changes in your symptoms, please contact your IBD healthcare team.

If you would like more support around managing your diet and IBD, please ask a member of the gastroenterology team to refer you to the specialist dietitians.

If you have any concerns at all relating to your health or wellbeing, please contact your GP who will support you in discussing these.

For more general non-urgent advice and support around living with IBD, you may be interested to visit the following useful websites:

https://crohnsandcolitis.org.uk/info-support/information-about-crohns-and-colitis/all-information-about-crohns-and-colitis/living-with-crohns-or-colitis/food

https://www.crohnscolitisfoundation.org/diet-and-nutrition/what-should-i-eat

Concerns About Mental Health

If you feel you need urgent help relating to your mental health or if you feel unable to keep yourself safe, please attend your local A&E department.

If you live in X, X, X or X you can contact the [name] line on [number] ** removed for participants recruited via social media and replaced by highlighted text below*

If you live in X you can contact the [name] Line on [number]. ** removed for participants recruited via social media and replaced by highlighted text below*

For non-urgent mental health support, please discuss this with your GP, who will be able to refer you to your local NHS mental health support service for free advice and support.

Wherever you live, you can access confidential support 24 hours a day 7 days a week, you can also contact the Samaritans for free on 116 123.

N. Letter Notifying IBD Healthcare Team of intention to participate

Canterbury Christ Church University

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG.
(0)1227 927126

** Highlighted text indicates approved adaptations for version provided to participants recruited via social media rather than via the NHS Trust*

Date:

Dear Healthcare Team,

Patient Name: **Patient ID:** * ***DOB:***

With their consent, I write to inform you that the above patient has consented to participate in the following research study:

A Grounded Theory of the Interplay between Inflammatory Bowel Disease (IBD) and Unhelpful Eating Behaviours

This is a research study conducted by myself as a trainee clinical psychologist under the supervision and sponsorship of Salomons Institute of Applied Psychology at Canterbury Christchurch University.

The participant has voluntarily responded to study advertisements at the Gastroenterology clinic at [Hospital Name], who are jointly supervising the study. * *The participant has voluntarily responded to our study advertisement on social media.*

Your patient's participation in the study will involve participating in one or more interviews with myself to discuss their experiences of living with inflammatory bowel disease. The study is expected to be complete by spring *Autumn 2023.

Upon completion of the study the participant will be provided with a summary report of the main findings of the study.

No action is required from you in response to this letter, it is provided for your records only.

If any particular concerns arise from their participation, then I will keep you informed. Otherwise, no further correspondence regarding participation is planned from me.

Yours sincerely,

[Name]

Trainee Clinical Psychologist

Salomon's Institute for Applied Psychology, Canterbury Christ Church University

O. Participant Screening Questionnaire

(Completed online via Gorilla)

Demographics and General Questions

- Age *(Enter age in years)**
- Weight and Height (relating to BMI and eligibility criteria)
- Gender *(Tick Box: Male, Female, non-binary)**
- Sexual orientation (*Tick box: Heterosexual, Homosexual, Bisexual, Queer, Other (please state)*)*
- Do you have a formal diagnosis of any mental health difficulties? If so please state what these are, and roughly how long you have experienced them for? *(Tick Box: Anxiety, Depression/Low mood, Bipolar, Psychosis, OCD, Other & Open Field)* **
- Whether yes or no to above, do YOU feel that you suffer with low mood or anxiety? *(Tick Box) ***

* Very minimal existing research around differences in experiences of inflammatory bowel disease between differing ages, gender and sexuality.

** Questions related to background research into prevalence of comorbidities between mental health difficulties, inflammatory bowel disease and eating difficulties, and polyvagal theory.

Questions Directly Relating to Eligibility Criteria

- Date inflammatory bowel disease diagnosis received *(open)* and type *(Tick box: Ulcerative Colitis or Crohns Disease)*
- Did you experience any impactful or problematic eating behaviours before living with inflammatory bowel disease, or did they start afterwards? (If yes, please give a brief description of what they were). *(Tick box: After or Before (prompted to give brief details of these). Followed by open text field)*
- Have you ever received a formal diagnosis from a medical professional of an eating disorder, such as anorexia or bulimia? (*Note that conditions such as anorexia and bulimia are specific illnesses and are NOT the focus of the current study, which is why we need to ask this question*). *(Tick Box: Yes or No)*
- Other than inflammatory bowel disease, do you currently have any other physical or mental difficulties <u>which impact on how you eat</u>? If yes, please briefly state what these conditions are: *(Tick box: Yes (prompted to give brief details in open field) or No.)*
- Are you booked in or on a waiting list to receive surgery for your inflammatory bowel disease OR have you had surgery for inflammatory bowel disease in the past six months? *(Tick Box: Yes or No)*

- Are you currently experiencing a clinical flare of your inflammatory bowel disease symptoms that is being treated either with prescription of steroids, or changes to your usual medication regime? *(Tick Box: Yes or No)*

Measures

- HBI *or* SCCAI (Simple clinical measures of current disease status. Participant to complete whichever one is relevant to their condition I.e. for Crohn's or for Ulcerative Colitis – Gorilla will bring up correct one) *Important as current active disease or clinical flare up is likely to interrupt usual eating behaviours* (see next Appendix)

Accessibility (relating to eligibility criteria)

- Do you have access to reliable video technology and stable internet connection? *(Tick Box: Yes or No)*

- If you became a participant for this study, you would be invited to participate in an English-speaking interview of approximately ninety minutes duration.

Do you have any communication difficulties which may make this difficult for you? *(Tick Box: Yes (Prompt to explain what they are and how they'd usually manage them) or No).*

Additional Questions and Comments

- If there is anything else relating to these questions which you feel it's important to clarify, please enter a brief description here *(Open Field)*

Thank you for completing the screening questionnaire.

The researcher will now review your answers to confirm your eligibility to take part in the study.

P. Clinical Measure 1 (used in screening)

Delivered via Gorilla, PDF version included here for reference

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Q. Clinical Measure 2 (Used in screening)

Delivered via Gorilla, PDF version included here for reference

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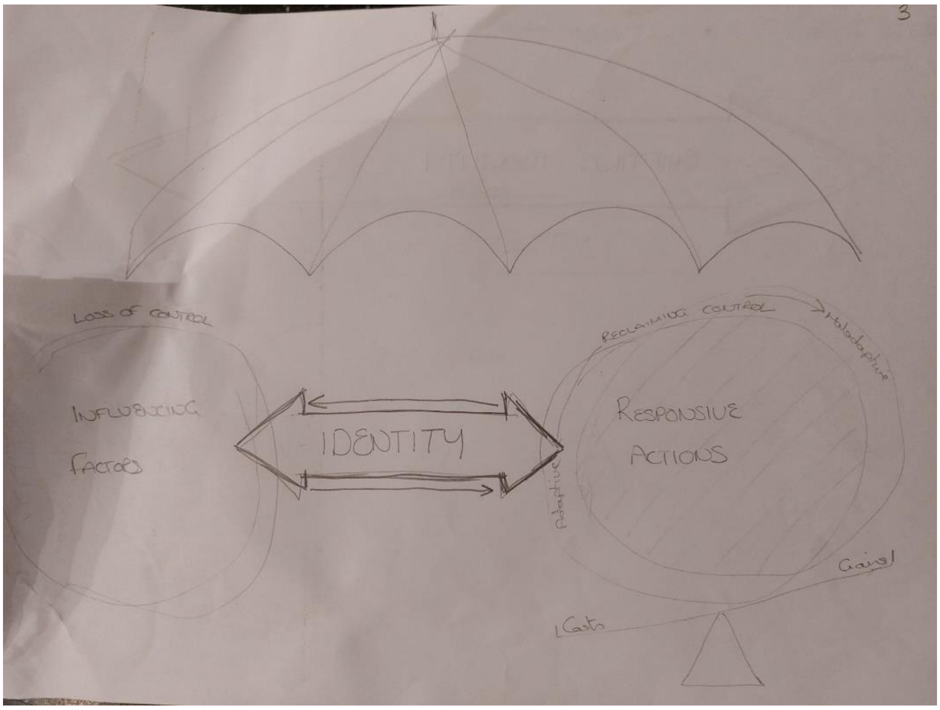
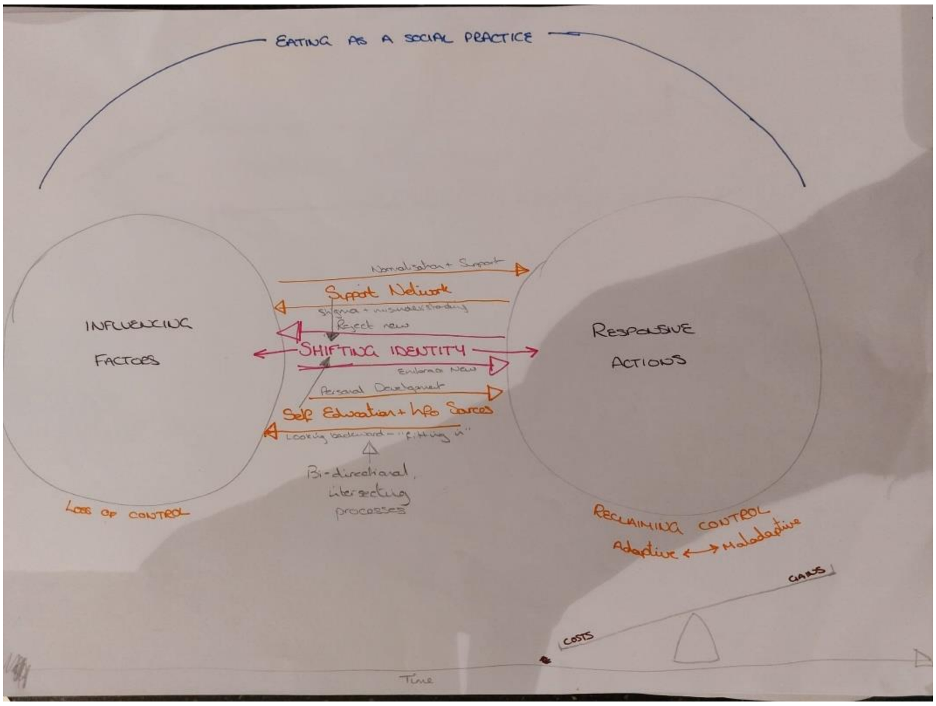
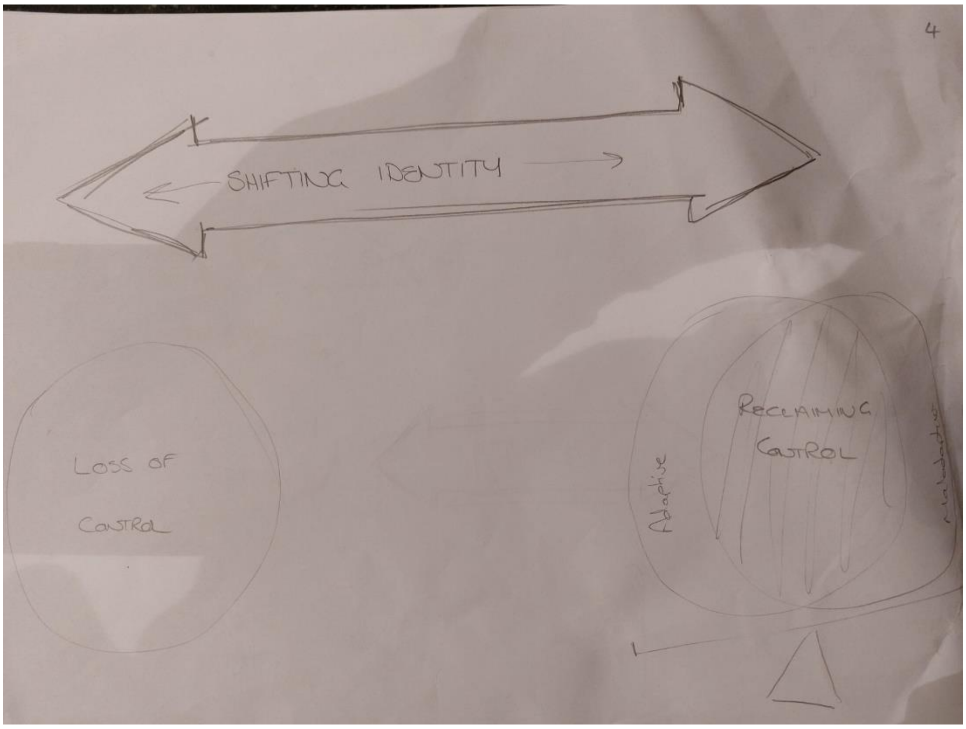
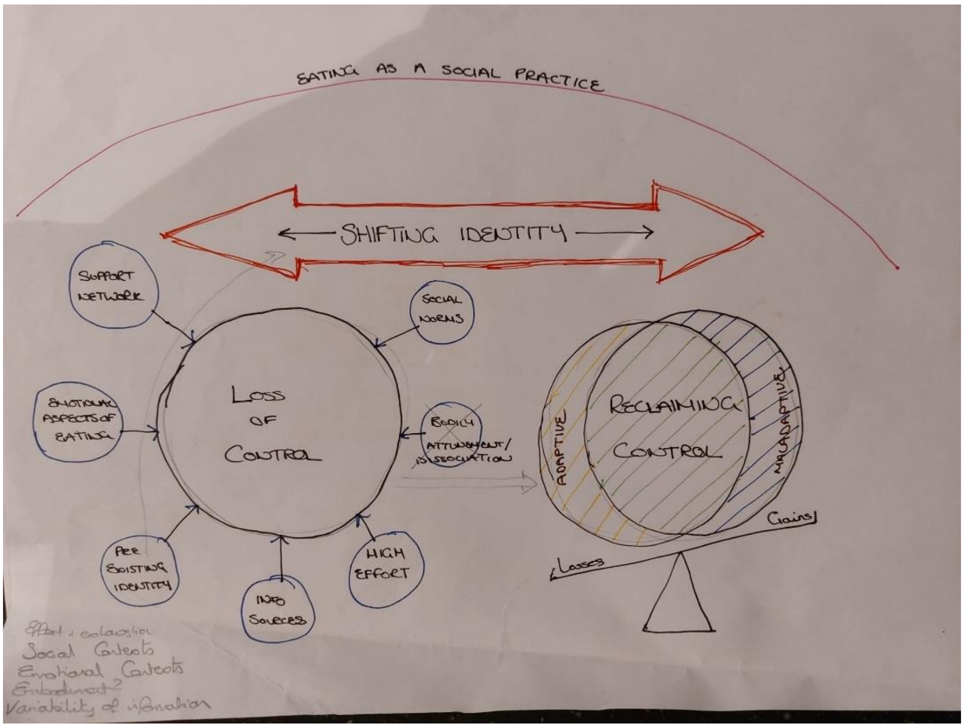
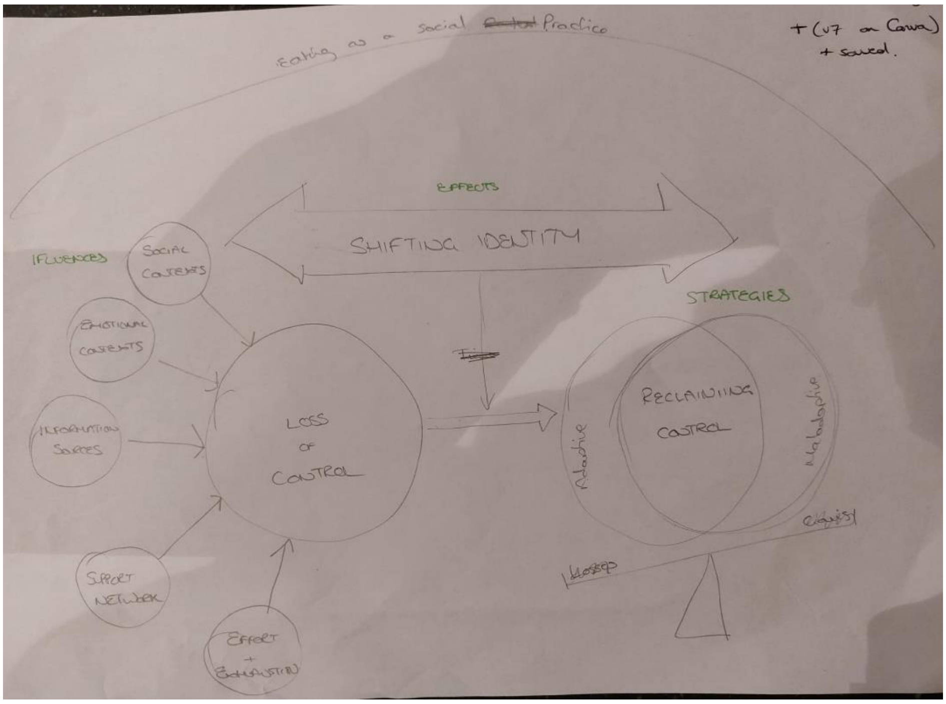
R. Development of Grounded Theory Conceptual Model

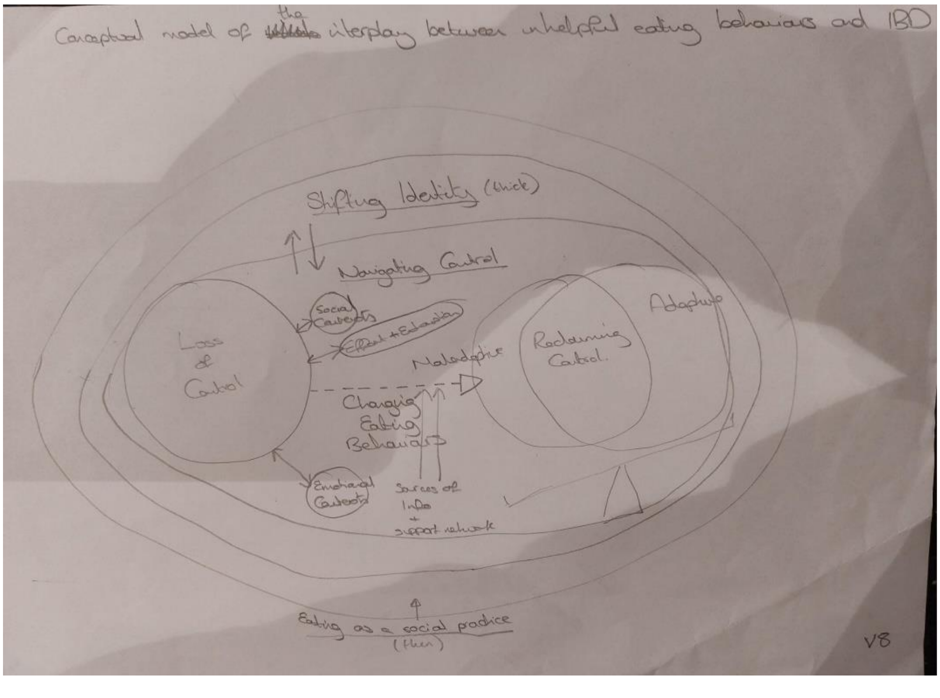


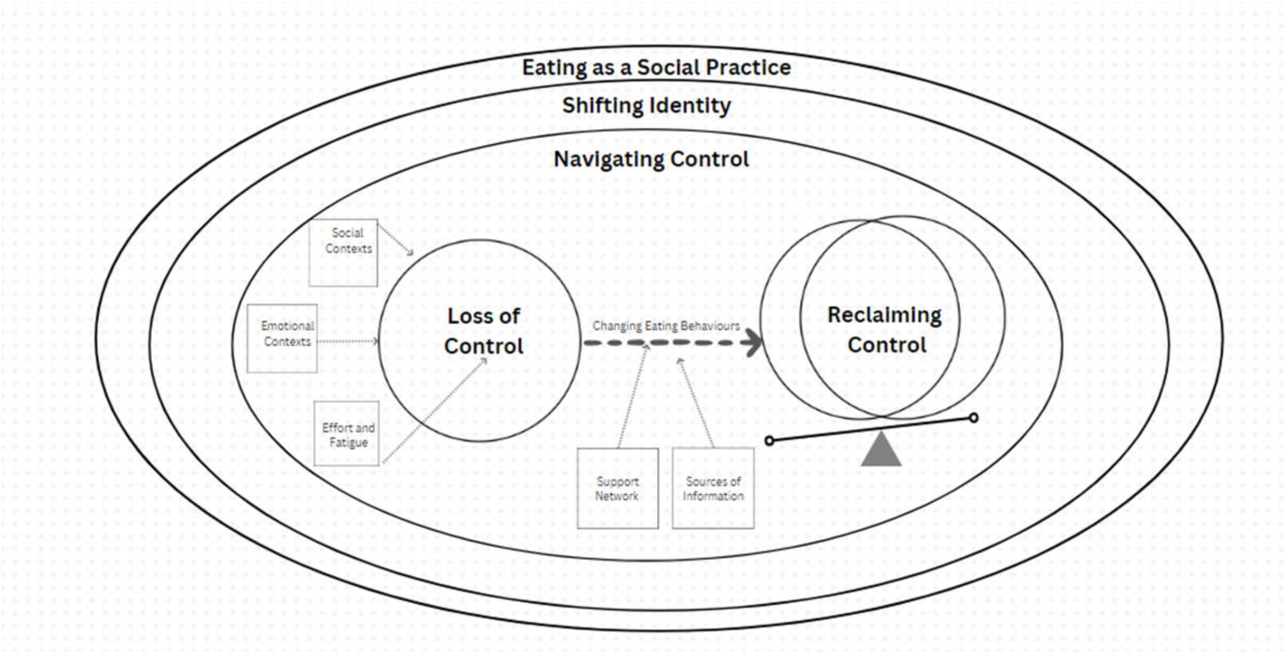



4
SHIFTING IDENTITY
LOSS OF CONTROL
RECLAIMING CONTROL
Adaptive
Maladaptive


EATING AS A SOCIAL PRACTICE
SHIFTING IDENTITY
SUPPORT NETWORK
SOCIAL NORMS
EMOTIONAL ASPECTS OF EATING
LOSS OF CONTROL
~~BODILY ATTUNEMENT/ DISSOCIATION~~
PRE EXISTING IDENTITY
INFO SOURCES
HIGH EFFORT
ADAPTIVE
RECLAIMING CONTROL
MALADAPTIVE
Gains
Losses
Effort + exhaustion
Social Contexts
Emotional Contexts
Embodiment?
Variability of information


Eating as a social ~~[illegible]~~ Practice
+ (v7 on Canva)
+ saved.
EFFECTS
SHIFTING IDENTITY
INFLUENCES
SOCIAL CONTEXTS
EMOTIONAL CONTEXTS
INFORMATION SOURCES
SUPPORT NETWORK
EFFORT + EXHAUSTION
LOSS OF CONTROL
STRATEGIES
RECLAINING CONTROL
Adaptive
Maladaptive

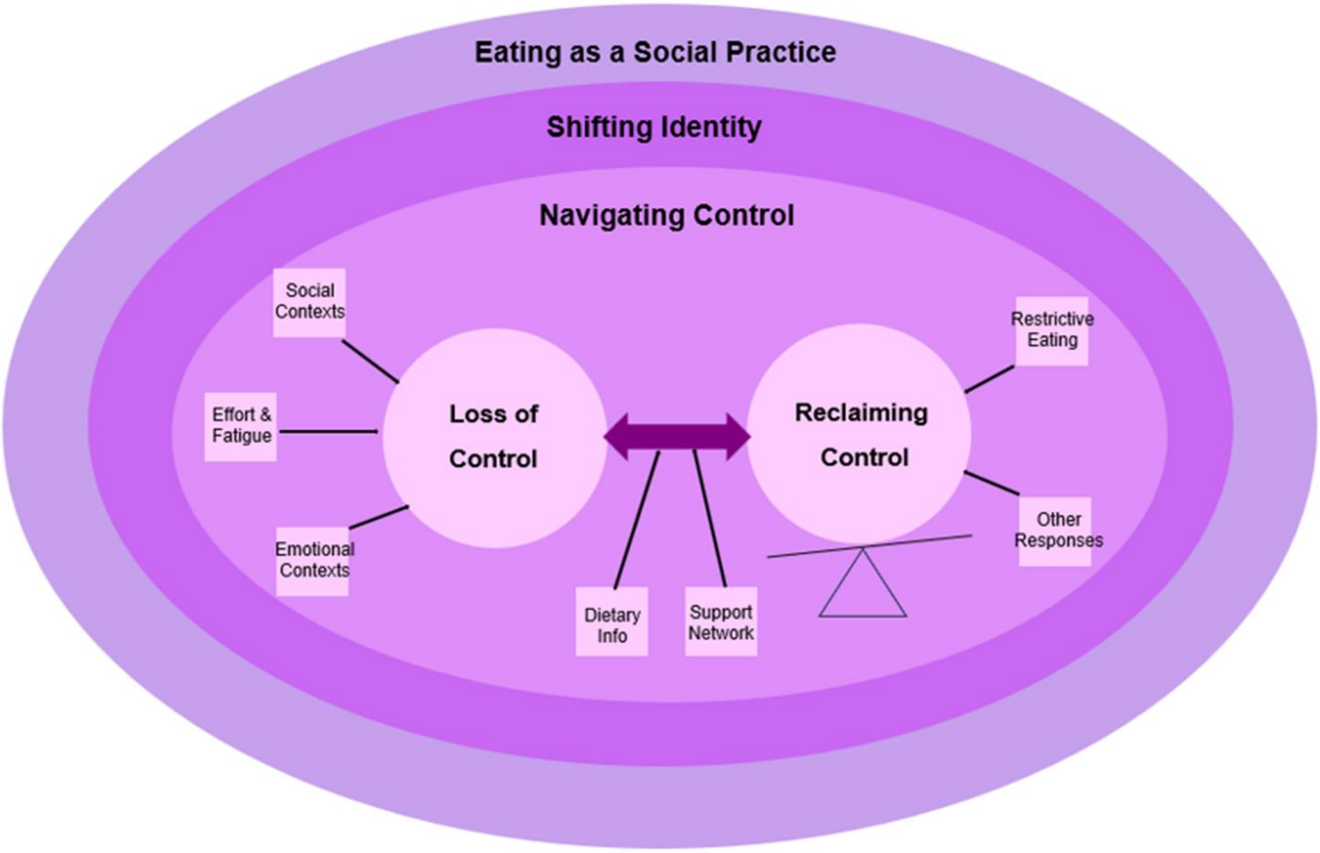

Conceptual model of ~~[illegible]~~ the interplay between unhelpful eating behaviours and IBD
Shifting Identity (thick)
Navigating Control
Social Contexts
Effort + Exhaustion
Loss of Control
Maladaptive
Reclaiming Control.
Adaptive
Changing Eating Behaviours
Emotional Contexts
Sources of Info + support network
Eating as a social practice (thin)
V8



Conceptual diagram of the interplay between unhelpful eating behaviours and IBD

Figure 1

Conceptual model of the interplay between unhelpful eating and Inflammatory Bowel Disease



“Mary’s” Interview
Initial Open Coding

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T. Mary’s Interview
Emerging Focussed Codes

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U. Excerpts of participant data demonstrating Theoretical Categories

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