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ILLNESS PERCEPTIONS, COPING AND PSYCHOSOCIAL OUTCOMES IN INFLAMMATORY BOWEL DISEASE

Section A: The role of Illness Perceptions in IBD Outcomes: A Literature Review

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Section B: Testing the Common Sense Model of Self-Regulation and the Role of Self-Compassion in IBD Outcomes: An Empirical Study

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Summary of Major Research Project

Section A: The role of Illness Perceptions in IBD Outcomes: A Literature Review

In Section A, I reviewed the literature regarding the role of illness perceptions in the key IBD outcomes of quality of life, psychological distress and medication adherence. I conducted a systematic literature search of five online databases, and after screening, found 25 empirical studies met eligibility criteria. Overall, globally poorer illness perceptions were associated with a lower quality of life and greater levels of psychological distress. A complex pattern of findings was reported regarding individual illness perceptions and outcomes. No single illness perception was observed to have a strong association with medication adherence. Findings were contextualised within the broader IBD literature. Clinical and research implications were provided, including the potential utility of total illness perception scores for clinical screening or as a target in future interventions.

Section B: Quality of Life in IBD: Testing the Common Sense Model of Self-Regulation and the Role of Self-Compassion

In Section B, I conducted an online, longitudinal questionnaire study which examined the Common Sense Model (CSM), a leading model of adjustment in the long-term conditions literature. 147 participated at timepoint 1, and 54 participated at timepoint 2, six months later. This study specifically examined whether the CSM findings observed cross-sectionally would hold longitudinally, with mixed results. Furthermore, the present study examined the role of self-compassion within the model, finding weak, limited evidence for theorised protective effects. A strength of the present study was the robust test of the CSM, adding longitudinal findings to a literature predominated by cross-sectional studies. Further research is needed to

replicate findings, and additional variables need to be explored within the CSM. Potential sources of error within the present study, as well as clinical implications, were discussed.

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Section A: The role of Illness Perceptions in IBD Outcomes: A Literature Review

Word Count: 7,979

Abstract

Introduction: Living with Inflammatory Bowel Disease (IBD) can bring significant psychosocial challenges, and have a detrimental impact of many aspects of an individual's life. Illness perceptions are thought to play a key role in processes of adjustment to IBD. This review aimed to synthesise the literature on illness perceptions in IBD, as it relates to the key outcomes of quality of life, psychological distress and medication adherence.

Method: Five online databases were systematically searched in October 2023 to identify relevant literature. A total of 25 studies met inclusion criteria. Studies were assessed and generally deemed to be of good quality. A narrative synthesis of findings was conducted.

Results: Poorer illness perceptions were associated with a lower quality of life and greater levels of psychological distress. A complex pattern of findings was reported regarding individual illness perceptions and outcomes. No single illness perception was observed to have a strong association with medication adherence.

Discussion: The complex pattern of findings limits firm conclusions. Findings were related to previous literature, and weaknesses of this literature were identified. Clinical and research implications are provided, including the potential utility of total illness perception scores for clinical screening or as a target in intervention research.

Keywords: Inflammatory Bowel Disease; Quality of Life, Psychological Distress, Illness Perceptions, Medication Adherence

Introduction

Inflammatory Bowel Disease (IBD) is an umbrella term for a number of chronic gastrointestinal conditions, primarily Crohn's Disease (CD) and Ulcerative Colitis (UC) (Baumgart & Carding, 2007). IBD has an unknown aetiology, with symptoms including persistent inflammation of the gastrointestinal tract, abdominal pain, frequency and urgency of bowel movements, and extraintestinal symptoms such as joint pain and fatigue (Guan, 2019). The typical course of IBD includes periods of 'active' disease or flare-ups, where symptoms increase in severity, and periods of remission where symptoms reduce or cease altogether (Trivedi et al., 2019). While IBD is incurable at present, symptoms can generally be managed through a combination of pharmacologic treatments, surgical intervention and lifestyle adjustments, although there is significant variation in individual outcomes (Cai et al., 2021; Crohn's and Colitis UK, 2021).

Globally, the prevalence of IBD is estimated at 0.3% of the adult population, with the highest rates of IBD seen in Western countries (Ng et al., 2017). Recent national surveys in the UK indicate an IBD prevalence of approximately 0.4 – 0.97% of the adult population (King et al., 2020, Pasvol et al, 2020). The incidence of new diagnoses has been rising consistently over the past two decades, with prevalence expected to rise above 1% of the UK population by 2025 (King et al., 2020). Management of IBD entails a significant economic cost for health services (Ghosh & Premchand, 2015), and many affected by the illness experience significant disruption to their work and relationships, alongside difficulties with daily functioning (see Jordan et al., 2016 for a review).

Living with and managing a long-term condition such as IBD will understandably have an impact on many aspects of an individual's life (Matcham et al., 2013). Alongside the physical health challenges, many studies have explored the impact of IBD on Quality of Life (QoL)

and Psychological Distress (PD) (see Knowles et al., 2018a; Barberio et al., 2021 for reviews). QoL has been defined as an individual's global "perception 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" (WHO, 1998, p.3). A further distinction is made in the literature between overall or general QoL, and 'condition-specific' or health-related quality of life (HR-QoL). HR-QoL refers to the individual's perception of the impact of their health condition and the associated treatments on their life, and commonly includes the domains of physical, emotional and social health (Gurkova, 2011). PD can be defined and measured in many ways, but is commonly conceptualised in terms of the prevalence and/or severity of mental health difficulties such as anxiety and depression (Polak et al., 2020).

Findings from this literature have consistently demonstrated that living with IBD is associated with a lower QoL compared to healthy, age-matched controls (Knowles et al., 2018a). Furthermore, rates of anxiety and depression within the IBD population are higher than the general population (Bernstein et al., 2019; Walker et al., 2008). The chronic and unpredictable nature of IBD can act as a maintaining factor for psychological distress in many (Caballero-Mateos, 2023), with deterioration in QoL and greater PD observed during flare-ups of the illness (Knowles et al., 2018b). These findings are reflected in current NICE (2019) quality standards, which highlight the need for IBD care to attend to psychological as well as physical needs.

Considering this research evidence as a whole, it is clear that IBD presents a wide range of challenges for those living with the condition. Many promising, novel treatments for management of the physical symptoms of IBD have been developed in recent years (Al-Bawardy et al., 2021), and while this is to be welcomed, all existing treatments can only reduce symptoms, with a cure for IBD remaining a distant goal. Indeed, some research evidence suggests that psychological distress and disease activity have a reciprocal

relationship, creating a 'vicious cycle' (Gracie et al, 2018). Appropriate intervention could potentially disrupt this cycle, improving both psychological *and* physical health outcomes. It is therefore essential that we understand the psychosocial processes involved in living with and managing IBD, in order to address the negative psychosocial outcomes observed and to provide holistic care (NICE, 2019).

A significant amount of research attention has been dedicated to understanding these processes, sometimes referred to as 'adjustment', in both the wider long-term conditions (LTCs) and IBD-specific literature (Hoyt & Stanton, 2018). Indeed, a plethora of models have been proposed which seek to delineate the process of psychological adjustment to living with a LTC and the determinants of psychosocial outcomes. A useful overview of these models is provided by Moss-Morris (2013), who notes that there is considerable variation in how researchers define 'adjustment' to chronic illness, as well as significant heterogeneity in the psychosocial outcomes measured. Adjustment has been defined by some as the presence or absence of mental health difficulties or psychiatric diagnoses, by others as the degree of daily functioning maintained during an illness, and elsewhere is operationalised in terms of positive affect, or 'emotional balance' (Moss-Morris, 2013, p. 683). Similarly, the psychosocial outcomes studied as 'endpoints' in adjusting to chronic illness include quality of life, psychological distress, and medication adherence, amongst others.

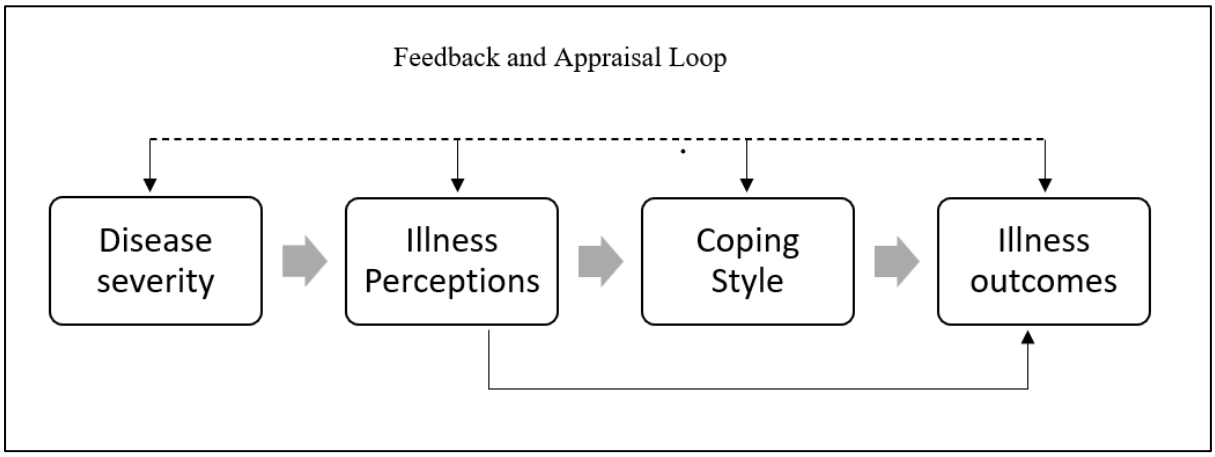
A commonality across most models of adjustment to chronic illness is the key role played by cognitive and emotional appraisals in response to illness-related stimuli, such as illness symptoms, treatment side-effects, and the impact of the illness on social and work life (Hoyt & Stanton, 2018: Jordan et al. 2016). Many models propose that the nature of these appraisals determine how an individual copes or responds to the stressor (e.g. avoidance, seeking support) which in turn can affect a wide range of outcomes such as mental wellbeing, medication adherence and quality of life (Hagger et al., 2017; Leventhal et al., 1992). As this

process of appraisal and reaction is iterative, it is hypothesised that an individual's appraisals may change in response to different outcomes (e.g. medication improving symptoms), new information or changes in their social and environmental context (e.g increased social support) (Leventhal et al., 1992).

One such model which has been tested extensively across a range of LTCs (see Hagger et al., 2017) is the Common Sense Model of Illness (CSM) (Leventhal et al., 1980). Linking social learning theory (Bandura, 1977) with cognitive theories of illness (Rogers, 1983), the CSM aims to articulate the relationship between disease severity or symptoms and psychosocial outcomes. The model proposes that these relationships are reflexive and dynamic, whereby the individual develops cognitive and emotional appraisals, or 'illness perceptions', in response to disease activity (e.g. in response to pain, perceiving the illness as serious and threatening), chooses coping strategies to manage the illness perception (e.g. taking medication), leading to various 'illness outcomes' (e.g. feeling low in mood, or anxious if the symptom has not been managed effectively). The CSM proposes that an individual continuously monitors their symptoms, illness perceptions and coping strategies, updating each variable continuously, creating feedback loops (see Figure 1).

Figure 1.

The Common Sense Model (Knowles, 2011; adapted from Hagger & Orbell, 2003)



Illness Perceptions can be defined as a set of integrated beliefs an individual has regarding their illness across several areas, such as perceived illness consequences and perceived illness controllability (Broadbent et al., 2006; Lacroix, 1991). Building upon the theoretical work of Leventhal et al. (1984), a number of measurement tools were developed to define and measure the concept of Illness Perceptions (IPs). Early measurement tools conceptualised IPs as having five distinct facets (e.g. Lau & Hartman, 1983), but further empirical work has identified eight distinct illness perceptions. See Table 1 below for a summary of these factors, adapted from Hayes et al. (2020).

The most commonly used IP measures are variations on the Illness Perception Questionnaire, developed by Weinman et al. (1996). Several revised and shortened versions now exist, including the Illness Perception Questionnaire – Revised (IPQ-R, Moss-Morris et al., 2002) and the Brief Illness Perception Questionnaire (BIPQ, Broadbent et al., 2006). These questionnaires have generally demonstrated strong psychometric properties in their application across a broad range of illnesses (Broadbent et al., 2006; Karatas et al., 2017; Rivera et al., 2022). There are many other illness-related constructs which are similar but conceptually distinct from IPs, such as self-efficacy beliefs about managing disease (Lorig et al., 2001) and treatment-necessity beliefs (Horne et al., 1999). The Illness Cognition Questionnaire (Evers et al., 2001) measures some similar constructs to the IPQ, such as perceived helplessness regarding an illness. However, most facets of the IPQ are not measured by the ICQ (e.g. perceived illness understanding, perceived chronicity), and as such the two scales can be viewed as measuring related but distinct concepts.

Table 1.

Definition of Individual Illness Perceptions

Illness Perception	Definition
Cause	Beliefs that individuals hold about the cause of an illness
Consequences	Beliefs about the influence of an illness on QoL
Identity	Beliefs about the label and symptoms associated with an illness
Timeline (chronic/cyclical and acute)	Beliefs about the course and duration of an illness (divided into enduring and cyclical dimensions in some measurement tools)
Controllability (personal and treatment)	Beliefs about the effectiveness of coping behaviours and treatments targeting an illness
Coherence	Beliefs about comprehension of an illness
Concern	Level of concern about the illness
Emotional representations	Beliefs about affective responses to having an illness

The validity of the CSM across the LTC literature is well-established, having been applied in over 250 empirical studies to successfully understand adjustment to diseases including diabetes, cardiovascular disease and cancers (Hagger et al., 2017). A meta-analysis of studies

which have used the CSM (Hagger et al., 2017) reported that IPs in particular play a key role in the process of adjustment to LTCs, as they are directly associated with a variety of outcomes. Coping strategies, comparatively, tended to show indirect associations with outcomes.

Moreover, Broadbent et al. (2015) reviewed use of the BIPQ across a range of illnesses and 188 empirical studies, noting that IPs had good predictive validity for a range of health outcomes, and findings were generally in line with adjustment theories such as the CSM. The clinical outcomes measured across these reviews varied significantly, but common outcomes included quality of life, psychological health or distress, and adherence to medical treatment. A recent review by Hayes et al. (2020) examined studies which have specifically utilised the CSM with IBD populations. The central importance of IPs was highlighted, with the authors noting direct and indirect statistical associations with psychosocial outcomes in IBD, and that IPs are potentially modifiable psychological processes. Taken together, these findings suggest that IPs may play a central role in the process of adjustment to LTCs, including IBD.

Although there have been recent reviews which examined the role of illness perceptions in IBD outcomes (Hayes et al.,2020; Polak et al., 2020), these reviews have significant limitations. Firstly, a significant amount of novel research has been published in this area in the intervening years. Secondly, Hayes et al. (2020) noted a number of limitations to their review, including a small number of included studies (n = 7), a lack of longitudinal studies and small heterogenous sample sizes. Polak et al. (2020) cited similar limitations, having found mixed support for the CSM in their review, commenting ‘firm conclusions could not be reached about the unique contribution of illness perceptions to the explanation of outcomes.’ Thirdly, neither review investigated the outcome of treatment adherence in IBD. This is a significant area of oversight as adherence is associated with a range of outcomes in IBD

(Chan et al., 2017), and some studies suggest IBD knowledge (similar to the illness perception *coherence*) is positively correlated with adherence (Moradkhani et al., 2011).

Furthermore, neither Hayes et al. (2020) nor Polak et al. (2020) focused on the role of illness perceptions and IBD outcomes specifically, as their reviews were concerning the broader CSM literature in the former, and questions regarding stigmatisation and negative emotional reactions towards IBD from the community in the latter. Given the significant body of research indicating the key role of illness perceptions in IBD, and the aforementioned limitations of recent reviews, an up-to-date review of the literature which singularly examines illness perceptions and IBD outcomes is needed.

The specific research questions posed by this review were:

1) What is the evidence regarding the association of illness perceptions and QoL in IBD?

2) What is the evidence regarding the association of illness perceptions and psychological distress in IBD?

3) What is the evidence regarding the association of illness perceptions and treatment adherence in IBD?

Method

Search Strategy

A number of online social science and medical databases were searched in order to identify papers for the present review (PsycInfo, Medline, CINAHL, Web of Science and ASSIA). There were three primary search terms, each with several synonyms and variations.

1. The term ‘illness perception’ was entered along with variations such as ‘illness representation’ to identify papers with the psychological variable of interest
2. The terms ‘Inflammatory Bowel Disease’, as well as the two primary types of IBD (Crohn’s disease and Ulcerative colitis) were entered to identify papers with the target population, with variations including ‘IBD’, ‘Crohn’s’ etc.
3. To identify papers with the outcomes of interest, terms such as ‘Quality of Life’, ‘anxiety’, ‘depression’ and ‘medication adherence’ were entered

The full search string is shown in Appendix A. Where possible, all search terms were entered with the ‘abstract’, ‘title’ and ‘keywords’ filters applied. The final search was conducted in October 2023.

Eligibility Criteria

In order to be included in the present review, studies needed to meet the following eligibility criteria:

1) Include an adult IBD population
2) Include a validated measure of illness perceptions, cognitions or representations
3) Include at least one statistical assessment of the association between illness perceptions and at least one of the three outcomes of interest (quality of life, psychological distress, treatment adherence)

4) Employ a cross-sectional or longitudinal study design, with intervention studies, experimental studies and observational studies all included
5) Be published in a peer-reviewed journal, after the year 2000 (23 years)
6) Be written in English

Studies prior to the year 2000 were excluded on the grounds that biologic treatments for IBD became widely available at this time, and represented a significant change in the management of the illness (Banerjee et al., 2020). In other chronic health conditions where significant treatment advances have been made, research has identified subsequent change in psychological outcomes and quality of life (Aspinall et al., 2022). It therefore seems plausible that studies of illness perceptions in IBD before the introduction of biologics would differ significantly, especially considering many illness perception scales assess beliefs about the effectiveness of treatments. The other exclusion criteria were as follows:

- Studies where it was not possible to distinguish between the IBD population and other groups (e.g. people with irritable bowel syndrome)
- Study protocols, conference abstracts, poster presentations and grey literature
- Studies with a mixed adult and youth (under 18 years of age) sample, where it was not possible to isolate data from the adult sample only

Procedure and Data Extraction

Identified records were screened by title and abstract, using the eligibility criteria described above. The remaining studies underwent full-text screening to identify the final set of studies to be included in the present review. All relevant study outcome data were extracted and tabulated (e.g. study design, sample size, instruments used, key results). Following this, a narrative synthesis of the findings was conducted. Meta-analysis was not deemed appropriate given the significant variation in outcomes measured, as well as the current need for a

narrative explanation of a complicated body of research.

All associations between illness perceptions and the three outcomes of interest were examined. The self-reported '*cause'* illness perception, where participants describe their beliefs about the cause of their illness, was not included in the analysis of findings due to heterogeneity in how this was recorded across studies and subsequent difficulty comparing findings.

Study Quality and Risk of Bias Assessment

Each study included in the present review was assessed on its methodological quality and risk of bias. Two quality appraisal tools were required due to the heterogenous design of the studies under review. The Joanna Briggs Institute (JBI) critical appraisal tools for cross-sectional studies (JBI, 2020a) and cohort studies (JBI, 2020b) were utilised on the relevant studies to assess study quality and risk of bias. JBI critical appraisal tools are widely used, validated instruments which assess a number of different domains of study quality, and can support interpretation of findings from literature reviews (Barker et al., 2023). Common features across these checklists include an assessment of whether outcomes were measured using valid and reliable instruments, whether study inclusion and exclusion criteria were clearly defined, and whether potential confounding factors were identified and managed appropriately. No study was to be excluded on the basis of this quality assessment; however, it informed interpretation of findings.

Results

Literature searching identified a total of 369 records. After removal of duplicates, 259 records underwent title and abstract screening against eligibility criteria. 102 papers were assessed at the full-text level, of which 25 met inclusion criteria. The PRISMA (Moher at al., 2009) flow-chart for the present review is shown in Figure 2. An overview of included studies is presented in Table 2. A narrative overview of included studies and their quality assessment is also shown below, followed by sections addressing each review question in turn.

Figure 2.

PRISMA flow-chart for study identification (Moher et al., 2009)

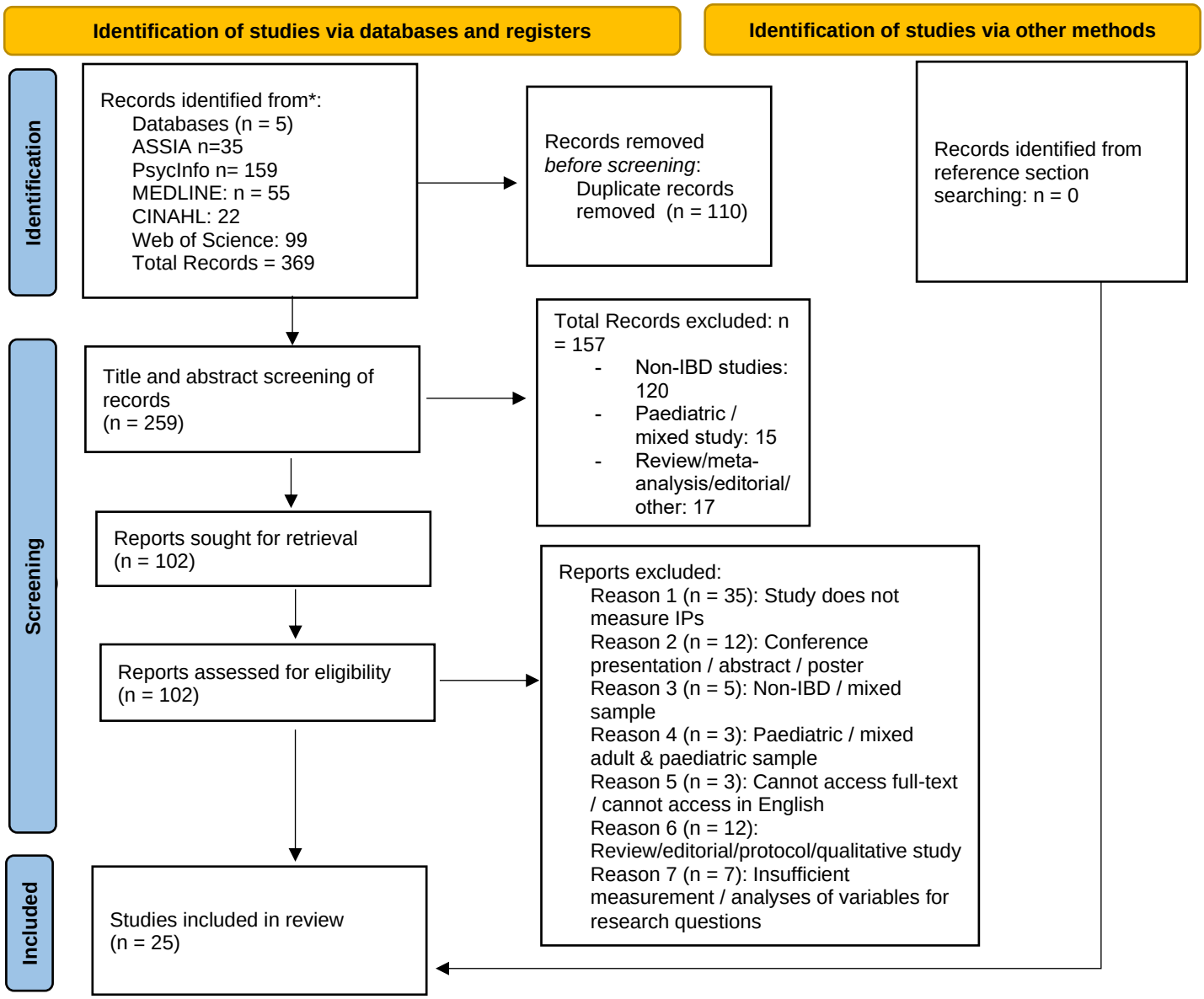


Table 2.

Overview of Included Studies

Authors, Year of Publication	Study Design and Setting	Sample size (N) and Participant Characteristics	Primary outcomes measured	Outcome measurement tools
Artom et al., 2017	Cross-sectional survey study, participants recruited from 3 outpatient IBD clinics in London, UK.	N = 182 (CD = 33%, UC = 64%, other IBD = 3%). Male: 43%. Median age: 37 years. Ethnicity data not recorded.	Disease activity, fatigue (IBD-specific and general), QoL, illness perceptions, anxiety, depression, stress, distress, coping behaviours, sleepiness	HBI, SCCAI, IBD-F, MFI, IBDQ, BIPQ, HADS, PSS, IBD-DS, CBSQ, ESS
Bennebroek Evertsz et al., 2020	Cross-sectional baseline analysis, sub-group of participants from an RCT. Recruitment from 4 IBD outpatient clinics in the Netherlands. Participants needed low QoL to be invited to participate.	N = 118 (CD = 57.6%, UC = 42.4%). Male: 36.4%. Mean age: 39 years. No ethnicity or nationality data recorded.	DSM-IV psychiatric diagnoses, dysfunctional attitudes / beliefs, illness perceptions, anxiety, depression	SCID-1, DAS, IPQ-R, HADS

Table 2. (continued)

Dorrian et al., 2009	Cross-sectional survey study. Participants identified by consultant, recruited from outpatient Intestinal Failure Clinic in UK hospital	N = 80, (CD = 32.5%, UC = 67.5%). Mean age: 40 years. Male: 46%. Ethnicity: Not reported.	Disease activity, Pain, Illness Perceptions, Coping strategies, anxiety, depression, HR-QoL, daily functioning	CDAI, SF-MPQ, IPQ-R, COPE, HADS, IBDQ, FLP
Eindor-Abarbanel Et al., 2018	Cross-sectional survey study of IBD outpatients currently receiving treatment. Recruited from 3 hospital clinics in Israel.	N = 311 (CD = 70.4%, UC = 26%, other IBD = 3.5%), Male: 37.6%. Median age: 34.8 years. No ethnicity data recorded.	Medication adherence, disease severity, illness perceptions, self-efficacy, sense of coherence, anxiety, depression	BIPQ, IBD-SE, SOC-13, HADS, MMS8
Eindor-Abarbanel et al., 2021	Cross-sectional survey study of outpatients from 3 IBD clinics in Israel.	N = 299 (CD = 70.9%, UC – 29.1%). Male: 37%. Median age: 34 years. No ethnicity data recorded.	Disease severity, treatment type, illness perceptions, self-efficacy, sense of coherence, anxiety, depression,	Adapted CDEIS, bespoke treatment type scale, BIPQ, IBD-SE, SOC-13, HADS

Table 2. (continued)

Glynn et al, 2022	Online, cross-sectional survey study. Participants recruited via Australian IBD charity newsletter	N = 211 (CD = 64%, UC = 31.3%, indeterminate IBD = 4.7%). Male: 12.3%. Mean age: 38.7 years. No ethnicity data recorded.	Disease severity, illness perceptions, coping styles, post-traumatic stress disorder symptoms, visceral sensitivity, psychological distress (depression, anxiety and stress), QoL	PRO3-CD, PRO2-UC, BIPQ, Brief COPE, PCL-5, GUTS, DASS, WHO-QOL
Han et al., 2005	Cross-sectional survey study, convenience sample of IBD patients from single hospital in UK.	N = 111 (all UC patients). Male: 48.6%. Mean age: 53.4 years. No ethnicity data recorded.	Disease severity, Disease-specific and general QoL, illness perceptions	CAI, IBDQ, SF-36, IPQ
Hayes et al., 2022(a)	Cross-sectional survey study. Recruitment via IBD charities/organisations and social media. Location: online	N = 319. IBD sub-types not reported. Male: 75.2%. Mean age = 40.37 years. Ethnicity not reported 48.5% European, 32.6% Australia & New Zealand. 11.3% North American.	IBD symptoms, Illness Perceptions, Fear of contracting Covid-19, Coping Styles, Psychological distress (depression, anxiety and stress), QoL	GSRS, BIPQ, FCCS, Brief-COPE, DASS-21, EUROHIS-QOL

Table 2. (continued)

Hayes et al., 2022(b)	Cross-sectional survey study, participants recruited from 2 IBD outpatient clinics in Australia	N = 141 (CD = 61%, UC = 39%). Males: 52.5%. Mean age: 40.4 years. No ethnicity data recorded.	Disease activity, illness perceptions, coping styles, acceptance, depression, anxiety, stress, QoL	CDAI, SCCAI, BIPQ, VSI, Brief COPE, AAQ-2, DASS, EUROHIS-QOL
Horne et al., 2009	Cross-sectional survey study, questionnaires posted to random cohort from IBD charity membership in the UK.	N = 1871 (CD = 44.8%, UC = 48.9%, other IBD = 6.3%). Male: 36.6%. Mean age: 50.1 years. No ethnicity data recorded.	Medication adherence, beliefs about medication, chronicity of condition, illness perceptions	MARS, BMQ, IPQ-R
Kantidakis et al., 2021	Cross-sectional survey study, mix of online and face-to-face participants. Recruitment online via Australian IBD charity, and IBD outpatient clinic (Australia).	N = 261 (CD = 64.8% CD, UC = 35.2%) Males: 24.1%. Mean age: 37 years. No ethnicity data recorded	Disease severity, disease-specific QoL, Coping styles, Mindfulness, Illness Perceptions, depression, anxiety, stress	sCDAI, LTI, IBDQ, NGSE, Brief-COPE, MAAS, BIPQ, DASS-21

Table 2. (continued)

Kiebles et al., 2010	Cross-sectional survey study. Patients recruited from IBD outpatient clinic in USA.	N = 38 (CD = 45%, UC = 55%). Male: 37%. Mean age: 36.2 years. Ethnicity: 82% White, no other ethnicity data recorded.	Illness perceptions, psychological distress (including depression and anxiety), emotional functioning, disease acceptance, coping, disease impact, disease specific and health-related QoL, adjustment	IBDQ, SF-12v2, IPQ-R, PSQ, BSI, DDAQ, Brief-COPE, PDS
Knowles et al., 2013	Online cross-sectional survey study. All participants had stomas. No recruitment strategy detailed.	N = 83 (CD = 37.3%, UC = 62.7%). Male: 28%. Mean age: 38.5 years. Ethnicity: 42.2%, 39.8% American, 9.6% Australian, 8.4% other.	Health status, illness perceptions, coping style, anxiety, depression	HSS, BIPQ, Brief-COPE, HADS

Table 2. (continued)

Knowles et al., 2011	Cross-sectional survey study. Participants recruited from outpatient IBD clinic in Australia.	N = 96 (all CD patients). Male: 35.4%. Mean age: 37.8 years. No ethnicity data recorded. Age > 40 excluded.	Disease severity, Illness Perceptions, coping style, anxiety, depression,	CDAI, BIPQ, Brief-COPE, HADS
Knowles et al., 2013a	Cross-sectional survey study, questionnaires mailed to all eligible participants. Recruitment from 2 IBD outpatient clinics in Australia.	N = 31 (all CD patients with an ostomy / stoma). Male: 54.8%. Mean age: 45 years. Ethnicity: 68% Australian, 23% European, 9% Other.	Ostomy type, surgery type, illness perceptions, anxiety, depression, stoma QoL	BIPQ, HADS, SQOL
Knowles et al., 2013b	Cross-sectional, online survey study. Participants required to be in romantic relationship. Recruited via online IBD support groups and IBD charities in Australia, US & Europe.	N = 74 (CD = 59.5%, UC = 40.5%). Male: 17.5%. Mean age: 38 years. Nationality: 54% American, 19% European, 11% Australian, 16% other nationalities. No ethnicity data recorded.	Illness Perceptions, anxiety, depression, sexual problems & satisfaction, marital functioning, family functioning, body image & self-consciousness	BIPQ, HADS, SPS, SSS, MFS, FFS, BISC

Table 2. (continued)

Larussa et al., 2020	Cross-sectional survey study, participants recruited from single outpatient IBD clinic in Italy. Only patients in remission included.	N = 202 (CD = 29%, UC = 71%). Male: 54%, Median age: 48. Ethnicity data not recorded.	Disease activity, QoL, anxiety, depression, illness perceptions	HBI, MS, s-IBDQ, HADS, BIPQ
Michetti et al., 2017	International cross-sectional survey study. Participants recruited from outpatient clinics in 33 countries areas, 501 different sites.	N = 1876 (CD = 66%, UC = 34%). Male: 50.3%. Mean age: 39.6 years. Ethnicity: 86% Caucasian, 6% Asian, 6.2% Hispanic, 0.4% Black, 1.4% Other	Current and past disease severity, treatment necessity beliefs, medication adherence, illness perceptions, depression	Bespoke disease severity scale (5-point Likert scale, single question), BMQ, MMAS, BIPQ, PHQ-2
Rochelle and Fidler, 2013	Cross-sectional survey study, convenience sample recruited from a single IBD outpatient clinic in London	N = 102 (CD = 45%, UC = 55%). Males: 34.3% Mean age: 41.9 years. Ethnicity data not recorded.	Disease severity, illness perceptions, anxiety, depression, QoL (IBD-specific)	Biomarkers for disease activity, IPQ-R, HADS, IBDQ

Table 2. (continued)

Severs et al., 2017	Longitudinal online survey study (2.5 years), participants recruited from 14 different outpatient IBD clinics in the Netherlands.	N = 2612 (CD = 59.6%, UC = 40.4%). Male: 42.2%. Mean age: 47.8 years No ethnicity data recorded.	Disease severity, healthcare utilisation, medication adherence, HR-QoL, illness perceptions	CDAI, MTWSI, bespoke visual medication adherence scale, 5 subscales of EQ-5D-3L, BIPQ
Tribbick et al., 2017	Cross-sectional survey study of IBD outpatients. Location: Australia.	N = 81 (CD = 69.1%, UC = 30.9%). Mean age = 35 years. Male = 48.1%. Ethnicity not reported. Nationality: 75% Australian, 2.5% New Zealander, 9.8% UK.	Disease activity, Anxiety, Depression, Illness Perceptions, QoL	MI, HADS, BIPQ, Who-QOL8
van Der Have et al., 2013	Cross-sectional survey study. Participants recruited from 1 site (Netherlands), recruited prior to colonoscopy appointment	N = 82 (all CD patients). Male: 37%. Mean age: 42 years. No ethnicity data recorded	Disease activity, perceived health, neuroticism, illness perceptions, coping, health-related QoL	CDAI, CDEIS, IPQ-R, SF-36 (single item), NPV-IN (neuroticism subscale), UCL, IBDQ-32

Table 2. (continued)

van Der Have et al., 2016	Longitudinal survey study over 12 months. Patients receiving anti-TNF therapy from 6 Dutch hospitals were invited to participate	N = 128 (CD = 81.3%, UC / IBD unclassified = 19.7%). Male: 45%. Mean age: 36.6 years. Ethnicity data not recorded	Medication adherence, disease activity, illness perceptions, treatment beliefs, loss of response	MMAS-8, HBI, SCCAI, BIPQ, BMQ
van Erp et al., 2017	Cross-sectional survey study, online & postal options. Recruitment from IBD outpatient clinic in the Netherlands.	N = 211 (CD = 73%, UC = 27%). Male: 39.8%. Mean age: 42.9. No ethnicity / nationality data recorded	Disease activity, joint/back pain, illness perceptions, coping strategies, QoL, work and activity impairment,	CDAI / SCCAI, bespoke joint/back pain questionnaire, IPQ-R, CRSQ, SF-36, WPAI
Zhang et al., 2016	Cross-sectional survey study. Participants recruited from IBD clinic (outpatient & inpatient) in China. Excluded from study if history of mental health difficulties / treatment.	N = 159 (All CD patients). Mean age, gender, ethnicity not reported.	Disease severity, illness perceptions, coping strategies, stress, anxiety, depression, QoL	CDAI, BIPQ, Brief COPE, PSS, HADS, IBDQ

Note: (see Appendix B for glossary of outcome measures)

General Overview of Included Studies and Quality Assessment

The majority of studies included in the present review (23/25) employed cross-sectional survey designs. Two studies were longitudinal in nature (Severs et al., 2017 & van Der Have et al., 2016). No studies utilising a randomised controlled design met criteria for inclusion in this review.

Cross-sectional Studies

The Joanna Briggs Institute (JBI) critical appraisal tool for analytical cross-sectional studies (JBI, 2020) was used to assess study quality for the 23 cross-sectional studies (see Appendix C for overview of this tool). Inclusion and exclusion criteria were clearly defined in nearly all studies (22/23). Sufficient information was generally provided (19/23 studies) regarding the study setting and demographic details of the participants. Males were generally under-represented in these studies, and information regarding ethnicity was often missing, raising potential difficulties for generalising from these findings. Recruitment dates and methods were insufficiently described in several instances (Bennebroek Evertsz et al., 2020; Dorrian et al., 2009; Hayes et al., 2022(a)).

IBD disease activity or severity was generally measured using validated self-report tools, however, a small number of studies (Eindor-Abarbanel et al., 2021; Glynn et al, 2022; Hayes et al., 2022(a); Rochelle & Fidler, 2013) utilised questionnaires which are not considered to meet current best practice (Walsh et al., 2016). Michetti et al. (2017) employed a novel, unvalidated clinician-rated scale for measuring disease activity, while Horne et al. (2009) did not include any measure of disease severity in their analysis. Results from these studies should thus be interpreted with caution. Similarly, Kiebles et al. (2010) utilised a HR-QOL instrument (the IBDQ (Guyatt et al., (1989))) to measure disease activity, contrary to the stated purpose of this instrument.

A particularly robust method for measuring disease activity was employed by van Der Have et al. (2013), who included both a gold-standard self-report measure, as well as a clinical disease activity score gathered from patient colonoscopies. Findings from this study may therefore be considered particularly reliable.

Consideration of possible confounding variables was considered in the majority of studies (18/23). Four studies (Kiebles et al., 2010; Knowles et al., 2013; Knowles et al., 2013 & Larussa et al., 2020) did not account for the possible role of confounding variables, however these studies were exploratory in nature and not testing specific hypotheses. The exclusion of a disease activity measure in Knowles et al. (2013) is particularly noteworthy as this may have significantly influenced findings regarding illness perceptions and HR-QoL amongst patients with a stoma. Bennebroek-Evertsz et al. (2020) cited insufficient statistical power as justification for not including potential confounders.

Key outcomes were measured using validated instruments in all studies. Illness perceptions were measured using the IPQ-R in eight studies and the BIPQ in 15 studies. Dorrian et al. (2009) note that the IPQ-R has not been validated with an IBD population and therefore may not be suitable for measuring illness perceptions with this population. The BIPQ has also not been specifically validated with an IBD population, however, it has been used in many previous studies with this population and produced results consistent with the broader LTC literature (Broadbent et al., 2015).

Appropriate statistical procedures were used to test hypotheses and generate results, with structural equation modelling (used in eight studies) and regression analyses (13 studies) being the primary methods of analysis. Correlational analyses and *t*-tests were used in some exploratory studies (e.g. Kiebles et al., 2010; Knowles et al., 2013).

Longitudinal Studies

Two studies included in the present review used a longitudinal study design (Severs et al., 2017 & van Der Have et al., 2016), both of which were investigating medication adherence in IBD. An adapted version of the JBI Critical Appraisal Tool for Cohort Studies (JBI, 2020b) was used to assess study quality for these studies (see Appendix D for an overview of this tool).

In both studies, validated tools were used to measure all clinical and psychological variables including IBD severity, with the exception of the medication adherence tool used by Severs et al. (2017) which was an unvalidated, novel scale. The follow-up time was reported in each study. The follow-up time was felt to be of sufficient length for the outcome to occur, as taking medication for IBD generally occurs at least bi-monthly (Denesh et al., 2021).

Appropriate statistical analyses were used to generate results in both instances (logistic regression), with a comprehensive range of demographic and clinical variables entered as possible confounders. It is noteworthy that loss to follow-up was high in Severs et al (2017), at approximately 50% over two years. Severs et al. (2017) report that study completers were significantly older and had longer disease duration, and were more adherent at the outset of the study. Data from those participants who completed the study may therefore be unrepresentative of the study population as a whole, and of the wider IBD population.

In summary, the quality of included studies was generally of a high standard but with significant variation. The overwhelming use of cross-sectional designs limits our ability to infer temporal relationships between variables, and the lack of true experimental studies means that causal claims cannot be inferred from any of the studies included in this review.

Overview of Studies which Examined Quality of Life and Illness Perceptions

A total of 17 studies included in this review examined the relationship between Quality of Life (QoL) (IBD-specific or general) and illness perceptions. Ten studies assessed IBD-specific or health-related QoL, seven assessed general QoL, with two studies including measures for both. The majority of included studies (15) utilised cross-sectional designs, with a minority of studies (two) longitudinal in design.

Illness perceptions were measured using the Brief Illness Perception Questionnaire (Broadbent et al., 2006) in 10 studies, the Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002) in six studies, and the original Illness Perception Questionnaire (Weinman et al., 1996) in one instance (Han et al., 2005). There was heterogeneity in the tools used to measure Quality of Life, with variations of the Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al.,1989) employed most often (9/17 studies). See Table 3 below for an overview of the different QoL tools used.

Studies took place in a wide range of countries, with the highest number of studies occurring in Australia (five), followed by the Netherlands and the UK (four each), with one study taking place in each of the U.S., China and Italy. One study (Hayes et al, 2022(a)) recruited internationally using online surveys.

Table 3.

Overview of QoL Measures Used in Included Studies

Quality of Life measure	Authors	Description	Studies Using this Measure
Inflammatory Bowel Disease Questionnaire (IBDQ)	Guyatt et al.,1989	Widely used IBD-specific / health-related QoL measure, containing 32 self-report items.	7
Inflammatory Bowel Disease Questionnaire – Short version (S-IBDQ)	Jowett et al., 2001	A 10-item, adapted version of the IBDQ.	1
Inflammatory Bowel Disease Questionnaire – United Kingdom (UK-IBDQ)	Cheung et al., 2000	A 32-item, adapted version of the IBDQ for the UK population.	2
EUROHIS-QOL8 / WHO-QOL8	Schmidt, Mulhan & Power, 2006	A widely-used 8-item general QoL measure	4
Short-Form 36 (SF-36)	Ware & Sherborune, 1992	Widely used 36-item general QoL measure, consisting of separate 'mental' and 'physical' QoL domains	3

Table 3 (continued)

Short-Form 12 – Version 2 (SF-12v2)	Ware, Kosinski & Keller, 1996	Adapted 12-item version of the SF-36, measuring general QoL	1
Stoma Quality of Life (SQOL)	Baxter et al., 2006	A 21-item self-report stoma-specific QoL measure	1
EUROQOL	The EUROQOL Group, 1990	5-item visual analogue scale measuring general QoL	1

Evidence regarding the Association of Illness Perceptions and IBD-specific QoL

A total of 10 studies (N = 1248, Crohn's disease: 52%, Ulcerative Colitis: 47.6%, Male: 40%) investigated associations between illness perceptions and IBD-specific QoL (see Table 4) Five studies recorded 'total' illness perception scores, and in each instance found a significant negative association between the total score and IBD-specific QoL (i.e. more threatening illness perceptions associated with poorer QoL). It is noteworthy that Larussa et al. (2020) observed this relationship despite only including patients in clinical remission. These results indicate that having globally poorer illness perceptions is associated with worse IBD-related QoL. Knowles et al. (2013) utilised a stoma-specific QoL measure which includes five domains, and observed that the total illness perception score was inversely related to QoL

across four of those domains. Total illness perception scores were an independent statistical predictor of IBD-specific QoL in Artom et al. (2017), Larussa et al. (2020) and Zhang et al. (2016) after accounting for demographic and clinical variables.

Six studies (Dorrian et al., 2009; Han et al., 2005; Kiebles et al, 2010; Rochelle & Fidler, 2013; van Der Have et al., 2013; Zhang et al., 2016) examined the relationships between individual illness perceptions and IBD-specific QoL. In each instance, higher perceived illness *consequences* (the perception that the illness had more severe, disruptive consequences in life) were significantly, negatively associated with QoL. Furthermore, Dorrian et al. (2009) observed perceived *consequences* of IBD to be the greatest statistical predictor of IBD-specific QoL, moreso than all other clinical, demographic and behavioural characteristics. Five studies measured the illness perception *identity,* and in four instances higher scores were associated with lower QoL. A statistically non-significant association was observed in Rochelle and Fidler (2013), which is a somewhat anomalous result given no obvious differences in their sample or measurement of variables.

The *identity* illness perception was measured in five studies, with four observing a significant, negative association with IBD-specific QoL. In Han et al. (2005), *identity* was retained as a predictor of IBD-specific QoL in a hierarchical linear regression model after backward-elimination, forward-entry of all clinical, demographic and behavioural variables. Rochelle and Fidler's (2013) study observed a non-significant relationship between *identity* and IBD-specific QoL.

The *timeline* illness perception was also measured in all six studies, and was sub-divided into *cyclical* and *acute/chronic* in four instances, yielding a complex pattern of results. Perceiving IBD as a more chronic, enduring illness was associated with poorer QoL in one study (Dorrian et al., 2009), but non-significant results were observed in all other instances.

Perceiving IBD as cyclical (relapsing and remitting) in nature was associated with poorer QoL in two studies, and with better QoL in one study (Rochelle & Fidler, 2013). Han et al. (2005) and Zhang et al. (2016) utilised integrated *timeline* illness perception questions, and each observed that perceiving IBD as more long-lasting was associated with poorer QoL, although Han et al. (2005) noted the association was weak.

Personal control refers to the extent to which one believes their own actions can control their IBD. This was observed to have a significant, positive association with QoL in two studies, and no significant association in a further two studies. Rochelle and Fidler (2013) reported a complex pattern of results, with higher perceptions of *personal control* associated with poorer 'social', 'emotional' and 'systemic' QoL, but better QoL regarding bowel function.

A similarly complex pattern of results was observed regarding the role of *treatment control.* Three studies observed a significant, positive association between this illness perception and QoL, meaning that a greater belief in the controllability of IBD symptoms through medical treatment was associated with better QoL. Indeed, Rochelle and Fidler (2013) observed that *treatment control* was an independent statistical predictor of IBD-specific QoL after accounting for clinical biomarkers and psychological variables. Three studies found no significant association between these variables, however.

Beliefs regarding disease *understanding / coherence* were not significantly associated with IBD-specific QoL in three instances, with significant positive associations observed in two studies.

A consistent set of results were observed regarding the association between the *emotional representations* illness perception and IBD-specific QoL. A total of four studies measured this illness perception, with all four observing significant, negative associations with IBD-specific

QoL. These findings suggest that stronger emotional responses to IBD symptoms are associated with poorer IBD-specific QoL.

The *concern* illness perception was only measured in one study (Zhang et al., 2016), where a significant, negative association with IBD-specific QoL was observed. In other words, perceiving IBD as more concerning was associated with poorer IBD-related QoL.

Table 4.

Associations between Illness Perceptions and IBD-specific QoL

Authors	Artom et al., 2017	Dorrian et al., 2009	Han et al., 2005	Kantidakis et al., 2021	Kiebles et al., 2010	Knowles et al., 2013	Larussa et al., 2020[a]
Design	Cross-sectional *N* = 182	Cross-sectional *N* = 80	Cross-sectional *N* = 111	Cross-sectional *N* = 261	Cross-sectional *N* = 38	Cross-sectional *N* = 31	Cross-sectional *N* = 202
Illness Perception							
Consequence	NM	-	-	NM	-*	NM	NM
Identity	NM	-	-	NM	NM	NM	NM
Timeline	NM	-	X	NM	X	NM	NM
Control (personal)	NM	X	+	NM	X	NM	NM
Control (treatment)	NM	X	+	NM	X	NM	NM
Coherence / Understanding	NM	X	NM	NM	X	NM	NM
Concern	NM	NM	NM	NM	NM	NM	NM
Emotional representations	NM	NM	NM	NM	-*	NM	NM
Illness Perception Total	-	NM	NM	-	NM	-*	-

Table 4. (continued)

Authors	Rochelle and Fidler, 2013	van Der Have et al., 2013	Zhang et al., 2016
Design	Cross-sectional	Cross-sectional	Cross-sectional
	N = 102	*N* = 82 (all CD)	*N* = 159 (all CD)
Illness Perception			
Consequence	-	-	-
Identity	X	-	-
Timeline	+*	-	-
Control (personal)	-*	X	+
Control (treatment)	+	X	+
Coherence / Understanding	+*	+	X
Concern	NM	NM	-
Emotional representations	-*	-	-
Illness Perception Total	NM	NM	-

Legend: X: No association found between variables. + or - : Significant positive / negative association found between variables (Note: '+' indicates that an increase in severity of this illness perception is associated with a higher quality of life. '-' indicates the opposite. This method was applied regardless of whether the specific QoL tool

used defined higher scores as indicating higher or lower QoL, in order to present results in a consistent manner). NM: IP not measured / not reported. * : Indicates a complex pattern of results (e.g. association only found for a sub-group / specific QoL domain) a : Study only included IBD patients in clinical remission

Evidence Regarding the Association between Illness Perceptions and Global QoL

Six studies investigated the association between illness perceptions and general or global QoL (Glynn et al., 2022; Hayes et al., 2022a, Hayes et al., 2022b, Kiebles et al., 2010; Tribbick et al., 2017; van Erp et al., 2017). An overview of results is presented in Table 5 below. Three studies examined the association between total illness perception score and general QoL, with all three observing a significant, negative relationship. In other words, poorer illness perceptions were associated with lower QoL. Furthermore, these studies also observed that illness perceptions had a direct, negative statistical effect on QoL after accounting for disease activity using structural equation modelling.

Individual illness perceptions were examined in relationship to global QoL in three studies. The most consistent findings were regarding perceived illness *consequences* and *emotional representations*, where each study observed significant, negative relationships between these perceptions and QoL (i.e. perceiving IBD as having more severe consequences and having more of an emotional impact was associated with poorer QoL). Kiebles et al. (2010) only observed these relationships with the 'mental' component of QoL, as measured by the SF12v2 (Ware et al., 1996).

Significant, negative associations between QoL and the illness perceptions *identity* and *timeline* were observed in two studies, while significant positive associations with *personal control* and *treatment control* were also observed in two instances. These results suggest that perceiving IBD as causing more ill-health symptoms, being more enduring and cyclical in nature, and as being less controllable through personal actions and medical treatment was associated with poorer overall QoL.

The *concern* illness perception was only measured in one study (Tribbick et al., 2017), and was significantly negatively associated with overall QoL (i.e. perceiving IBD as more

concerning was related to poorer QoL). Illness *coherence* was not significantly associated with QoL in two out of three studies where it was measured, however, van Erp et al. (2017) reported a significant, positive relationship with QoL, with *coherence* having a direct statistical effect on QoL in a mediation analysis. The small number of studies which measured the illness perceptions *coherence* and *concern* demands caution in over-interpreting these findings.

Table 5.

Associations between Illness Perceptions and Global QoL

Authors	Glynn et al, 2022	Hayes et al., 2022(a)	Hayes et al., 2022(b)	Kiebles et al., 2010	Tribbick et al., 2017	van Erp et al., 2017
Design	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional
	N = 211	*N* = 319	*N* = 141	*N* = 38	*N* = 81	*N* = 211
Illness Perception						
Consequence	NM	NM	NM	-*	-	-
Identity	NM	NM	NM	X	-	-
Timeline	NM	NM	NM	X	-	-
Control (personal)	NM	NM	NM	X	+	+
Control (treatment)	NM	NM	NM	X	+	+
Coherence / Understanding	NM	NM	NM	X	X	+
Concern	NM	NM	NM	NM	-	NM
Emotional representations	NM	NM	NM	-*	-	-
Illness Perception Total	-	-	-	NM	NM	NM

Legend: X: No association found between variables**,** + or -: Significant positive / negative association found between variables ((Note: '+' indicates that an increase in severity of this illness perception is associated with a higher quality of life. '-' indicates the opposite.This method was applied regardless of whether the specific QoL tool being used defined higher scores as indicating higher or lower QoL, in order to present results in a consistent manner). NM: IP not measured / not reported**.** * : Indicates a complex pattern of results (e.g. association only found for a sub-group / specific QoL domain)

Overview of Studies which Examined Illness Perceptions and Psychological Distress

A total of 15 studies (*N* = 2093, CD: 66.3 %, UC: 33.1%, Male: 39.7%)[1] investigated the associations between illness perceptions and psychological distress (PD) (see Table 6). All studies employed cross-sectional designs. Psychological distress was measured using the Hospital Anxiety and Depression Scale (HADS; Spinhoven et al., 1997) in 10 studies, the Depression, Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995) in four studies and the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) in one study (Kiebles et al., 2010). The validity of these instruments for use in IBD populations is mixed. The HADS demonstrates adequate psychometric properties for IBD populations (Bernstein et al., 2018), while the DASS-21 has been validated with other LTC populations (Nanthakumar et al., 2017). The BSI has not been validated with IBD or other LTC populations.

Six studies took place in Australia, two in the UK, and one in each of the Netherlands, China, the US and Israel. Three studies recruited internationally using online recruitment methods.

Evidence Regarding the Association between Illness Perceptions and Psychological Distress

A consistent finding was observed across the nine studies which investigated the association between *total* illness perceptions and psychological distress. In all cases, a significant, positive association was observed, meaning that higher levels of psychological distress were associated with poorer illness perceptions. Eindor-Abarbanel et al. (2021) found total illness perceptions to significantly predict psychological distress after accounting for demographic

[1] Note: Not all studies reported IBD diagnoses or gender. Statistics reported are therefore based on the studies which provided the required data

and disease variables, and six studies observed illness perceptions to have a direct statistical effect on psychological distress using structural equation modelling (Hayes et al., 2022(a), Hayes et al., 2022(b), Kantidakis et al., 2021, Knowles et al, 2013a, Knowles et al., 2011, Knowles et al., 2013c). These findings suggest that more threatening illness perceptions are associated with higher levels of psychological distress.

Eight studies investigated the relationships between individual illness perceptions and psychological distress. The most consistent findings were observed regarding perceived *consequences* and *emotional representations*, with both of these illness perceptions found to positively correlate with psychological distress in six studies. In other words, these results indicated that perceiving IBD as having more severe consequence and a greater emotional impact was correlated with higher levels of psychological distress.
Bennebroek-Evertsz et al. (2020) found the *emotional representations* illness perception to be a unique predictor of psychological distress in a hierarchical regression, after accounting for all other illness perceptions and 'general dysfunctional beliefs.' Similarly, Eindor-Abarbanel et al. (2021) found *emotional representations* to predict psychological distress after accounting for demographic and clinical variables, while Tribbick et al. (2017) reported *emotional representations* to significantly predict anxiety (but not depression), after controlling for disease type and activity, and gender. These findings suggests that the *emotional representations* illness perception is particularly strongly associated with psychological distress.

On the other hand, perceiving IBD as more controllable through personal actions (*control personal),* medical treatment (*control treatment*)*,* and having a stronger sense of illness *coherence*, were all associated with lower levels of psychological distress in five, four and three studies respectively. Eindor-Abarbanel et al. (2021) reported that the *personal control* illness perception significantly predicted anxiety and depression after accounting for

demographic and disease activity, while illness *coherence* significantly predicted anxiety but not depression. In both instances, a higher perceived sense of control was associated with lower distress.

Less consistent results were observed regarding the relationships between the illness perceptions *identity, timeline* and *concern* and PD. *Identity* was only measured in three studies, however in each instance was found to have a positive, significant correlation with psychological distress (Eindor-Abarbanel et al., 2021, Dorrian et al., 2009 & Zhang et al., 2016). In other words, these findings suggest that perceiving one's IBD as highly symptomatic is associated with greater distress.

The perceived illness *timeline* was measured in seven studies, with three studies reporting non-significant relationships with PD, and four reporting positive correlations (i.e. perceiving IBD as more enduring / cyclical related to higher levels of distress). Lastly, the illness perception *concern* was measured in two studies, with both reporting significant, positive correlations with psychological distress. It is therefore difficult to draw firm conclusions regarding the role of these illness perceptions and PD in IBD.

Table 6.

Associations between Illness Perceptions and Psychological Distress

Authors	Bennebroek Evertsz et al., 2020	Dorrian et al, 2009	Eindor-Abarbanel et al., 2021		Glynn et al, 2022	Hayes et al., 2022(a)		Hayes et al., 2022(b)	Kantidakis et al., 2021
Design	Cross-sectional	Cross-sectional	Cross-sectional		Cross-sectional	Cross-sectional		Cross-sectional	Cross-sectional
	N = 118	*N* = 80	*N* = 299		*N* = 211	*N* = 319		*N* = 141	*N* = 261
Distress sub-divisions	NA	NA	Dep	Anx	NA	Dep	Anx	NA	NA
Illness Perception									
Consequences	+	+	+	+	NM	NM	NM	NM	NM
Identity	NM	+	+	+	NM	NM	NM	NM	NM
Timeline	X	+*	NM	NM	NM	NM	NM	NM	NM
Control (personal)	-	X	-	-	NM	NM	NM	NM	NM
Control (treatment)	-	X	X	X	NM	NM	NM	NM	NM
Coherence / Understanding	X	-	X	X	NM	NM	NM	NM	NM
Concern	NM	NM	+	+	NM	NM	NM	NM	NM
Emotional representations	+	NM	+	+	NM	NM	NM	NM	NM
Illness Perception Total	NM	NM	+	+	+	+	+	+	+

Table 6. (continued)

Authors	Kiebles et al., 2010		Knowles et al, 2013a		Knowles et al., 2011		Knowles et al., 2013c		Knowles et al., 2013b		Rochelle and Fidler, 2013		Tribbick et al., 2017		Zhang et al., 2016	
Design	Cross-sectional *N* = 38		Cross-sectional *N* = 83		Cross-sectional *N* = 96		Cross-sectional *N* = 31		Cross-sectional *N* = 74		Cross-sectional *N* = 102		Cross-sectional *N* = 39		Cross-sectional *N* = 159	
Distress sub-divisions	NA		Dep	Anx	Dep	Anx	Dep	Anx	Dep	Anx	Dep	Anx	Dep	Anx	Dep	Anx
Illness Perception																
Consequence	X		NM	NM	NM	NM	NM	NM	+	+	X	X	+	+	+	+
Identity	NM		NM	NM	NM	NM	NM	NM	+	+	NM	NM	NM	NM	+	+
Timeline	X		NM	NM	NM	NM	NM	NM	+	+	X	X	+	X	+	+
Control (personal)	X		NM	NM	NM	NM	NM	NM	-	-	X	X	X	-	-	-
Control (treatment)	X		NM	NM	NM	NM	NM	NM	-	-	X	X	-	X	-	-
Coherence / Understanding	X		NM	NM	NM	NM	NM	NM	X	X	-	X	-	-	X	X
Concern	NM		NM	NM	NM	NM	NM	NM	+	+	NM	NM	NM	NM	+	+
Emotional representations	+		NM	NM	NM	NM	NM	NM	+	+	X	X	+	+	+	+
Illness Perception Total	NM		+	+	+	+	+	+	+	+	NM	NM	NM	NM	NM	NM

Legend. X: No association found between variables NM: IP not measured / not reported * : Indicates a complex pattern of results (e.g. association only found for a sub-group)

+ or -Sig. positive / negative association found between variables (Note: '+' indicates that as this illness perception increases, anxiety / depression also increases i.e. poorer mental health).

Overview of Studies which Examined Medication Adherence and Illness Perceptions

A total of 5 studies (*N* = 4630, Crohn's Disease: 59.18%, Ulcerative Colitis: 39.9%, Male: 42.9%) investigated the association between illness perceptions and medication adherence (Eindor-Abarbanel Et al., 2018; Horne et al., 2009; Michetti et al., 2017; Severs et al., 2017; van Der Have et al., 2016). An overview of findings is presented in Table 7.

All studies used the Brief Illness Perceptions Questionnaire (Broadbent et al., 2006) as their IP measure, with the exception of Horne et al. (2009), who utilised a single item from the Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002). Similarly, the Morisky Medication Adherence Scale (MMAS, Morisky et al., 1986) (4-item and 8-item versions) was used in four of the five studies, with Horne et al. (2009) using the Medication Adherence Report Scale (MARS) (Horne & Weinman, 2002). van Der Have et al. (2016) used an additional measure of medication adherence by measuring pharmacy refills of medication and comparing this to the prescribed medication refill rate. 80% was the cut-off point for 'high medication adherence' across all studies.

Three studies employed cross-sectional designs, and two studies had longitudinal designs. Four of the five studies in this group reported large sample sizes, ranging from 311 to 2612 participants. Two studies took place in the Netherlands, one each in the UK and Israel, with one international study recruiting participants from 33 countries.

Table 7.

Associations between Medication Adherence and Illness Perceptions

Study Authors	Eindor-Abarbanel et al., 2018	Horne et al., 2009	Michetti et al., 2017		Severs et al., 2017		van Der Have et al., 2016
Design	Cross-sectional	Cross-sectional	Cross-sectional		Longitudinal		Longitudinal
IBD sub-group	N/A *N* = 311	N/A *N* = 1871	CD *N* = 1242	UC *N* = 634	CD = 259	UC = 185	N/A *N* = 128
Illness Perception							
Consequence	X	NM	X	X	X	X	X
Identity	X	NM	+	X	X	X	+
Timeline	X	X	X	X	X	+	+
Control (personal)	X	NM	X	X	+	+	X
Control (treatment)	X	NM	+	X	+	X	X
Coherence / Understanding	+	NM	X	+	X	+	X
Concern	X	NM	X	X	X	X	X
Emotional representations	X	NM	X	X	X	-	-
Total IP score	X	NM	NM	NM	NM	NM	NM

Legend

X: No association found between variables.

+ or - : Significant positive / negative association found between variables (+ indicates that as this variable increases, medication adherence increases also)

NM: IP not measured

Evidence Regarding the Association Between Illness Perceptions and Medication Adherence

Both longitudinal studies found evidence that higher scores on the *emotional representations* illness perception were associated with lower medication adherence, meaning that those who experienced their IBD as causing more negative affect were more at risk of low adherence or non-adherence (although Severs et al. (2017) only observed this relationship amongst the UC sub-group of participants). *Emotional representations* was not significantly associated with medication adherence in the cross-sectional studies which tested for this relationship. Both longitudinal studies recruited participants solely from the Netherlands, while studies based in other countries failed to replicate this finding. Furthermore, the three studies which did not observe a significant association between *emotional representations* and medication adherence also did not report a power calculation for their studies, whereas both of the longitudinal studies which observed an association reported adequate statistical power.

Greater perceived illness *coherence* or *understanding* was associated with higher rates of adherence in three studies. Severs et al. (2017) and Michetti et al. (2017) found a significant, positive association between medication adherence and scores on the *coherence* IP, only amongst the UC sub-group of participants. *Coherence / understanding* was the only IP to have a significant correlation with adherence in Eindor-Abarbanel et al. (2018), with lower *understanding* correlated with lower medication adherence.

Interestingly, greater *treatment control* beliefs were associated with higher rates of adherence in only two studies, Michetti et al. (2017) and Severs et al. (2017), and in each case for Crohn's disease patients only. Greater perceived *personal control* over IBD was found to be associated with higher rates of medication adherence in both CD and UC patients in Severs et al. (2017). Lastly, higher scores on the *illness identity* IP were associated with greater medication adherence in Michetti et al (2017) (CD patients only), and corroborated by van

Der Have et al. (2016) who found lower *illness identity* scores correlated with lower medication adherence. In other words, both of these studies found that medication adherence was higher in patients who attributed more of their physical symptoms to their IBD.

Michetti et al. (2017) also investigated the association of IPs on 'treatment necessity beliefs', which had a significant, positive correlation with medication adherence in their IBD sample. They observed that a number of IPs including *consequences, timeline* and *treatment control* were independently associated with treatment necessity beliefs in a multivariable regression analysis. In this way, several IPs also had an indirect statistical effect on medication adherence.

The *consequences* and *concern* IPs were not significantly associated with medication adherence in any studies which investigated these relationships.

Discussion

The aims of the present review were to examine the evidence regarding the associations between illness perceptions and QoL, psychological distress and medication adherence. A total of 25 studies met criteria for inclusion in this review, which were grouped according to the outcome investigated.

Quality of Life (IBD-specific and General)

Each study which investigated the association between total illness perceptions and QoL observed a significant negative relationship, meaning that globally poorer illness perceptions regarding IBD were associated with poorer QoL. This result was consistent regardless of whether IBD-specific or general QoL was being measured. This finding was also consistent across studies which employed a variety of statistical techniques to test the association, and controlled for the impact of clinical characteristics and demographic variables. This is consistent with and updates findings from Hayes et al. (2020) and Polak et al. (2020).

Regarding individual illness perceptions, the most consistent evidence was found regarding perceived *consequences* and *emotional representations,* with both inversely associated with QoL across all studies where it was measured (nine and seven studies, respectively). In other words, perceiving IBD as having more severe consequences and causing greater levels of emotional distress was associated with poorer QoL. These findings are consistent with the broader literature regarding QoL, illness perceptions and LTCs; for example, Broadbent et al. (2015) also observed that perceived *consequences* and *emotional representations* had the strongest associations with QoL across psychological and physical domains.

It is noteworthy that the four studies which observed non-significant associations between both *treatment control, personal control* and QoL all utilised the IPQ-R. As noted by Dorrian et al. (2009), this tool has not been validated with an IBD population, and therefore inaccurate measurement of illness perceptions may have influenced results.

Psychological distress

In each instance where total illness perceptions were recorded, a significant positive association with psychological distress (PD) was found (i.e. more severe illness perceptions associated with higher levels of PD). A complex set of results was found regarding the associations of individual illness perceptions and PD, and firm conclusions cannot be drawn from the available evidence. This relative complexity may be partly explained by total scores being a more reliable measure than individual items, although research regarding the item-total reliability of illness perception questionnaires suggests this is unlikely (Rivera et al., 2024).

The strongest findings were again observed regarding the illness perceptions of *consequences* and *emotional representations,* with each positively associated with PD in six studies. This pattern of findings reflects those regarding QoL discussed above, and suggests that scores on these two IPs are particularly reflective of an individual's wellbeing across a broad range of domains. Confidence in these findings is also strengthened by the fact that they were observed in several studies which utilised stringent statistical methods, which accounted for the role of relevant clinical and demographic factors (Bennebroek-Evertsz et al, 2020; Eindor-Abarbanel et al., 2021; Tribbick et al., 2017).

Medication Adherence

The studies reviewed regarding the role of illness perceptions in IBD medication adherence provide some useful insights, and to the best of the author's knowledge this specific question has not been reviewed in the existing literature. Strengths of the reviewed studies include large, adequately-powered sample sizes, a variety of study locations, the use of validated measurement tools in nearly all instances and participants from diverse backgrounds.

It is significant to note that despite all 5 studies using variations of the same IP tool, no single IP was found to consistently correlate with medication adherence or non-adherence. Indeed, two studies each found significant relationships between medication adherence and illness perceptions including *timeline, emotional representations, treatment control* and *illness identity.* A significant association between the IP *coherence / understanding* and medication adherence was observed in 3 studies, however this relationship was only observed amongst the UC sub-group in two instances.

The lack of a consistent set of findings makes it difficult to draw firm conclusions regarding the overall association between IPs and medication adherence in the IBD population. Future research could explore this question further using qualitative methods to gain a better understanding of the factors which influence medication adherence in IBD.

Strengths and Limitations

The present review makes a significant contribution to the IBD literature regarding the role of illness perceptions and key outcomes. It provides an update to findings from Polak et al. (2020) and Hayes et al. (2020), with an additional five papers published in the intervening years, as well as expanding the scope of their reviews to

include studies of medication adherence, central to a range of IBD outcomes (see Chan et al., 2017). The overall quality of included studies was high, with the majority using well-validated instruments for measuring variables and appropriate statistical analyses with adequate consideration of confounding variables. The mean sample size of included studies was significantly larger than in previous reviews (mean $N = 387$, range: 31 – 2612, eight studies with $N < 100$), however, there was heterogeneity in sample sizes with three studies reporting sample sizes over 1500.

A number of limitations to the present review should be noted. Firstly, studies which utilised measurement tools similar to the illness perceptions questionnaires, such as the Illness Cognition Questionnaire (ICQ; Evers et al., 2001), were excluded. This decision was partly due to important differences in the constructs (e.g. the ICQ does not measure illness chronicity or coherence), and partly for practical concerns about how to convey the already complex pattern of results if different constructs were included.

Secondly, psychological distress was defined narrowly in terms of anxiety and depression symptoms in the present review, which limits the generalisability of results. This decision was largely driven by the fact that most of the literature in this area define psychological distress in this manner. However, living with a chronic illness such as IBD can understandably lead to a variety of psychological challenges beyond anxiety and depression.

Thirdly, the majority of reviewed studies employed cross-sectional survey designs (23/25). As noted by Polak et al. (2020) and Hayes et al. (2020), there is a pressing need for more longitudinal studies to more robustly test the proposed chain of effects in the CSM. Furthermore, cross-sectional studies which are investigating mechanisms of proposed temporal change, such as those in the CSM, can significantly over-

estimate associations between variables (Maxwell & Cole, 2007), and so longitudinal studies would address some of these shortcomings.

Fourthly, the fact that most studies included in this review depended on participants volunteering to complete surveys for little or no compensation raises the possibility of significant volunteer and non-response bias (Sedgwick, 2015), and thus limits the generalisability of findings to the wider IBD population.

Lastly, the observed results regarding the illness perceptions of *consequences* and *emotional representations* and their association with QoL may represent a degree of shared measurement, as noted by Broadbent et al. (2015). Many items in HR-QoL measurement tools assess the impact of living with an illness and how it effects one's emotional well-being, with the former being similar to the *consequences* illness perception and the latter the *emotional representations* illness perception.

A further, more general limitation should be noted, in that many results in the present study are presented in accordance with the CSM order of variables (i.e.. Disease symptoms → Illness Perceptions → Coping → QoL). By ordering associations in accordance with the CSM, it should *not* be inferred that this reflects a direction of temporal or causal effects. It would be just as valid, on page 48 for example, to state that '*psychological distress* was positively correlated with perceived illness consequences and emotional representations'.

Relatedly, the placement of disease symptoms at the base of a perceptual, emotional and behavioural chain, ending in outcomes such as QoL or PD, may be a theoretical weakness of the CSM. As supported by the bi-directional findings from Gracie et al. (2018), it may be the case that PD can trigger changes in IBD symptoms, as well as symptoms influencing illness perceptions. While the CSM includes feedback loops,

allowing for variables which appear ‘later’ in the chain to effect variables ‘earlier’ in the chain, the primacy of disease symptoms within the model is questionable in light of these findings.

Clinical Implications and Directions for Future Research

Given that total illness perception scores were associated with poorer QoL and higher levels of PD, this measure could have clinical utility in IBD healthcare settings as a screening tool to identify individuals who may warrant additional psychosocial support. Such an approach would be consistent with NICE (2019) guidance regarding holistic IBD care.

The present review found some of the strongest evidence regarding the role of the *emotional representations* and *consequences* illness perceptions, and so future research could examine whether these perceptions are modifiable following psychological interventions. These particular perceptions could theoretically be targeted clinically with education regarding IBD prognoses or third-wave cognitive behavioural interventions (see Ost, 2008).

Due to the heterogenous nature of the results regarding IPs and medication adherence, further research is required in this area. Particular attention may be warranted to investigate patients’ illness perceptions regarding *treatment control*. Theoretically, we might expect this illness perception to map onto adherence behaviour closely, but the contrary findings presented in this review suggest a need for further exploration. Further insight on this question could be useful for clinicians supporting newly-diagnosed IBD patients with commencing and maintaining medical treatment.

As highlighted in other reviews (Hayes et al., 2020; Polak et al., 2020), there is a marked lack of longitudinal studies in this area of research. Future studies should seek

to employ longitudinal designs to more robustly test the CSM and the purported statistical effects of illness perceptions on psychosocial outcomes. Existing cross-sectional findings have demonstrated that the classic CSM variables do not explain all the variance observed in outcomes, and therefore future exploratory studies are required (Polak et al., 2020).

Furthermore, there is scope for a review of the literature which adopts a broader definition of psychological distress than the one used in the present study. Potentially useful investigations could examine the literature regarding illness perceptions and self-esteem, self-efficacy beliefs or shame, for example.

Given the critiques above regarding the CSM structure, future research could test a 'circular CSM', in which all variables are related and bi-directional effects can be explored further.

Lastly, the studies included in the present review utilised a broad range of IP, QoL and PD measurement tools with significant variation in their validity for use with IBD populations. Future researchers should strive to use tools which have proven validity with this population, such as the IBD-specific QoL tools, the BIPQ for measuring illness perceptions and the HADS (Spinhoven et al., 1997) for measuring PD.

Conclusion

The present review illustrated the complex interplay between illness perceptions and psychosocial outcomes in IBD. In general, stronger, more threatening illness perceptions were associated with poorer QoL and higher levels of psychological distress. Patterns in the literature regarding the relationships between specific illness perceptions and core clinical outcomes were delineated, in an updated overview of the literature in this area. Limitations of this body of literature included the predominance

of cross-sectional studies and use of inappropriate instruments for measuring key variables. Many areas for future research are suggested to further our understanding of the processes underpinning adjustment to IBD, as well as potential clinical applications of the review findings.

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Section B: Quality of Life in IBD: Testing the Common Sense Model of Self-Regulation and the Role of Self-Compassion

Word Count: 7,792

Abstract

Introduction: The Common Sense Model (CSM) suggests the impact of Inflammatory Bowel Disease (IBD) on quality of life is mediated by illness perceptions and coping. While supporting cross-sectional evidence exists, the model lacks explanatory power and supporting longitudinal data. Self-compassion has been theorised to play a role in the process of adjustment to IBD. The present study investigated the CSM with an adult IBD population longitudinally, and explored the role of self-compassion as a predictor of psychosocial outcomes.

Method: An online, longitudinal questionnaire study was conducted (N = 147), which gathered data on CSM variables, self-compassion, demographics and IBD history. Serial mediation and moderated-mediation models were used to test the CSM, while linear regression was utilised to test the predictive power of self-compassion.

Results: Consistent with the CSM and previous findings, IBD symptoms were associated with QoL. Evidence was not observed for full serial mediation. Illness perceptions acted as a statistical mediator in some cases. Self-compassion did not predict outcomes, but moderated some CSM associations.

Discussion: Future studies are required to validate longitudinal findings and additional variables need to be explored within the CSM. Potential sources of error within the present study, as well as clinical implications, are discussed.

Keywords: Inflammatory Bowel Disease, Quality of Life, Self-compassion

Introduction

Inflammatory Bowel Disease (IBD) refers to a group of chronic, autoimmune gastrointestinal diseases, the most prevalent of which are Crohn's disease and ulcerative colitis (Fakhoury et al., 2014). IBD is characterised by inflammation of the gastrointestinal tract, with common symptoms including frequency and urgency of bowel movements, diarrhoea, abdominal pain, and systemic inflammation which can result in painful joints and inflammatory skin and eye conditions (Guan, 2019; Vavricka et al., 2015). IBD has an unclear aetiology, but is thought to develop in genetically-susceptible individuals through exposure to environmental triggers (de Souza et al., 2017; NICE, 2023). The incidence of IBD is rising globally, while prevalence in the UK is estimated at 0.81% (King et al., 2020; Pasvol et al., 2020).

IBD typically follows a 'relapsing-remitting' course, with disease severity increasing during 'flare-ups', followed by periods of remission which can extend for months or years in which symptoms are minimal or absent (Trivedi et al., 2019). There are currently no curative treatments, however, symptoms can be managed through a combination of pharmaceutical treatments, surgical interventions and lifestyle adjustments (Lamb et al., 2019; NICE, 2019). Despite this, there is substantial individual variation in clinical outcomes such as disease activity and impairment to daily functioning (Colombel et al., 2020; Leso et al., 2021; van Gennep et al., 2021).

Living with a chronic, unpredictable health condition such as IBD is also known to have a significant impact on a wide range of psychosocial outcomes (see Jordan et al., 2016). For example, fluctuations in disease severity and the subsequent disruption to everyday activities, employment and relationships have all been implicated in the higher prevalence of psychological distress observed in IBD populations (Barberio et

al., 2021; Kemp et al., 2012). In an attempt to quantify the global impact of IBD on an individual, researchers have increasingly included Quality of Life (QoL) as a key outcome (Armuzzi & Liguori, 2021; Ghosh & Mitchell, 2007; Windsor et al., 2023).

QoL can be defined as an individual's "perception 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" (WHO, 1998, p.3). In IBD clinical practice, the use of patient-reported QoL measures has become more common, with a variety of IBD-specific and generic measures available (Alrubaiy et al., 2015b). Recent meta-analytic findings support this shift in perspective; it has been demonstrated that IBD has a significant, detrimental impact on QoL (compared to healthy control groups), and in general, QoL deteriorates as disease severity increases (Knowles et al., 2018a; Knowles et al., 2018b). The converse also appears to be true, with evidence that effectively treating physical IBD symptoms leads to an overall improvement in QoL (Siffledeen, 2024). Accordingly, there have been substantial research efforts devoted to discovering more effective biological treatments for IBD in recent years (Hvas et al., 2018).

While many novel and emerging pharmaceutical treatments hold great promise, IBD remains an incurable condition with a significant burden of disease for many (Farrell et al., 2016). Furthermore, studies have shown that the relationship between IBD severity and QoL is not always straightforward. For example, Rubin and colleagues (2021) reported how certain IBD symptoms, such as bowel movement urgency, are highly impactful on QoL but do not impact disease severity measures as significantly. Moreover, it has been observed that the higher rates of depression and anxiety observed in IBD populations remain elevated when examining the sub-group of patients in clinical remission, and these mental health difficulties themselves may

actually trigger IBD flare-ups (Gracie et al., 2018; Mikocka-Walus et al., 2007). Severe IBD often requires interventions such as stoma surgery (5-10% of Crohn's disease patients will require a stoma (Everhov et al., 2022)), and studies report this intervention can dramatically increase the psychological burden of IBD for some, while improving overall QoL for others (Knowles et al., 2013b; de Gouevia et al., 2006).

Findings such as these have generated theories that QoL is not simply the down-stream product of physical IBD symptoms. Rather, there appears to be a complex inter-relationship between physical symptoms, psychological interpretations *of* and responses *to* those symptoms, and QoL, which warrants further investigation (Korzenik, 2019). The fact that there is currently a limited, poor-quality evidence-base for psychological interventions in IBD only further reinforces this pressing need (Riggott et al., 2023). Current NICE guidance (2019, p. 26) for treating IBD also reflects this complexity, stating that clinicians need to support patients with the 'emotional, psychological and social consequences' of the condition, not solely the physical symptoms.

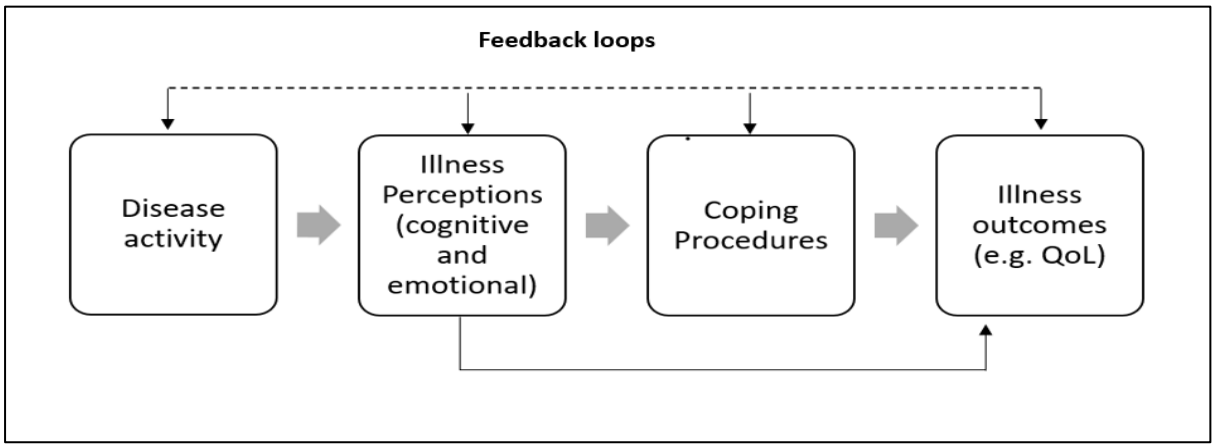
The processes involved in determining how an individual perceives and copes with their symptoms has been called 'adjustment' within the long-term condition (LTC) literature. Moss-Morris (2013) notes that there is substantial heterogeneity in how this term has been defined and measured. Adjustment has variously been defined as the presence or absence of mental health difficulties, the degree of daily functioning maintained, or the change in QoL caused by the condition (Moss-Morris, 2013). This variation is partially due to the different challenges posed by different conditions. For example, adjusting to life with IBD may involve managing anxiety regarding symptoms while aiming for minimal loss in daily functioning, while adjusting to

another LTC such as arthritis may pose different challenges, such as managing acute pain or loss of mobility.

Relatedly, a wide-range of models have been proposed to understand the processes of adjustment in LTCs (Hoyt & Stanton, 2018, Moss-Morris, 2013). Of these, arguably the most widely utilised model within IBD adjustment research (see Hayes et al., 2020; Polak et al., 2020) is the 'Common Sense Model of Self-regulation' (Leventhal et al., 1980; hereafter referred to as the Common Sense Model or CSM). The CSM proposes that the relationship between experienced 'disease threats' or symptoms and 'health outcomes' (such as QoL) is mediated by at least two psychosocial processes: illness representations and coping procedures (Levanthal et al., 1997). In response to experienced disease symptoms, the model posits that an internal representation or perception of that symptom is generated, both emotionally and cognitively (e.g. perceiving abdominal pain as fearful, uncontrollable, and potentially damaging). Subsequently, we adopt coping procedures to deal with the threat posed, such as seeking medical treatment, or avoidance. Illness representations are thought to act on health outcomes directly, as well as indirectly via coping procedures (see Figure 1).

Figure 1.

Adapted version of the Common Sense Model (from Knowles et al., 2011)



Lastly, according to the CSM, we appraise the effectiveness of the chosen coping procedures and recalibrate our perceptions accordingly (e.g. if the symptom resolves, our illness perceptions regarding the illness may become less threatening). The CSM therefore proposes that the relationships between variables are dynamic, and can be recalibrated via several mechanisms including feedback loops, acquiring new illness information (e.g. new treatments becoming available) or changes in our environment (e.g. loss of social support) (Hagger et al., 2017; Leventhal et al., 1997).

The CSM also allows for the possibility that these internal processes may be unconscious, and the links between a particular illness perception and the subsequent coping procedure will vary from person to person (Levanthal et al., 1997). Feelings of fear triggered by a symptom may motivate one individual to seek medical care, for example, while another may use avoidance to manage the emotional discomfort. It is important to note, however, that the CSM assumes the coping procedure chosen appears to be a 'common sense' solution to the illness threat faced, regardless of whether or not it is effective.

As outlined in Hagger et al. (2017, p.1124), instruments such as the Illness Perception Questionnaire (Weinman et al., 1996) have helped operationalise the construct by identifying a number of specific illness perception dimensions. Coping procedures, meanwhile, have generally been operationalised in terms of 'adaptive' and 'maladaptive', or 'problem-focused' and 'emotion-focused' coping (Carver et al., 1989). Table 1 provides an overview of both illness perceptions and coping procedures, adapted from Hayes et al. (2020) and McCombie et al. (2016).

Table 1.

Overview of Illness Perceptions and Common Coping Procedures

Illness Perception	**Description**
Cause	Beliefs regarding the cause of an illness
Consequence	Beliefs regarding the consequences of an illness on wellbeing or QoL
Identity	Beliefs regarding the illness label / diagnosis, and illness-related symptoms
Timeline (chronic/cyclical and acute)	Beliefs regarding the course and duration of an illness
Controllability (personal and treatment)	Beliefs regarding the controllability of an illness, through personal coping behaviours or treatments
Coherence	Beliefs regarding the understanding of an illness
Emotional representations	Beliefs regarding the emotional responses to having an illness
Common Coping Procedures	**Description**
Avoidance	Avoiding directly addressing the problem, symptom or issue
Relaxation	Deliberate attempts to relax oneself
Distraction	Taking one's mind off the problem
Emotional support	Seeking support from others to deal with difficult emotions
Denial	Refusing to acknowledge the problem, symptom or issue
Humour	Joking about the situation, symptom or issue
Acceptance	Accepting the reality of the situation, symptom or issue

The CSM has been extensively researched and validated across a variety of different LTCs including diabetes (Hudson et al., 2014), cancer, arthritis, chronic pain (Hagger & Orbell, 2003; Hagger et al., 2017), skin conditions and cardiovascular disease (Dempster et al., 2015). Evidence supporting the theorised relations between model variables has generally been observed, with some over-arching patterns emerging that appear consistent across conditions. For example, highly threatening illness perceptions tend to lead to greater use of emotion-focused coping (e.g. distraction) and less problem-focused coping (e.g. seeking medical treatment), which can lead to poorer illness outcomes long-term.

These general trends notwithstanding, each LTC presents unique challenges and therefore the relevance of the CSM to a particular condition needs to be assessed individually. Indeed, it has been noted that while 'problem-focused' coping strategies may generally be adaptive, in the context of an illness which is genuinely uncontrollable they can become maladaptive (Lazarus & Folkman, 1984). Over the past two decades, a body of research has developed investigating the CSM in IBD, leading to two recent systematic reviews and meta-analyses (Hayes et al., 2020; Polak et al., 2020).

Both reviews found support for the central propositions of the CSM, with illness perceptions statistically mediating the association between disease activity and QoL, such that more threatening illness perceptions were associated with lower QoL. Illness perceptions accounted for between 4-32% of the variance in QoL amongst reviewed studies (Polak et al., 2020). Evidence regarding the mediating role of illness perceptions on coping styles and coping styles on QoL was mixed, with reviewers noting that use of *maladaptive coping* strategies (e.g. decreasing activity) had a more significant, negative association with QoL than use of adaptive strategies. This

mirrors findings from McCombie et al. (2016) and van Der Have et al. (2013), who both found maladaptive coping to be associated with outcomes including QoL and psychological distress, while use of adaptive coping was not.

On a broader level, continued research of the CSM in IBD is prudent as it may identify targets for psychological treatment, which differ from those identified in existing psychotherapeutic models, such as Cognitive Behavioural Therapy models (see Mikocka-Walus et al., 2017). Such targets would be highly valuable in the current IBD treatment landscape, as existing psychological therapies have generally demonstrated a poor level of effectiveness for psychosocial outcomes in IBD, often failing to outperform control groups in randomised controlled trials (Paulides et al., 2021; Riggott et al., 2023). Furthermore, the role of illness perceptions within the CSM warrants further investigation, as many illness perceptions could be directly influenced by IBD clinicians in routine care (e.g. providing accurate information to newly-diagnosed patients regarding the effectiveness of current treatments could plausibly change the *treatment control* illness perception).

While these reviews lend support to use of the CSM in explaining adjustment to IBD, they each come with significant limitations and many important unanswered questions remain. The review from Hayes et al. (2020) included only seven studies, all of which were cross-sectional in design. Polak et al. (2020) noted similar limitations, meaning conclusions regarding temporal relationships and causation could not be confirmed, with both reviews commenting on the need for longitudinal studies to test the CSM more robustly. Furthermore, many of the reviewed studies failed to adequately control for IBD comorbidities, or to use appropriately sophisticated statistical techniques. Lastly, both reviews credibly argue that a wider range of psychosocial variables need

to be considered within an expanded CSM, as the classical variables do not explain all the variance in outcomes (see Hayes et al., 2022a and 2022b).

One such variable, which has been identified as warranting further exploration within the CSM (Hayes et al., 2020) but as of yet has not been empirically tested, is self-compassion. Self-compassion can be defined as a way of relating to oneself with kindness and acceptance, particularly at times of stress or failure (Neff, 2003b). Neff (2009) theorised that self-compassion is comprised of self-kindness (as opposed to self-judgment), a sense of common humanity (as opposed to isolation), and mindfulness (as opposed to over-identification). Higher levels of self-compassion could theoretically lead to more helpful illness perceptions and coping procedures, as self-compassion entails an ability to view one's difficulties, thoughts and behaviours as part of a common struggle, not as shameful, individual failures (Terry & Leary, 2011).

Indeed, research has shown that self-compassion is a modifiable psychological process, a key mechanism of change in many psychotherapies (Gilbert, 2010; Kuyken et al., 2010), and is highly correlated with QoL amongst individuals with physical poor health (Allen et al., 2012). Furthermore, while change in illness perceptions over time is commonly reported in other LTCs (Bonsaksen et al., 2015; Broadbent et al., 2015; Gwinnutt et al., 2021), it is not known whether self-compassion influences such change in IBD.

For the theoretical reasons cited above, we might expect self-compassion to exert a protective effect on temporal changes in illness perceptions and coping styles, as well as a moderating effect on the CSM variables when examined cross-sectionally. This has yet to be empirically tested, and similarly, the classical CSM has not been examined longitudinally with an IBD population.

The Present Study

The present study aims to address these current gaps in knowledge by testing the CSM longitudinally with an IBD population. Furthermore, it will explore the potential statistical moderating role of self-compassion within the model, as well as the possible protective role of self-compassion over time. The specific hypotheses to be tested are shown in Table 2.

Table 2.

Hypotheses to be tested in the Present Study

Hypothesis Number	Hypothesis
1	The relationship between disease activity and quality of life will be statistically mediated by illness perceptions and maladaptive coping styles, serially (i.e. Disease activity → illness perceptions → maladaptive coping styles → QoL)
2	Self-compassion will statistically moderate the mediation relationships hypothesised in (1). In particular, 2a: self-compassion will statistically moderate the relationship between disease activity and illness perceptions and 2b: self-compassion will statistically moderate the relationship between illness perceptions and maladaptive coping styles; such that in both cases higher self-compassion is associated with a lower strength of these relationships.
3	Higher self-compassion will predict a lower level of negative change in (3a) illness perceptions, (3b) maladaptive coping styles and (3c) QoL over a 6-month period, controlling for baseline levels of each variable and disease activity.
4	Hypotheses 1, 2 and 3 will hold for the sub-group of participants who have IBD only and no other chronic illnesses

Method

Research Design

The present study employed an online, longitudinal questionnaire design, with a 6-month interval between the two timepoints (T1 and T2). Data from T1 were analysed cross-sectionally to test Hypotheses 1 and 2, while data from both time points were used for Hypothesis 3 and the relevant part of Hypothesis 4.

Ethics

Ethical approval for the present study was provided by the Ethics Panel at Canterbury Christ Church University, Salomons Institute for Applied Psychology (Appendix E). Participants were informed in the study Information Sheet (Appendix F) that taking part would require answering potentially distressing questions regarding their IBD symptoms and the impact on their daily life. Participants were therefore advised to consider their wellbeing prior to participating. Contact details were provided for IBD charities and mental health helplines in the study debrief sheet (Appendix G). Participants were also provided with the contact details of the lead researcher to ask any questions before or after participation, and alternative contact details were provided if participants wished to make a complaint. All participants completed a consent form (Appendix H) before progressing with the study.

All data gathered during the present study were stored and processed on encrypted file space. Participants were made aware that their anonymised data would be used for the purposes of writing this report, and could potentially be published in a journal article or conference presentation. Identifiable information (e.g. email addresses) were removed from the dataset and stored separately during data analysis. Participants' data were used strictly in accordance with their declared preferences.

Consultation with Experts by Experience

Two adults living with IBD in the UK were recruited as experts by experience (EbE) via a national IBD charity, and acted as research consultants in the design phase of the present study (Appendix I). Input from EbE's and subsequent amendments to the present study are shown in Table 3 below.

Table 3.

Overview of EbE Involvement during the Design Phase of the Present Study

Activities undertaken by EbE Consultants	Feedback from EbE Consultants	Actions taken
Reviewed drafts of information, consent and debrief sheets.	Materials were generally easy to understand, suggested some minor wording changes	- Changed wording of questionnaires accordingly
Reviewed a range of questionnaires for measuring study variables	Discussed which measurement tools felt more accessible, identified confusing medical jargon, reflected on the presentation of questions on-screen and possible changes	- Joint discussion regarding which instrument to choose for each variable - Added explainers of medical jargon, where possible - Edited the presentation of questionnaires on-screen to increase user-friendliness

Table 3. (continued)

Recorded the approximate amount of time taken to complete the full survey	Duration of time to complete questionnaire was 20 – 30 minutes	- Noted the likely duration of time needed to complete the survey in Information Sheet
Considered the online IBD groups they interact with	Identified online IBD support groups on social media and forums	- Considered advertising the study in these groups
Provided additional, general feedback on their experience of completing the survey	Reflected that current symptoms can be a poor reflection of long-term experience of IBD. In particular, past surgeries including stoma surgery, managing prescribed medications and years since diagnosis were identified as potentially important factors to consider	- Created an IBD history questionnaire measuring these factors - Integrated these variables into hypothesis testing

Participants and Recruitment

Recruitment into the present study was achieved primarily through online advertising. Study advertisements were placed in several online support groups for people living with IBD on two social media platforms, Facebook and Reddit (Appendix J). A study advertisement was also placed on the website of a national IBD charity, and advertised through several other IBD charities' newsletters or social media sites.

Recruitment was also aided through collaboration with another researcher, whereby consenting participants in a separate IBD research project were contacted directly via email and invited to take part in the present study.

The recruitment window ran from July to September 2023. All participants who completed the initial survey were invited via email to take part in the follow-up survey approximately 6 months later. An incentive was offered for participation whereby participants could earn entries into a prize draw for a £100 Amazon voucher by completing the survey at each timepoint.

Eligibility criteria for the present study included 1) being an adult at the time of participation (18+ years old), 2) that is a UK resident and 3) has a self-reported, clinical diagnosis of IBD, with 4) sufficient proficiency in English to understand and complete the survey. Participants with other diagnosed LTCs were eligible to take part.

Research Materials and Questionnaires

The following questionnaires were administered to participants in the present study, via Gorilla online research software (http://www.gorilla.sc/, Anwyl-Irvine et al., 2018). All questionnaires were administered at both T1 and T2.

Brief Illness Perceptions Questionnaire (BIPQ)

The BIPQ (Broadbent et al., 2006) has been used to measure illness perceptions across a wide range of illnesses, including IBD. The BIPQ contains nine items, with each item assessing a particular dimension of illness perceptions (e.g. perceived treatment control) along a 10-point scale. Higher item scores indicate a stronger, more

threatening illness perception. Broadbent et al. (2015) demonstrated that the BIPQ has good concurrent and predictive validity for a range of physical and psychological health outcomes, as well as good test-retest and discriminant validity. Permission has been sought and granted from the author of the BIPQ to use in this study.

For the present study, an adapted version of the BIPQ was used. The subjective response 'causal' question, which is included if the research wishes to assess participants' beliefs about the cause of their illness, was removed as this was not relevant for the present study, A total score was created by summing all 8 items, using the same method as Knowles et al. (2013b) and Zhang et al. (2018), to avoid multiple hypothesis testing using each IP as a distinct measure. The internal consistency of the BIPQ using this method is adequate-to-good, with Cronbach's alpha ranging from 0.69 – 0.83 (Hallegraff et al., 2013; Timmermans et al., 2017; Zhang et al., 2017).

IBD-Cope

The IBD-Cope (McCombie et al, 2016) was developed to measure coping styles specifically for IBD, as the particular challenges presented by IBD and the subsequent coping strategies required were not reflected in generic coping instruments. There are six items overall, with 3 items measuring 'good' (or adaptive) coping styles and 3 measuring 'bad' (or maladaptive) coping styles. Participants rate the frequency with which they have used a particular coping strategy over the past month, and items are scored from 0-7. Example items include 'Have you laid awake worrying about your IBD or other things in life?' and 'Have you blamed yourself for making your IBD worse?'. Higher scores indicate greater use of that coping strategy, and subscale scores can be calculated by summing item scores (McCombie et al., 2016).

IBD-Cope scores are moderately correlated with the widely-used 28-item Brief COPE (Carver, 1997). The IBD-COPE demonstrates good face validity, test-retest reliability,

and internal consistency with two well-developed subscales (McCombie et al., 2016). An adapted version of the IBD-Cope, containing three 'maladaptive' coping items only, was used in the present study. This decision was primarily driven by research findings which have consistently observed use of maladaptive coping strategies (but not adaptive coping strategies) to correlate with IBD disease outcomes (McCombie et al., 2016; van Der Have et al., 2013; Polak et al., 2020). Furthermore, during consultation with EbEs, the adapted three-item version of the IBD-Cope was deemed to have face validity, and the reduced questionnaire length was felt to improve participant's experience. Taken together, it was felt that the adjusted version of the IBD-Cope was preferable for the present study.

Self-compassion scale (SCS)

The SCS (Neff, 2003a) is a widely-used questionnaire measuring self-compassion across six subscales: self-kindness, self-judgment, common humanity, isolation, mindfulness and over-identification. The full questionnaire contains 25 questions which are answered on a scale ranging from 1 ('Almost never') to 5 ('Almost always'), and includes items such as 'I'm kind to myself when I'm experiencing suffering'. A total self-compassion score can be generated by summing the means of the six sub-scales and averaging the score to create a total mean, ranging from 1-5. Higher scores are indicative of greater levels of self-compassion (Neff, 2003a).

The SCS demonstrates good discriminant validity from concepts like self-esteem, good construct validity, test-retest reliability, internal consistency ($\alpha = 0.92$) and is significantly correlated with positive mental health and life satisfaction (Neff, 2003a; Neff & Pommier, 2013).

Crohn's and Ulcerative Colitis Questionnaire – 8 (CUCQ-8)

The CUCQ-8 (Alrubaiy et al., 2015a) is an eight-item quality of life measurement tool, developed to specifically assess QoL in IBD. It has been validated with large IBD samples in the UK (Alrubaiy et al., 2015a; Hutchings et al., 2017), and has demonstrated good psychometric properties including construct validity, test-retest reliability, and internal consistency ($\alpha = 0.84$). The CUCQ-8 assesses quality of life over the past two weeks, with six questions requiring the respondent to enter the number of days in that time period they have experienced a particular difficulty (e.g. 'On how many days in the last two weeks have you had to rush to the toilet?'). There are two closed questions, each with four response options (ranging from 'not at all' to 'yes, all of the time'). Total scores are calculated by summing item scores, and range from 0 – 90, with higher scores indicating *poorer* QoL. Scores on the CUCQ-8 have been shown to strongly correlate with the two most commonly used clinician-administered measures of disease activity in IBD, namely the Harvey-Bradshaw Index and the Simple Clinical Colitis Activity Index (Harvey & Bradshaw, 1980; Walmsley et al., 1998).

Inflammatory Bowel Disease Symptom Inventory Short-Form (IBDSI-SF)

The IBDSI-SF (Sexton et al, 2019) measures IBD symptoms over the past week and can be administered across both Crohn's disease and ulcerative colitis populations. The IBDSI-SF was developed by adapting questions from the most commonly used IBD symptom inventories and testing them in line with COSMIN standards (Mokkink et al., 2010). The IBDSI-SF is entirely patient-rated, unlike many IBD disease activity measures, and contains 25 Likert-style questions, each scored from 0-4. A total score is reached by summing all items, with higher scores indicative of more active disease.

Clinical cut-offs are provided to differentiate between those with active disease and those in clinical remission (Sexton et al., 2018). The IBDSI-SF demonstrated good psychometric properties in the original validation study, including strong internal consistency (α = 0.92), test-retest reliability, and construct and convergent validity (Sexton et al., 2018).

IBD History Questionnaire

A bespoke IBD history questionnaire was created for the present study (Appendix K). Variables including IBD sub-type, years since diagnosis and the absence / presence of other chronic conditions were included to aid interpretation of findings, as is standard practice within IBD research (Knowles et al., 2018b; Rubin et al., 2021). Furthermore, a number of potential confounding variables were identified in discussion with EbE's (see Table 3). This feedback was considered alongside the published literature and additional variables were added to the questionnaire accordingly. Specifically, surgical history with IBD was included given the findings that QoL improves significantly following surgery (Baczyk et al., 2017). The presence or absence of a stoma was included given conflicting research regarding the psychological impact of this intervention (Ayaz-Alkaya, 2019; Bianchi et al., 2022). Lastly, the prescription / non-prescription of IBD medication was included given the reported psychological burden of such treatments (Jackson et al., 2010; Selinger et al, 2011).

Demographics Questionnaire

A demographic questionnaire was developed following ONS guidelines (2021), including questions regarding participants' age, gender, ethnicity, educational attainment and relationship status. An additional question regarding how participants

became aware of the study was also added to this questionnaire (Appendix L). These data were gathered to aid in interpretation of findings and to provide summary data of the achieved sample.

Data Analysis

Data Reliability

As the present study took place entirely online and offered an incentive to take part, a number of steps were taken to screen for bots (Ferrara et al., 2016), completions by ineligible participants, repeated completions by the same participant (duplicates) and spurious completions (Teicher et al., 2015). Table 4 below outlines the strategies employed to ensure data validity. Responses which were identified by these screening strategies were removed from the dataset and were not included in any subsequent analyses.

Table 4.

Screening Strategies for Identifying Unreliable Data

Screening strategy	Details
Bot detector	Integrated a visual 'bot check' task into the beginning of the survey. Failure of the task ended participation immediately
Identification of unusual response trends	Visual inspection of the data searching for unusual trends, such as: - Several consecutive respondents with identical answers to all questions in 1 or more questionnaire - Identical demographic information entered by several respondents consecutively - High volume of completions (10+) within a very short time period (< 10 mins) on same device type
Identification of spurious respondents	Visual inspection of respondents' email addresses to identify false email addresses (did not include '@'), unusual trends (e.g. 30+ consecutive outlook.com addresses), and accounts highly unlikely to be genuine (e.g. email addresses with 20+ characters in unusual order)
Inconsistent or spurious answers	Searched for inconsistences or contradictions within respondents' data, such as: - 'Years since IBD diagnosis' > 'age' - Entering 'not applicable' for all free-text questions in contradiction to previous responses - Responses outside question limits (e.g. responses > 14 or < 0 when asked 'how many days in the past two weeks have you experienced…')

Table 4. (continued)

Removal of duplicates	Identified respondents who completed the survey multiple times under the same email address

Suitability of the Data for Regression Analyses

As Hypotheses 1 & 2 utilised bootstrapping approaches, assessing the normality of underlying distributions was not required (Field, 2013). A number of steps were taken to assess normality as required for testing hypotheses 3 and 4. As noted by Hayes (2018), violations of assumptions does not prohibit the use of regression for hypothesis testing, rather it necessitates careful interpretation of how influential the violations have been on observed results. It is also important to note that a sufficient sample size was achieved cross-sectionally to assume normality via the central limit theorem (Field, 2013).

Inspection of histograms and residual z-scores for all variables indicated no significant deviation from normality, with the exception of IBD symptoms which were negatively skewed, meaning scores clustered at the lower end of the scale (indicating less severe symptoms). All other model assumptions regarding linearity, homogeneity of variance, lack of autocorrelation and multicollinearity were assessed according to Field's (2013) recommendations and met satisfactorily.

The presence of outliers was minimal, with > 93.2% of *z*-scores on all measures falling within the normal range. For each regression model, Cook's distance and Leverage were calculated to assess the influence of potential outliers. In each instance, there was insufficient evidence to suggest outliers exerted significant

influence, according to Cook and Weisberg (1982) and Steven's (2002) criteria, respectively.

Statistical Analyses

All data analyses were conducted using IBM SPSS Statistics software (version 29). Demographic information for the achieved sample are presented with means (M), standard deviations (SD) and frequencies were applicable. The internal consistency of each scale and sub-scale was calculated using Cronbach's alpha and McDonald's omega. The suitability of the data for analysis with parametric tests was determined by assessing normality, the presence and/or influence of outliers, multi-collinearity, and homogeneity of variance, according to Field's (2013) recommendations.

In order to test Hypotheses 1 and 2, mediation models and moderated mediation models with bootstrapping (5000 samples) were constructed using Hayes' (2018) PROCESS macro for SPSS. Hypothesis 3 was tested by constructing a series of multivariate regression models. Hypothesis 4 was tested using the same procedures as Hypotheses 1-3 respectively, but with the subset of participants with IBD only. Further details are provided in the results section.

Power Analysis

A precise power calculation was not possible due to uncertainty over the expected size of the effects. However, a number of steps were taken to estimate the required sample size for hypothesis testing. Based on simulations of moderated mediation models from Preacher et al. (2007), a minimum sample size of 100 participants appeared necessary to detect a medium-sized effect. Furthermore, in order to test Hypothesis 3 with a multiple linear regression, a sample size of at least 100 participants was required to detect a medium effect (Field, 2013).

Results

Demographics and Summary Data

A total of 248 participants completed T1 measures. Screening for bots and spurious responses removed 101 respondents' data leaving a final T1 dataset of 147 participants. 54 eligible participants completed the follow-up survey at T2. A participant flow diagram is presented in Figure 2, with summary data shown in Table 5.

As can be seen in Table 5, the majority of participants were female at both timepoints. Participants were mostly White, with relatively few participants from Asian / Asian British, Mixed and Other ethnicities. Nearly two-thirds of participants had higher-level education qualifications, and the majority were recruited via an IBD charity.

An overview of participants' IBD history is presented in Table 6. There was an approximately equal split of participants with Crohn's disease (45.6%) and Ulcerative Colitis (49%). The mean duration since IBD diagnosis was 9.47 years (SD = 9.04), with a range of 0 – 40 years. The majority of participants (60.5%) had not received surgery for an IBD-related issue, but most respondents were prescribed IBD medication (85.7%). A substantial minority of participants reported co-occurring long-term conditions (43.6%).

Figure 2.

Participant flow diagram

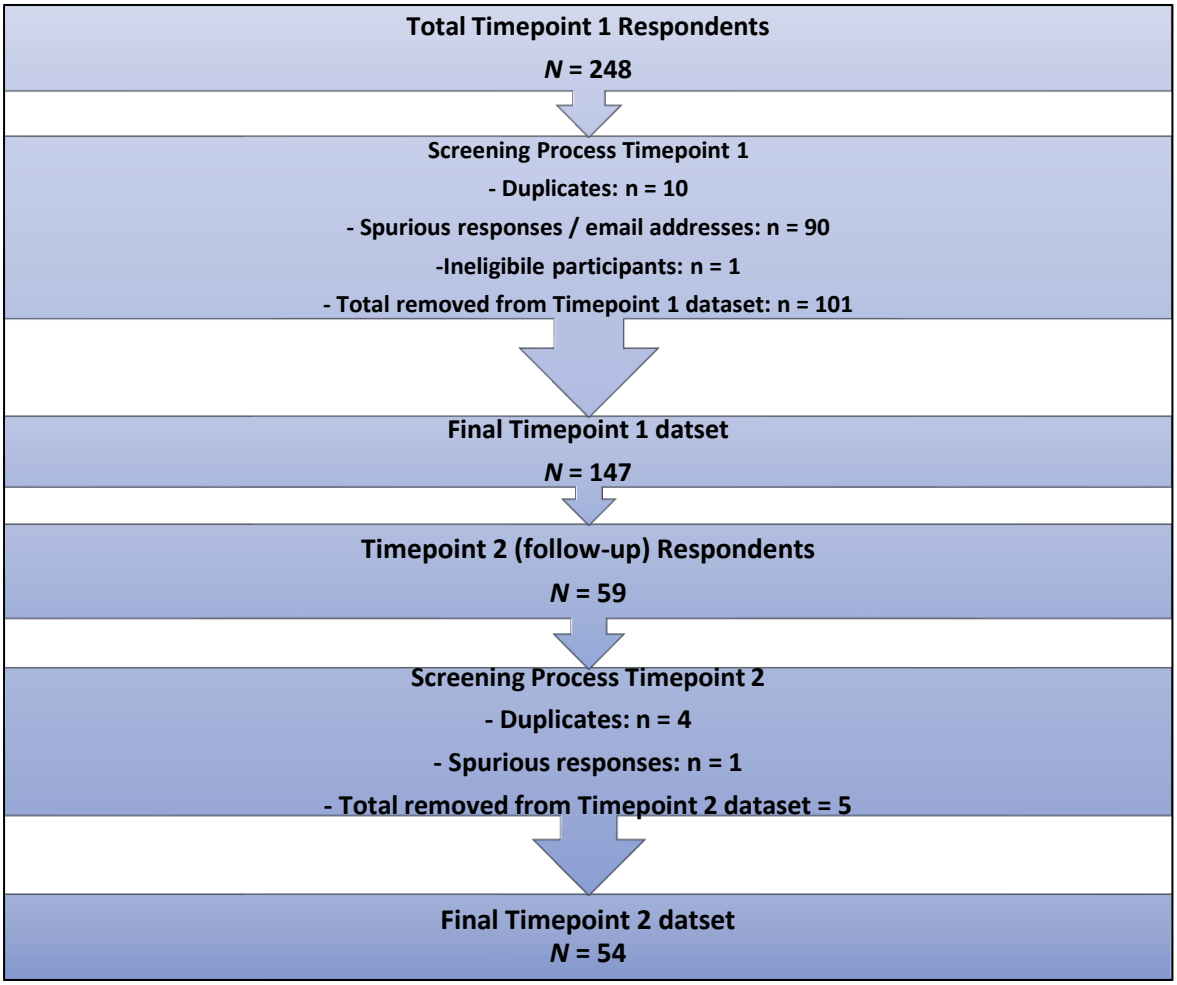


Table 5.

Demographics and Summary Data of Participants

Demographic variable	Timepoint 1	Timepoint 2
Number of Participants (*N*)	147	54
Age (Mean) (SD)	39.38 (12.15)	41.8 (11.03)
Gender		
Female	102 (69.4)	41 (75.9)
Male	44 (29.9)	13 (24.1)
Prefer not to say	1 (0.7)	0
Ethnicity		
White	137 (93.2)	49 (90.7)
Asian / Asian British	5 (3.4)	2 (3.7)
Mixed / Multiple Ethnicities	2 (1.4)	1 (1.9)
Other Ethnicity	2 (1.4)	2 (3.7)
Prefer not to say	1 (.7)	0
Educational Status		
No formal qualification	3 (2)	1 (1.9)
Foundation diploma / GCSE (grades D-G) or equivalent	5 (3.4)	3 (5.6)
Higher diploma / GCSE (grades A-C) or equivalent*	12 (8.2)	7 (13)
Apprenticeship	1 (0.7)	0
Advanced Diploma / two A-levels or equivalent	21 (14.3)	4 (7.4)
Certificate of Higher Education / BTEC professional or equivalent	18 (12.2)	3 (5.6)
Bachelor's degree	46 (31.3)	14 (25.9)
Postgraduate Certificate or Diploma / Master's degree	35 (23.8)	19 (35.2)
Doctorate degree	5 (3.4)	2 (3.7)
Other qualifications	1 (0.7)	1 (1.9)

Table 5. (continued)

Relationship Status		
Single	47 (32)	14 (25.9)
Married	58 (39.5)	23 (42.6)
Civil partnership	1 (0.7)	1 (1.9)
Divorced	6 (4.1)	4 (7.4)
Separated	4 (2.7)	2 (3.7)
Long-term relationship	17 (11.6)	7 (13)
Widowed	3 (2)	0
Co-habiting	8 (5.4)	2 (3.7)
Prefer not to say	2 (1.4)	0
Other (please describe	1 (0.7)	1 (.7)
Study Recruitment Route		
IBD charity (e.g. Crohn's and Colitis UK)	74 (50.3)	Not applicable
Social media (e.g. Facebook)	57 (38.8)	
Word of Mouth	5 (3.4)	
Other	9 (6.1)	
Prefer not to say	1 (0.7)	
Unsure	1 (0.7)	

Note: All data presented are frequencies followed by percentages (in brackets), except where otherwise specified.

Table 6.

IBD History and Information

IBD Characteristic	***N* (%)**	
	T1	**T2**
IBD type	Crohn's Disease: 67 (45.6) Ulcerative Colitis: 72 (49) Indeterminate / mixed IBD: 6 (4.1) Unsure: 2 (1.4)	Crohn's Disease: 27 (50) Ulcerative Colitis: 26 (48.1) Indeterminate / mixed IBD: 1 (1.9) Unsure: 0
IBD surgeries	0 surgeries: 89 (60.5) 1 surgery: 26 (17.7) 2+ surgeries: 32 (21.8)	0 surgeries: 36 (66.7) 1 surgery: 9 (16.7) 2+ surgeries: 9 (16.7)
Stoma / pouch	No stoma / pouch Hx: 116 (78.9) Current stoma / pouch: 22 (15) Past stoma / pouch: 9 (6.1)	No stoma / pouch Hx: 44 (81.5) Current stoma / pouch: 9 (16.7) Past stoma / pouch: 1 (1.7)
IBD medication	Currently prescribed medication: 126 (85.7) Not currently prescribed medication: 21 (14.3)	Currently prescribed medication: 45 (83.3) Not currently prescribed medication: 9 (16.7)
Co-occurring Dx	No other Dx: 83 (56.5) One other Dx: 47 (32) 2+ other Dx: 17 (11.6)	No other Dx: 33 (61.1) One other Dx: 14 (25.9) 2+ other Dx: 7 (13)
Years since Dx	0 – 5 years: 68 (46.3) 6 – 10 years: 24 (16.3) 11 – 20 years: 35 (23.8) 21+ years: 20 (13.6)	0 – 5 years: 20 (37) 6 – 10 years: 7 (13) 11 – 20 years: 15 (27.8) 21+ years: 12 (22.2)

Note: Hx = history, Dx = diagnosis.

Data Screening

Missing Data

Missing data were minimal as the research software forced participants to complete each questionnaire fully to proceed through the survey. However, as 'decline to answer' was a response option for IBD-Cope items (McCombie et al., 2016), some missing data was possible. There were 3 cases of missing data for this questionnaire, which represented < 1% of response data for the IBD-Cope and < 0.001% of all responses. A number of imputation methods were trialled, as per recommendations from Hawthorne et al. (2005), and no differences were observed between analyses regardless of which method was employed. All subsequently displayed analyses have therefore used listwise deletion of missing data.

Internal Consistency

Internal consistency was found to be adequate-to-strong for all scales, with the exception of coping (see Table 7).

The adapted, three-item version of the IBD-Cope scale utilised in the present study had a Cronbach's alpha of .393 which is generally considered a poor level of reliability (Cronbach, 1951; Tavakol & Dennick; 2011). It should be noted that Cronbach's alpha is influenced by the number of items in a scale, which may partially explain the low level of reliability observed (Field, 2013). McDonald's omega was .651, which is borderline in terms of acceptable internal consistency (Kalkbrenner, 2024). Caution is therefore warranted when interpreting tests which used the IBD-Cope. Removing item two from the IBD-Cope was found to improve internal consistency ($\alpha = .471$), but did not significantly alter any subsequent results or

hypothesis testing (Appendix M). The original three-item scale was therefore maintained throughout all analyses.

Table 7.

Reliability Analyses of Scales and Subscales

Measurement scale / subscale	**Cronbach's Alpha**	**McDonald's Omega**
IBD-Cope (negative coping subscale)	.393	.651
Self-compassion Scale	.942	.939
Self-kindness Subscale	.885	.890
Self-judgment Subscale	.867	.869
Common Humanity Subscale	.757	.769
Isolation Subscale	.809	.810
Mindfulness Subscale	.761	.761
Over-identification Subscale	.809	.808
Brief Illness Perceptions Questionnaire	.758	.766
Inflammatory Bowel Disease Symptom Inventory	.933	.938
Crohn's and Ulcerative Colitis Questionnaire – 8	.830	.860

Hypothesis testing

Hypothesis 1: The relationship between disease activity and quality of life will be statistically mediated by illness perceptions and maladaptive coping styles, serially (i.e. Disease activity → illness perceptions → maladaptive coping styles → QoL)

Hypothesis 1 was tested by creating a serial mediation model with T1 Illness Perceptions and Coping entered as mediators in the relationship between T1 IBD symptoms and QoL (using model 6 of Hayes' (2018) PROCESS macro). As can be seen from Table 8 and Figure 3, results demonstrated a non-significant, indirect effect of IBD symptoms on QoL through Illness Perceptions and Coping. Both the total and direct effect of IBD symptoms on QoL were found to be significant.

On inspection of the individual mediation pathways (see Figure 3), we can see that while Illness Perceptions were found to act as a statistical mediator between IBD symptoms and QoL, Coping did not. The full, serial mediation proposed by the Common Sense Model was therefore not supported in cross-sectional data, but there was evidence of statistical mediation via Illness Perceptions. Illness perceptions were also independently associated with QoL, in line with CSM predictions.

Table 8.

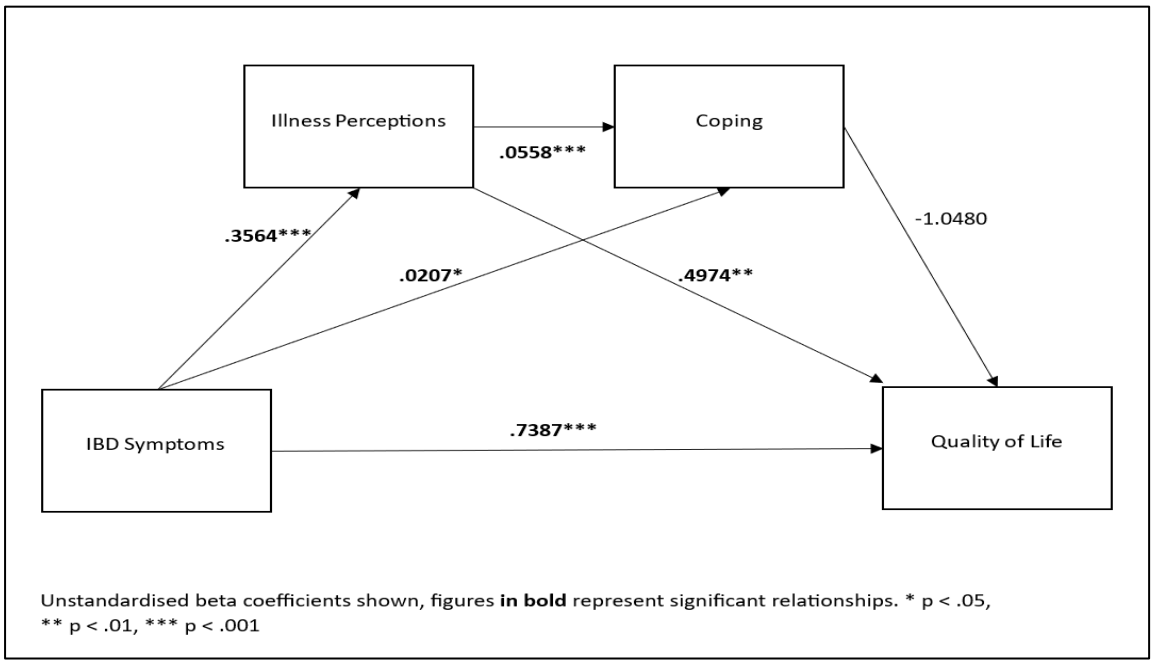
Results of Serial Mediation Analysis (cross-sectional data)

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	.8723***	.7387***	.1336*	.1773*	-.0217	-.0220
95% Confidence Intervals	[0.7201, 1.0245]	[0.5546, 0.9928]	[.0499, .2988	[.0389, .2391]	[-.0566, .0091]	[-0.0600, 0.0166]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Figure 3.

Serial Mediation Model for Testing Hypothesis 1 cross-sectionally (using Hayes' (2018) PROCESS Macro, model 6)



In order to test this hypothesis longitudinally, additional mediation analyses were carried out using change scores on each variable (i.e. T2 score - T1 score). A total effect of IBD symptoms change on QoL change was observed, however, neither the direct effect nor any of the indirect effects were statistically significant (Appendix N). No evidence was therefore observed to support Hypothesis 1 longitudinally.

In order to test whether the observed statistical direct effect of IBD symptoms on QoL held for both those in remission and those experiencing active disease, further serial mediation models were created. Results were compared, for both timepoints, between those with IBD symptoms in remission and those experiencing a flare-up, according to IBDSI-SF clinical cut-off points (Sexton et al., 2018). A direct statistical effect of IBD symptoms on QoL was found in all instances with sufficient sample size, meaning this association was observed regardless of disease status (see Appendix O).

Hypothesis 2: Self-compassion will statistically moderate the mediation relationships hypothesised in (1).

Hypothesis 2 was tested cross-sectionally by creating a moderated-mediation model (using a custom model in Hayes' (2018) PROCESS macro), with self-compassion entered as a moderator. Self-compassion did not statistically moderate the mediation relationships within the CSM (see Table 9 and Figure 4).

This process was repeated for longitudinal data, using change scores (T2 -T1 for each variable). Consistent with hypothesis 2a, self-compassion was observed to statistically moderate the relationship between IBD symptoms change and Illness Perceptions change. The moderation effect was such that higher levels of self-compassion were associated with a weaker strength of this relationship (see Table 9 and Figure 5).

As the moderating effect of self-compassion was only observed in longitudinal data, it was prudent to test whether this result was influenced by selective drop-out of participants between timepoints. A series of independent sample *t*-tests were therefore conducted, comparing the baseline levels of each study variable in T1-only responders against those who completed both timepoints. No significant differences were observed for any variable ($p > .05$) (see Appendix P). Selective drop-out does not therefore appear to have influenced the discrepancy between cross-sectional and longitudinal findings regarding the moderating effect of self-compassion.

In summary, partial support was observed for hypothesis 2a in longitudinal data. No evidence was observed to support hypothesis 2b cross-sectionally or longitudinally.

Table 9.

Results of Moderated-Mediation Analysis

	Cross-sectional Data		**Longitudinal Data**	
	Interaction Effect 1	Interaction Effect 2	Interaction Effect 1	Interaction Effect 2
Beta coefficient	-.0112	.0052	-.2647*	.0113
95% Confidence Intervals	[-.1136, .1112]	[-.0175 .0279]	[-.4389, -.0544]	[-.1158, .1384]

Note: Interaction Effect 1 = IBD Symptoms X Self-compassion → Illness Perceptions. Interaction Effect 2 = Illness Perceptions X Self-compassion → Maladaptive Coping. Figures in **bold** represent statistically significant results. * denotes $p < .05$.

Figure 4.

Moderated Mediation Model, with Self-Compassion as Moderator, in Cross-sectional Data

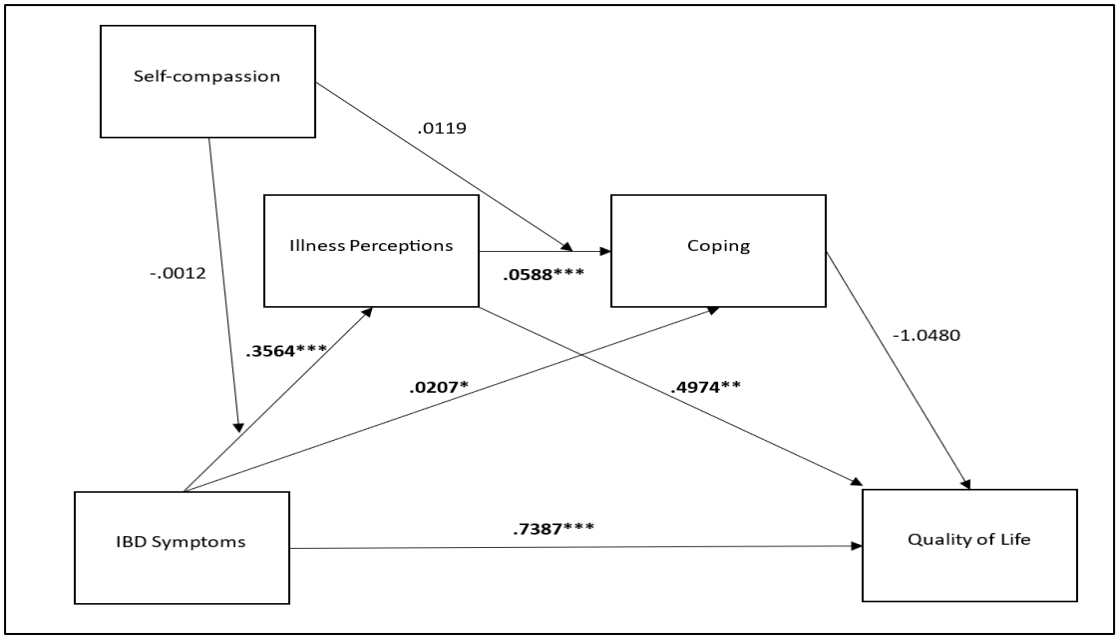
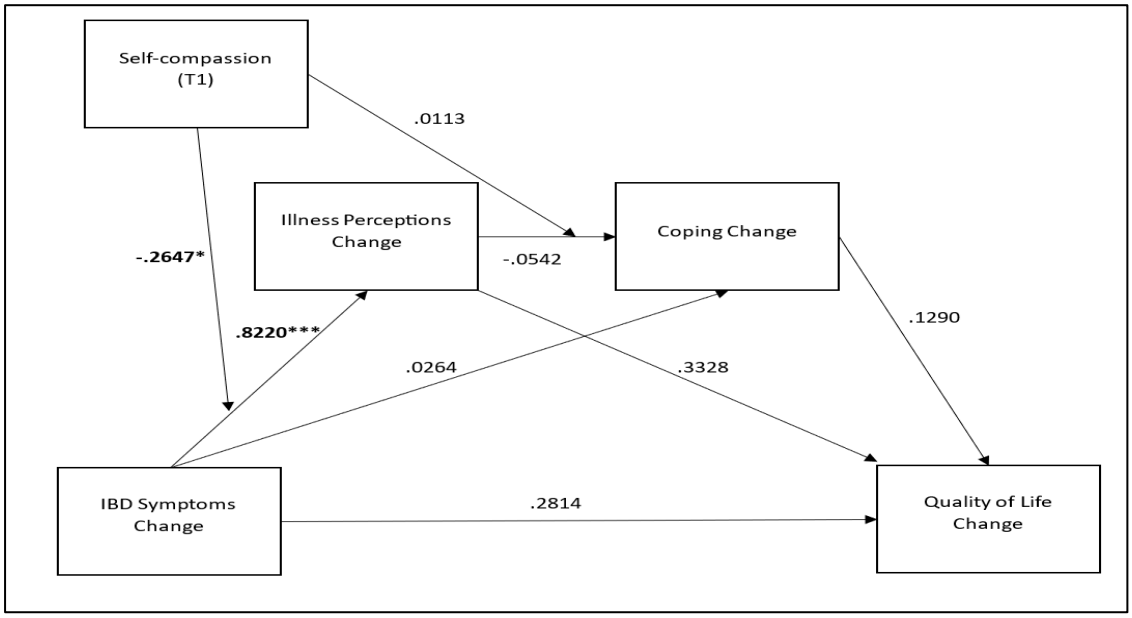


Figure 5.

Moderated Mediation Model, with Self-compassion as Moderator, in Longitudinal Data



Note: In both Figures above, unstandardised beta coefficients are shown. Figures in **bold** represent statistically significant relationships. * denotes $p < .05$, ** denotes $p < .01$, and *** denotes $p < .001$

Hypothesis 3: Higher self-compassion will predict a lower level of negative change in (3a) illness perceptions, (3b) maladaptive coping styles and (3c) QoL over a 6-month period, controlling for baseline levels of each variable and disease activity

In order to test whether self-compassion at baseline (T1) predicted change in illness perceptions, coping styles and quality of life (hypothesis 3), a series of hierarchical regression models were constructed. Each model controlled for IBD history (IBD type, number of IBD-related surgeries, presence of a stoma / pouch, years since diagnosis, prescribed IBD medication, co-occurring chronic illnesses), and current IBD symptoms, as well as the baseline level of the relevant dependent variable. It is important to note that as the sample size at T2 was 54 and the models had 8 predictors, the regression models were under-powered to detect medium-sized effects (Field, 2013), and results should be interpreted in this light.

As shown in Model 2 of Table 10 below, baseline illness perceptions were a significant predictor of illness perceptions at follow-up ($p < .001$) after accounting for the control variables. Illness perceptions at baseline accounted for an extra 36.5% of the variance. Self-compassion ($p = .287$) was not a significant predictor when added to the model (Model 3). There was therefore insufficient evidence to support hypothesis 3a.

With regard to hypothesis 3b, as shown in Table 11, T1 coping was a significant predictor of coping at T2 ($p < .001$), explaining an additional 23.7% of the variance. Self-compassion ($p = .287$) was not a significant predictor of T2 coping. Therefore, there was insufficient evidence to support hypothesis 3b.

For hypothesis 3c, quality of life at T1 significantly predicted quality of life at T2 ($p < .001$), above and beyond the effect of the control variables (see Table 12). Quality of

Life at T1 accounted for an additional 7.9% of the variance. As shown by Model 3, self-compassion (p = .213) did not significantly predict quality of life at T2. There was therefore insufficient evidence to support hypothesis 3c.

A possible explanation of these findings is that the variables did not change from T1 to T2, in which case there would be no change to predict. This possibility was examined by conducting repeated-measures *t*-tests, pairing T1 and T2 scores for IBD symptoms, illness perceptions, coping and QoL, respectively. As shown in Table 13, significant change was observed for IBD symptoms ($p = .022$) and illness perceptions ($p = .004$) only. Looking to the means, we observe that IBD symptoms at follow-up were significantly lower than at baseline (i.e. significant improvement in symptoms). Similarly, the mean illness perceptions score was significantly lower at follow-up, signifying less threatening illness perceptions. The null findings for hypotheses 3b and 3c may therefore reflect a lack of change in coping and QoL respectively, rather than the predictive ability of T1 self-compassion.

Table 10

Hierarchical multiple regression testing Hypothesis 3a

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF from Model 1 (df)	ΔR^2	*B*	*T*	95% CI for B LB	UB
Model 1 (Controls)		.383	.289	4.077** (7, 46)	N/A	N/A				
	IBD type						1.771	.631	-3.875	7.417
	Number of IBD surgeries						.714	.310	-3.927	5.354
	Stoma / pouch						1.688	1.427	-.696	4.069
	Years since Dx						-.093	-.568	-.423	.237
	Prescribed IBD medication						.257	.053	-9.541	10.055
	Co-occurring Dx						2.258	1.510	-.751	5.267
	Current IBD symptoms						.395	4.277***	.209	.581
Model 2		.748	.703	16.708*** (8, 45)	65.259 (1, 45)	.365				
	IBD type						.884	.487	-2.772	4.540
	Number of IBD surgeries						-.766	-.511	-3.788	2.256
	Stoma / pouch						.959	1.247	-.590	2.509
	Years since Dx						.050	.467	-.166	.266
	Prescribed IBD medication						-1.665	-.528	-8.016	4.685
	Co-occurring Dx						1.520	1.567	-.434	3.473
	Current IBD symptoms						.231	3.657***	.104	.358
	Illness Perceptions t1						.686	8.078***	.515	.857
Model 3		.755	.704	15.034 (9, 44)***	1.163 (1, 44)	.006				
	IBD type						.971	.536	-2.684	4.627
	Number of IBD surgeries						-.922	-.613	-3.954	2.110
	Stoma / pouch						.779	.991	-.805	2.363
	Years since Dx						.041	.379	-.176	.257
	Prescribed IBD medication						-1.431	-.454	-7.789	4.927
	Co-occurring Dx						1.254	1.256	-.759	3.267
	Current IBD symptoms						.237	3.749***	.110	.365
	Illness Perceptions t1						.749	7.288***	.542	.956
	Self-compassion t1						1.641	1.078	-1.426	4.708

Note: DV = Illness Perceptions T2. Key: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Table 11.

Hierarchical multiple regression testing Hypothesis 3b

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF from Model 1 (df)	ΔR^2	*B*	*T*	95% CI for B LB	UB
Model 1 (Controls)		.309	.199	2.812* (7, 44)	N/A	N/A				
	IBD type						-.229	-.496	-1.157	.700
	Number of IBD surgeries						-.373	-.951	-1.165	.418
	Stoma / pouch						-.036	-.180	-.434	.363
	Years since Dx						.028	.975	-.029	.085
	Prescribed IBD medication						.600	.736	-1.044	2.245
	Co-occurring Dx						.669	2.649*	.160	1.178
	Current IBD symptoms						.050	3.292**	.019	.081
Model 2		.546	.462	6.464*** (8, 43)	22.434*** (1, 43)	.237				
	IBD type						.110	.286	-.665	.885
	Number of IBD surgeries						-.271	-.839	-.922	.380
	Stoma / pouch						-.099	-.607	-.427	.229
	Years since Dx						.046	1.971	-.001	.094
	Prescribed IBD medication						.700	1.045	-.650	2.049
	Co-occurring Dx						.511	2.433*	.087	.934
	Current IBD symptoms						.019	1.318	-.010	.047
	Coping t1						.551	4.737***	.316	.786
Model 3		.547	.450	5.633*** (9, 42)	.087 (1, 42)	.001				
	IBD type						.096	.242	-.696	.886
	Number of IBD surgeries						-.268	-.821	-.927	.391
	Stoma / pouch						-.088	-.519	-.428	.253
	Years since Dx						.048	1.968	-.001	.097
	Prescribed IBD medication						.687	1.014	-.680	2.055
	Co-occurring Dx						.530	2.283*	.081	.980
	Current IBD symptoms						.018	1.266	-.011	.047
	Coping t1						.538	4.272***	.284	.792
	Self-compassion t1						-.089	-.295	-.695	.518

Note: DV = Coping T2. Key: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Table 12.

Hierarchical multiple regression testing Hypothesis 3c

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF (df)	ΔR^2	*B*	*T*	95% CI for B LB	UB
Model 1 (Controls)		.674	.624	13.588*** (7, 46)	N/A	N/A				
	IBD type						-2.488	-.655	-10.135	5.519
	Number of IBD surgeries						-1.685	-.540	-7.969	4.599
	Stoma / pouch						1.547	.965	-1.678	4.771
	Years since Dx						-.080	-.360	-.526	.367
	Prescribed IBD medication						-3.791	-.575	-17.060	9.479
	Co-occurring Dx						-.791	-.391	-4.865	3.284
	Current IBD symptoms						1.104	8.821***	.853	1.356
Model 2		.753	.709	17.107*** (8, 45)	14.281*** (1, 45)	.079				
	IBD type						-2.309	-.690	-9.049	4.432
	Number of IBD surgeries						-1.073	-.390	-6.622	4.475
	Stoma / pouch						1.347	.954	-1.497	4.192
	Years since Dx						.000	-.001	-.396	.396
	Prescribed IBD medication						-3.643	-.627	-15.339	8.053
	Co-occurring Dx						-.149	.083	-3.757	3.459
	Current IBD symptoms						.766	5.388***	.479	1.052
	Quality of Life t1						.383	3.779***	.179	.588
Model 3		.761	.712	15.585*** (9, 44)	1.597 (1, 44)	.009				
	IBD type						-2.651	-.795	-9.374	4.072
	Number of IBD surgeries						-1.109	-.405	-6.625	4.407
	Stoma / pouch						1.589	1.122	-1.265	4.442
	Years since Dx						.032	.165	-.364	.429
	Prescribed IBD medication						-4.438	-.765	-16.133	7.257
	Co-occurring Dx						.147	.082	-3.470	3.765
	Current IBD symptoms						.767	5.443***	.482	1.051
	Quality of Life t1						.336	3.123**	.119	.553
	Self-compassion t1						-3.113	-1.264	-8.078	1.852

Note: DV = QoL T2. **Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Table 13.

Paired Samples t-tests of CSM Variables from Baseline (T1) to Follow-up (T2)

Paired variables (T1 & T2)	**Mean (SD)**	***t*- statistic**	***p* value (2-tailed)**	**95% Confidence Intervals**
IBD Symptoms	T1: 28.76 (16.19) T2: 24.75 (15.63)	2.36	.022*	{0.603, 7.434}
Illness Perceptions	T1: 49.0 (11.22) T2: 46.04 (11.49)	3.033	.004*	{1.003, 4.923}
Maladaptive Coping	T1: 3.52 (1.87) T2: 3.42 (1.76)	.455	.651	{-0.328, 0.521}
Quality of Life	T1: 40.54 (21.13) T2: 37.85 (21.41)	1.319	.193	{-1.397, 6.767}

Note: * denotes statistical significance

In summary, no evidence was found to support the hypothesis that baseline (T1) levels of self-compassion were predictive of change in illness perceptions, coping style or quality of life after six months, after controlling for IBD characteristics and baseline levels of each dependent variable. Findings for hypothesis 3b and 3c may reflect a lack of significant change temporally in the respective dependent variables.

Hypothesis 4: Hypotheses 1, 2 and 3 will hold for the sub-group of participants who have IBD only and no other chronic illnesses

In order to test Hypothesis 4, the statistical analyses used for testing hypothesis 1 - 3 were repeated on the sub-group of participants with IBD only, with an identical

pattern of findings observed (Appendix Q). Therefore, participants with IBD-only did not differ significantly from those with co-occurring conditions for any of the hypotheses tested. It should be noted that the sample size available for testing hypothesis 4 was 84 for T1 and 25 for T2, and so the analyses were underpowered to detect medium-sized effects.

Discussion

Summary and Interpretation of Findings

The present study was primarily an empirical investigation of the Common Sense Model of Self-Regulation (Leventhal et al., 1980) with an adult IBD population. Hypothesis 1 specifically tested whether the relationship between IBD symptoms and quality of life was mediated by illness perceptions and maladaptive coping. A statistically significant, positive total effect was observed of IBD symptoms on QoL in both the cross-sectional and longitudinal data, meaning that more severe symptoms were associated with *poorer* QoL, consistent with the wider literature (Knowles et al., 2018b).

Within cross-sectional models, illness perceptions acted as a statistical mediator between IBD symptoms and QoL, IBD symptoms and coping, and also exerted a direct statistical effect on QoL. These findings support some tenets of the CSM, however, the full proposed chain of mediation via illness perceptions and coping was not observed. In longitudinal data, no evidence of statistical mediation was observed. As such, no evidence was found to support the proposed chain of mediation in the CSM.

The present study is the first longitudinal test of the CSM in an IBD population, to the best of the author's knowledge. Several noteworthy findings arose from the longitudinal data. It is important to note prior to interpretation of findings that there did not appear to be a 'selective drop-out' effect, as no significant differences were observed between 'T1-only' participants and those who completed the follow-up survey. It therefore appears unlikely that longitudinal data are over-represented by participants with less severe IBD symptoms, for example.

Firstly, statistically significant change was observed between timepoints for IBD symptoms and illness perceptions, but not for maladaptive coping or QoL. The change observed in IBD symptoms is contrary to findings by Sexton et al. (2017), who found disease activity to be highly stable over an equivalent time period. The present study had a particularly high rate of participants experiencing an IBD flare-up at T1 (80.6%, as opposed to 47.7% in Sexton et al. (2017)), and so the observed change scores may represent somewhat of a regression to the mean.

Secondly, longitudinal data supported the finding that IBD symptom changes are associated with QoL changes, which has been widely reported in the literature cross-sectionally (Siffledeen et al., 2024). It is noteworthy that this relationship was observed given the change in IBD symptoms may have been clinically insignificant for many participants (the mean symptom score at T2 was still in the 'active disease' range).

Thirdly, the observed change in illness perceptions supports the CSM contention that the relationships between model variables are dynamic (Leventhal et al., 1997), and is in line with empirical findings from other long-term conditions where disease severity is positively correlated with illness perceptions (Bijsterbosch et al., 2009; Broadbent et al., 2015).

Findings regarding the statistically mediating and direct effects of illness perceptions in the cross-sectional data further highlight the central role of this variable in a range of psychosocial processes. This is consistent with recent review findings (Hayes et al., 2020; Polak et al., 2020). The lack of such strong findings longitudinally may reflect the lack of statistical power for longitudinal hypothesis testing in this instance.

On the other hand, the finding that maladaptive coping did not statistically mediate the relationship between IBD symptoms and QoL, both cross-sectionally and longitudinally, fits into a pattern of previous ambiguous results (Hayes et al., 2022a, Hayes et al., 2020). As noted earlier, the maladaptive coping measure used in the present study had borderline internal consistency, and therefore these findings may reflect issues with the scale's reliability rather than a good test of this aspect of the hypothesis.

The heterogeneity of findings regarding the role of coping in the CSM in IBD potentially opens up the question of whether the method used to measure and operationalise each variable has a significant effect on observed results. In the present study, there is reason to suspect coping was not measured well, which may have introduced substantial error into the results. In other studies, when IBD-specific QoL is the primary outcome, the evidence for coping as a mediator in the CSM is slightly weaker than when, for example, psychological distress is the outcome (Hayes et al., 2020; Polak et al., 2020). A potential solution is to include several outcomes, for example, generic and IBD-specific QoL (e.g. Artom et al., 2017).

The current study was also the first empirical investigation of the theorised effects of self-compassion on CSM variables in IBD. No evidence was found to support the hypothesis that self-compassion moderated the mediation relationships between CSM variables cross-sectionally. T1 Self-compassion was found to moderate the relationship between IBD symptoms and illness perceptions temporally, however, with higher levels of self-compassion weakening the strength of this relationship. One possible interpretation of this finding could be that the protective effects of self-compassion become more apparent over time, as more self-compassionate individuals are more likely to respond to health challenges with self-kindness and acceptance,

which in turn may produce less threatening illness perceptions, a more adaptive coping style and better QoL. Such an interpretation would fit with the proposed self-regulating effect of self-compassion outlined by Terry and Leary (2011), as well as recent empirical findings in IBD and other long-term conditions cohorts (Sirois et al., 2015; Trindade & Sirois, 2021).

Alternative interpretations of this data include the possibility that self-compassion itself, as a trait, is influenced by IBD symptomatology. When IBD symptoms improve, as was the case from T1 to T2 in the present study, individuals may become more self-compassionate (or more receptive to self-compassion), and this could potentially influence subsequent illness perceptions. It is also plausible that certain IPs, such as *personal control,* may be particularly responsive to changes in decreased symptoms, and increase receptivity to self-compassion. Any interpretations of these findings must be interpreted with caution, however, due to the small sample size and lack of supporting evidence cross-sectionally.

Lastly, T1 self-compassion was not found to be a significant predictor of illness perceptions, coping, or QoL after 6 months, when accounting for disease characteristics and baseline levels of the outcome. A diverging finding was reported by Trindade and Sirois (2021), who found that self-compassion at baseline predicted stress, anxiety and depression at 9-month follow-up in an IBD sample. Potential reasons for these conflicting findings could be the additional IBD history predictors added to the regression models in the present study, or the different psychosocial outcome measures used. It is important to reiterate that for longitudinal hypothesis testing, the present study was underpowered, and so it is possible genuine protective effects of self-compassion were not observed for this reason. Further replication of findings are needed before any firm conclusions regarding the role of self-compassion

in adjustment to IBD can be drawn.

Strengths and Limitations

The longitudinal design of the present study was a strength, as this addressed a gap in the existing IBD and CSM literature. An adequate sample size was recruited for cross-sectional hypothesis testing, and the statistical analyses utilised allowed for robust hypothesis testing while controlling for IBD symptoms and history. In particular, the use of more detailed IBD history variables is a strength as it reflects the long-term impact living with IBD can have, above and beyond current symptoms.

Recruitment and participation in the present study took place entirely online, the benefits of which included increased reach during recruitment and greater accessibility for participants. Most participants were recruited via a national IBD charity website or online support group, and therefore it is possible this biased the achieved sample. For example, there is some evidence from the broader literature that online health-related support groups are used more by females, those with poorer overall health, and those with stronger self-efficacy beliefs regarding their health (Atkinson et al., 2009; Coulson, 2009; Dutta & Feng, 2007).

This approach also necessitated a complete reliance on participant self-report, which may have introduced some error into the measurement of variables. However, the only variable in the present study which could arguably have been assessed more objectively was IBD symptoms, and the self-report tool utilised generally shows strong agreement with clinician-administered tools (Sexton et al., 2018). Lastly, while conservative screening strategies were utilised in an effort to produce trustworthy

data, it is possible some bots or spurious completions remained in the final datasets which may have affected the validity of findings.

Further limitations of the present study include a lack of statistical power for longitudinal hypothesis testing. The demographics of the achieved sample broadly mirror those of the IBD population as a whole in the UK (Misra et al., 2019), but there are some notable differences which effect the generalisability of findings, namely the over-representation of female and white participants (Greuter et al., 2020: Misra et al., 2019).

Moreover, the attrition of participants between timepoints may have introduced some bias into the study findings which was undetected. The poor internal consistency of the adapted IBD-Cope scale suggests that coping may not have been measured well in the present study.

Lastly, while the longitudinal nature of the present study allowed for a more robust test of the CSM, all findings were correlational in nature and therefore causal relationships cannot be inferred from these data.

Clinical and Research Implications

The observed statistical effects of IBD symptoms on QoL provides further support for having clinical remission as the primary treatment target in IBD care, given both the psychological and physical health benefits associated with reduced symptoms. The present study replicated findings regarding the centrality of illness perceptions in psychosocial adjustment to IBD. As noted by Kantidakis et al. (2021), future research should examine whether psychosocial interventions in IBD can target illness

perceptions directly, and if successful, this could have clinical utility for IBD clinicians seeking to provide holistic care consistent with NICE (2019) guidance.

While none of the additional IBD history variables accounted for in the present study were significant predictors of core outcomes, it is noteworthy that during EbE consultation these factors were highlighted. Gathering a comprehensive IBD history from patients which covers these aspects could aid clinicians in developing rapport and trust, which could positively influence treatment adherence and outcomes.

The present study was the first longitudinal investigation of the CSM with an adult IBD population, and so further replication of findings is required. In particular, the potential protective effects of self-compassion over time need to be robustly tested in future studies, and particular attention should be given to the accurate measurement of coping styles. Any such studies should carefully consider the sample size required at baseline to allow for adequate statistical power at follow-up, accounting for significant participant attrition. More complex study designs, such as a cross-lagged approach, could be useful in disentangling the temporal order of effects within the CSM. Furthermore, researchers should consider their study aims carefully and whether QoL or an alternative psychosocial outcome (e.g. psychological distress) is most appropriate.

Conclusion

Findings from the present study were consistent with some aspects of the CSM in IBD; namely, symptoms were positively associated with QoL both cross-sectionally and longitudinally, and illness perceptions acted a statistical mediator within the model cross-sectionally. Support was not found in the present study for the full proposed serial mediation within the CSM, however, this may have been due to issues

in the measurement of maladaptive coping. Self-compassion did not predict change in any CSM variables temporally, however, higher levels of self-compassion were associated statistically with a weaker relationship between symptoms and illness perceptions. All findings require replication in future longitudinal studies, and it is important to stress that causal relationships cannot be inferred from these data. The findings from the present study may support future applied research efforts and subsequent clinical practice.

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Section C: Appendices

Appendix A

Full Search String used for Literature Searching

(“illness perception*” OR “illness representation*” OR “illness cognition*’’ OR “illness belief*”) and (“Inflammatory bowel disease” OR IBD OR Colitis* OR UC OR Crohn* OR CD) and (“quality of life” OR QOL OR “health-related quality of life” OR HR-QOL OR HRQOL OR wellbeing OR well-being OR “psychological health” OR “psychological distress” OR “psychological outcomes” OR “emotional health” OR “emotional distress” OR adjustment OR depression OR anxiety OR stress OR “mental health” OR self-esteem OR self-efficacy OR non-adheren* OR adheren* OR “treatment outcome” OR prognosis OR remission OR “active disease”)

Appendix B

Glossary of terms from Table 2

AAQ-2 = Acceptance and Action Questionnaire-II

BIPQ = Brief Illness Perceptions Questionnaire

BISC = Body Image and Self-Consciousness During Intimacy Scale

BMQ = Beliefs about Medication Questionnaire

Brief-COPE = Brief Coping Operations Preference Enquiry

BSI = Brief Symptom Inventory

CAI = Clinical-Activity Index

CBSQ: Cognitive Behavioural Response to Symptoms Questionnaire

CDAI = Crohn's Disease Activity Index

CDEIS = Crohn's Disease Endoscopic Index of Severity

CES-D = Center for Epidemiological Studies Depression scale

COPE = Coping Operations Preference Enquiry

CRSQ = Coping with Rheumatic Stressors Questionnaire

DAS = Dysfunctional Attitude Scale

DASS = Depression, Anxiety and Stress Scale

DASS-21 = Depression, Anxiety and Stress Scale

DDAQ = Digestive Diseases Acceptance Questionnaire

ESS = Epworth Sleepiness Scale

EUROHIS-QOL = European Health Interview Survey – Quality of Life

EQ-5D-3L = EuroQoL – 5

FCCS = Fear of Contracting Covid-19 Scale

FFS = Family Functioning Scale

Appendix B (continued)

FLP = Functional Limitations Profile

FSSQ = Functional Social Support Questionnaire

GQ-6 = Gratitude Questionnaire – 6

GSRS = Gastrointestinal Rating Scale

GUTS: Gastrointestinal Unhelpful Thinking Scale

HADS = Hospital Anxiety and Depression Scale

HBI = Harvey Bradshaw Index

HSS = Health Status Subscale (of Health Orientation Scale)

IBD-DS = Inflammatory Bowel Disease – Distress Scale

IBD-F = IBD Fatigue Scale

IBDQ = Inflammatory Bowel Disease Questionnaire

IBDQ-32 = Inflammatory Bowel Disease Questionnaire – 32 item version

IBD-SE = Inflammatory Bowel Disease Self-Efficacy Scale

ICQ = Illness Cognition Questionnaire

IPQ = Illness Perceptions Questionnaire

IPQ-R = Illness Perceptions Questionnaire – Revised

LTI = Ulcerative Colitis Lichtiger Index

MFI = Multidimensional Fatigue Inventory

MFS = Marital Functioning Scale

MAAS = Mindful Attention Awareness Scale

MARS = Medication Adherence Revised Scale

MI = Manitoba Index

MMAS = Morisky Medication Adherence Scale

Appendix B (continued)

MMS8 = Morinsky Medication Adherence Scale - 8

MS = Mayo Score

MTWSI = Modified Truelove and Witts Index

NGSE = New General Self-Efficacy Scale

NPV-IN: Dutch personality questionnaire – Neuroticism Subscale

PCL-5 = PTSD Checklist for DSM-5

PDS = Perceived Disability Scale

PHQ-2 = Patient Health Questionnaire – 2

PRO3-CD: Patient Reported Outcome measure 3 – Crohn's Disease

PRO2-UC: Patient Reported Outcome measure 2 – Ulcerative Colitis

PSQ = Perceived Stress Questionnaire

PSS = Perceived Stress Scale

PTS = Psychological Thriving Scale

SCCAI = Simple Clinical Colitis Activity Index

sCDAI = short Clinical Disease Activity Index

SCID-1 = Structured Clinical Interview for DSM-IV Disorders – 1

SF-12v2 = Short-Form 12v2 Health Survey

SF-36 = Short-Form 36

SF-MPQ = Short-Form McGill Pain Questionnaire

SOC-13 = Sense of Coherence scale (13)

SQOL = Stoma Quality of Life scale

SPS = Sexual Problems Scale

SSS = Sexual Satisfaction Scale

Appendix B (continued)

UCL = Utrecht Coping List

VSI = Visceral Sensitivity Index

WHO-QOL = World Health Organisation Quality of Life Questionnaire

WHO-QOL8 = World Health Organisation Quality of Life Questionnaire – 8 item version

WPAI – Work Productivity and Activity Impairment Questionnaire

Appendix C

JBI (2020a) Critical Appraisal Tool for Cross-sectional Studies

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Appendix D

JBI (2020b) Critical Appraisal Tool for Cohort Studies

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Appendix E

Ethical Approval from Salomons Ethics Panel

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Appendix F

Information Sheet for Participants

Study title: Investigating the role of self-compassion, illness perceptions and coping strategies in Inflammatory Bowel Disease (IBD)

Research background: My name is James Guerin and I am a trainee Clinical Psychologist, studying at Salomons Institute for Applied Psychology, Canterbury Christ Church University, under the supervision of Dr Fergal Jones and Dr Georgina Knott (Clinical Psychologists).
I would like to invite you to take part in my research study, which is exploring how people with IBD cope with their illness.

What is the purpose of this study: We know that the challenges of living with IBD influences people's quality of life. What is less well understood are the links between the physical symptoms of the illness, the ways people cope, and how these interact with one another. I am hoping to explore these links in this study to better understand how we can improve quality of life for people with IBD.

Who can take part? To take part in this study, you must have received a diagnosis of IBD from a registered healthcare professional.

*'You have been invited to take part in this follow-up survey as you completed Part 1 of this study approximately 6 months ago and indicated you were happy to be contacted for follow-up'

Appendix F (continued)

What are the benefits of taking part? By taking part in this study, you would be helping to generate knowledge which can be used to improve the quality of life for those with IBD. As a token of gratitude for taking part in this study, you will have the option of being entered into a prize draw to win a £100 Amazon voucher. You can earn two entries into the prize draw and 'double your chances' by completing both the baseline and 6-month follow-up surveys.

*You may have chosen to enter this prize-draw during Part 1 of the study, and so you have the opportunity to 'double your chances' by completing and this follow-up survey.

What's involved in taking part? If you participate in the study, you will be asked to complete a series of questionnaires as part of an online survey. These questionnaires will ask you about your experiences with IBD (both in the past and at present), how you cope with the illness, and your overall quality of life. After 6 months, if you have consented, you will be asked to complete some of these questionnaires a second time. Completing the online survey each time should take approximately 30 minutes of your time. There is no physical examination or face-to-face interaction involved in this study.

Do I have to take part? No. Taking part in this study is completely voluntary. Should you start the survey and then change your mind, you are free to discontinue the study at any point. If you take part in the first survey, you are under no obligation to complete the survey again after 6 months.

Can I change my mind and withdraw my data after I've completed the survey? There will be a 2-week period following completion of the survey where it will be possible to contact the researcher and have your data removed, if you provided an email address when you completed the survey. Following this 2-week period, it will not be possible to withdraw your data from the study as data analysis may have started.

Appendix F (continued)

What are the risks involved for me? As this study does not involve any intervention and can be completed online at your leisure, it is felt that the study is low risk for most participants. However, completing the study does require answering questions about your experiences with IBD, and it is possible that doing so could cause distress. It is advised that you consider your own well-being before completing the survey. If you think that completing questionnaires on these topics is likely to be distressing, we would recommend that you do not participate. If you start to experience distress part way through the survey, you can stop answering questions and move to the end of the survey, where sources of support will be listed.

How will my information be used? Is it confidential? All responses to survey questions will be kept strictly confidential. You will be given the choice to provide your email address at the end of the study. You will need to provide your email address if you:

a) wish to be entered into the prize draw, and/or

b) wish to notified in 6 months time to complete the follow-up survey, and/or

c) if you wish to have the option of withdrawing your data for 2 weeks following completion of the study.

d) you wish to be contacted to hear about other ICD research being conducted by the university

Please note: You can choose to consent to some of the above options and not others, and your data will only be used in line with what you have consented to.

*'Should you decide to provide your email address, please use the same email address provided in Part 1 (that was used to invite you to take part in this follow-up survey). This will allow your data from both surveys to be linked.'

If you opt to enter the prize draw and win, then your email address (but not any other information) will be passed to the University's finance department to issue the electronic prize voucher.
At the end of the study, the data will be totally anonymised as all email addresses will

Appendix F (continued)

be deleted. Should you decline to provide an email address at the end of the study, then your responses will be anonymous throughout.

Anonymous data from the study will be made publicly available for other researchers to access, and the anonymous study findings may be published in the form of a thesis, journal article and/or conference presentation.

Data from the study will be stored on secure, encrypted file space for the duration of the project. After completion of the project, information from the study will be stored securely at Salomons Institute for Applied Psychology for 10 years. Data protection and storage will follow all legal requirements including GDPR. If you would like more information about Canterbury Christ Church University's approach to data protection, please see here: https://www.canterbury.ac.uk/services/governance-and-legal-services/data-protection

Who can I contact for more information? If you would like any more information on this study, or have any questions, please do not hesitate to contact me via email at: jg851@canterbury.ac.uk. If you have any concerns about the study, please contact me. If I am not able to address those concerns, or if you wish to make a formal complaint, please contact Professor Margie Callanan, Director of Salomons Institute for Applied Psychology on: Margie.callanan@canterbury.ac.uk

If you would like to take part in the study, please click 'Next' below to move on to a Consent Form.

Note: * indicates statements which appeared in the information sheet at timepoint 2 only

Appendix G

Participant Debriefing Sheet

Thank you for taking the time to complete the survey.

Do you wish to be entered into / earn another entry into the draw for the £100 Amazon voucher? Yes/No

*Do you wish to opt-in to receive an email invitation to complete the follow-up survey in 6 months time, which allows a second entry into the prize draw? Yes/No

Do you wish to receive a summary of the study findings when the study is complete? Yes/No

I might want to withdraw my study data within the next two weeks. Yes/No

Do you wish to hear about other research regarding IBD being conducted by the university? Yes/No

[If the answer is yes to any of the above, then the following question will appear]

Please enter your email address below (Note: email addresses will only be used in line with your stated preferences):

You can unsubscribe from hearing about further research at anytime by emailing James Guerin (jg851@canterbury.ac.uk).

If completing the survey has highlighted issues for you that you wish to receive further support with, below are some helpful resources you can access:

- Crohn's and Colitis UK operate a helpline service, Monday to Friday between 9 AM and 5 PM, that is free to access. The helpline can provide information on a range of subjects including: managing symptoms, medication, diet, wellbeing, employment and help to find support from others living with the condition The helpline can be accessed on 0300 222 5700, or visit crohnsandcolitis.org.uk for more details

Appendix G (continued)

- There are a number of phonelines and webchat / text services available to support people experiencing mental health difficulties. A helpful list of what is available can be accessed here: https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/helplines-listening-services/
- If you would like to discuss your individual health concerns regarding your IBD, your GP or IBD team will likely be best placed to provide this support

Should you wish to withdraw your data from the study, please contact me directly within the next two weeks via email at: jg851@canterbury.ac.uk. Withdrawal will only be possible if you enter your email address above. If you have any feedback about the study, you are welcome to email me.

Thank you again for taking the time to participate in the study.

Note: * indicates statements which were not displayed in the timepoint 2 debrief sheet

Appendix H

Participant Consent Form

Please indicate whether you agree with each of the following statements.

- I have read and understand the study Information Sheet presented on the previous page (Yes/No)

- If I had any questions that the Information Sheet didn't answer, I have had a chance to ask these (Yes/No)

- **I confirm that I took part in Phase 1 of this study approximately 6 months ago (Yes/No)

- I confirm that I am an adult, resident in the UK who has received a diagnosis of IBD (i.e. Ulcerative Colitis or Crohn's disease) from a healthcare professional (Yes/No)

- I understand that if I

    a) *wish to take part in the follow-up survey in 6 months time, and/or
    b) wish to enter the prize draw for the £100 Amazon voucher, and/or
    c) **wish to earn an additional entry into the prize draw
    d) wish to receive a summary of the study's findings, and/or
    e) *wish to be contacted about other IBD research being conducted by the university

I will need to supply my email address Yes/No

- I am aware that in the 2 weeks following completion of the survey, I can contact the researcher and ask for my data to be removed from the study, so long as I provided an email address when I completed the survey Yes/No

- I understand that anonymous data from the study will be made publicly available Yes/No

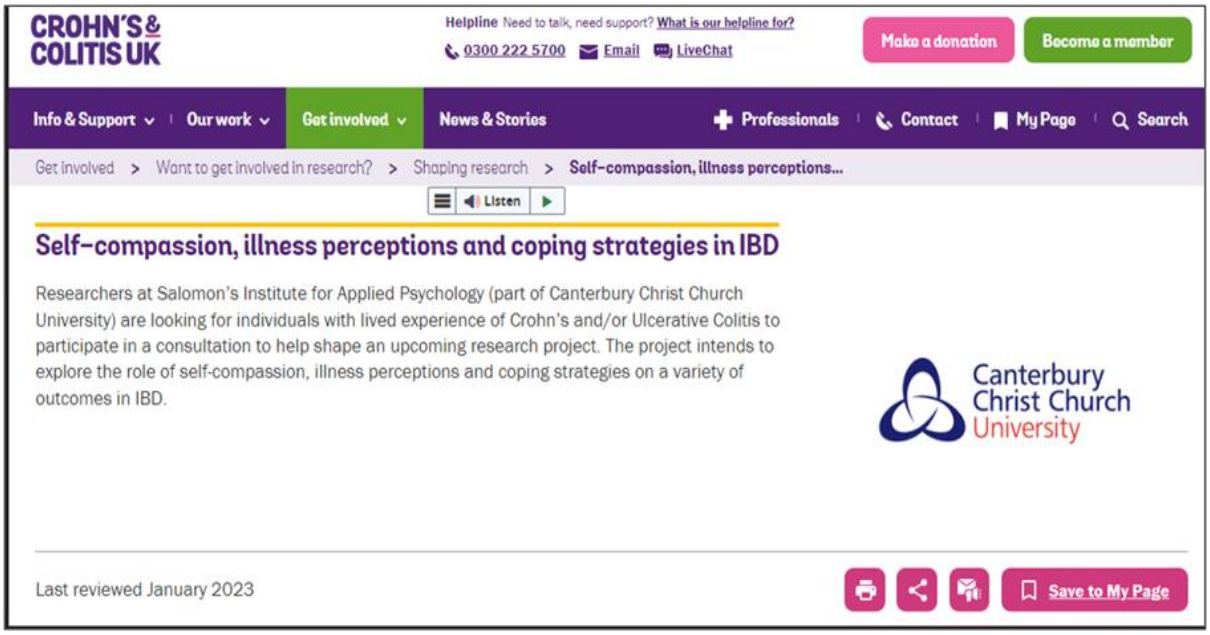
- *At the end of this research, you will be offered the opportunity to hear about more research into IBD being run by the university by providing your email address. If you agree to this, your email address will only be retained for this purpose until the end of 2023. Prior to then, if you'd like to withdraw your email address, please contact James Guerin (jg851@canterbury.ac.uk).

- I am happy to take part in the study Yes/No

Note: * indicates statements which appeared at timepoint 1 only, ** indicates statements which appeared at timepoint 2 only

Appendix I

Advertisement placed with National IBD charity for expert by experience consultants



Appendix J

Study advertisement used for social media

Hi everyone,

Hope you are all doing okay. My name is James, I'm a trainee clinical psychologist based in the UK at Canterbury Christ Church university. I'm doing some research involving people living with IBD, and I'm currently looking for some participants. My study is a short online survey (10-25 mins), that is open to any adult in the UK with a diagnosis of IBD. Participants also have the chance to win a £100 amazon voucher, as a 'thank you' for your time.

My study is exploring the links between the physical symptoms of IBD, a variety of psychological factors and quality of life. I've had Crohn's disease myself for 12 years, which is a big part of why I am interested in researching this topic, and I hope I have been able to use that experience to ensure the questions are worded sensitively.

The link to the study is below, but if you have any questions please feel free to get in touch with me at: jg851@canterbury.ac.uk

Thank you!

James

Appendix K

Bespoke IBD Information Questionnaire

IBD Disease History and Diagnoses

1. Please indicate which type of IBD you are currently diagnosed as having (circle your response)

Crohn's Disease Ulcerative Colitis I don't know / unsure

2. Please indicate if you have undergone surgery for an IBD-specific problem (circle your response)

Yes, on one occasion Yes, on multiple occasions No

3. Please indicate whether you have currently, or have had in the past, a stoma or pouch? (circle your response)

I currently have a stoma I currently have a pouch I previously had a stoma
I previously had a pouch I have never had a stoma or pouch

4. Please indicate whether you are currently prescribed medication for your IBD by a healthcare professional.

   Yes No

5. Please indicate if you have been diagnosed with any other chronic illnesses, other than IBD (e.g. arthritis) (circle your response)

   Yes, I have been diagnosed with one other chronic illness (please specify)

   Yes, I have been diagnosed with more than one other chronic illness (please specify)

   No, I have not been diagnosed with another chronic illness

6. Please indicate the approximate number of years since you were diagnosed with IBD

   ____ years

Appendix L

Demographics Questionnaire

Please indicate how you would describe your gender

- Female
- Male
- Other (please describe):
- Prefer not to say

Please type in your age in years:

Please indicate your ethnicity:

- White British
- Mixed ethnicity
- Asian / Asian British
- White Irish
- Black British / Black / African / Caribbean
- Other Ethnic Group (please describe)

Please indicate your highest level of educational attainment (circle your response)

- No formal qualifications
- Foundation diploma / GCSE (grades D-G) or equivalent
- Higher diploma / GCSE (grades A*-C) or equivalent
- Apprenticeship
- Advanced Diploma / two A-levels or equivalent
- Certificate of Higher Education / BTEC professional or equivalent

Appendix L (continued)

- Bachelor's degree
- Postgraduate Certificate or Diploma / Master's degree
- Doctorate degree
- Other qualifications (please describe):

Please indicate your current relationship status:

Single	Separated
Married	Long-term relationship
Civil Partnership	Widowed
Divorced	Co-habiting
Other	Prefer not to say

Please indicate how you became aware of this study:

IBD charity (e.g. Crohn's and Colitis UK)	Social Media (e.g. facebook)
Word of Mouth	Prefer not to say
Other (please specify):	Unsure

Appendix M

Exploratory Analyses Investigating the Internal Consistency and Inter-item Correlations of the IBD-Cope and its Effect on Hypothesis Testing

Table M1.

Item Inter-correlations (Spearman's Rho) for IBD-Cope

Correlations

			IBD Cope	Cope2t1	Cope3t1
Spearman's rho	IBD Cope	Correlation Coefficient	1.000	.033	.299**
		Sig. (2-tailed)	.	.692	<.001
		N	147	144	147
	Cope2t1	Correlation Coefficient	.033	1.000	.168*
		Sig. (2-tailed)	.692	.	.045
		N	144	144	144
	Cope3t1	Correlation Coefficient	.299**	.168*	1.000
		Sig. (2-tailed)	<.001	.045	.
		N	147	144	147

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table M2.

Internal Consistency if Item Deleted

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
IBD Cope	1.81	2.069	.247	.271
Cope2t1	3.17	2.760	.125	.471
Cope3t1	2.50	1.776	.334	.074

Note: It was not possible to test McDonald's omega with Item 2 deleted as this would have left 2 items in the scale, which violates assumptions of the test.

Appendix M (continued)

Hypothesis 1 with Adjusted Coping Measure

Table M3.

Results of Serial Mediation Analysis (cross-sectional), with adapted 2-item Coping Measure

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	**.8727*** **	**.7137*** **	**.1589***	**.1249***	.0002	.1589
95% Confidence Intervals	[0.7220, 1.0234]	[0.5316, 0.8958]	[.0466, .2848]	[.0367, .2252]	[-.0209, .0307]	[.0464, 0.2835]

Note: Total Effect = Total Indirect Effect + Direct Effect. Total Indirect Effect = Sum of indirect effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p < .001$.

Table M4.

Results of Serial Mediation Analysis (longitudinal), with adapted 2-item Coping Measure

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	**.5839***	.5208	.0631	.1006	-.0385	.0010
95% Confidence Intervals	[.0935, 1.0743]	[-.1265, 1.1681]	[-.4546, .6527]	[-.3852, .6157]	[-.2290, .1509]	[-.0919, 0.0763]

Note: Total Effect = Total Indirect Effect + Direct Effect. Total Indirect Effect = Sum of indirect effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL, Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$.

Appendix M (continued)

Hypothesis 2 with Adjusted Coping Measure

Table M5.

Moderation-only Model Testing Hypothesis 2b cross-sectionally, with adapted 2-item Coping Measure

Hypothesis	**Hypothesis 2b**
Variables	IV: Illness Perceptions (t1) DV: Maladaptive coping (t1)
	W = Self-compassion (t1)
Direct effect	*b* = .0320
Interaction effect (moderator)	*b* = .-0012
95% Confidence Intervals	LL: -.0200
	UL: .0176

Note: IV = Independent variable, DV = Dependent variable, t1 = timepoint 1, *W* = Moderator, *b* = unstandardised beta coefficient, LL= Lower limit, UL = Upper limit.

Table M6.

Moderation-only Model Testing Hypothesis 2b longitudinally, with adapted 2-item Coping Measure

Hypothesis	**Hypothesis 2b**
Variables	IV: Illness Perceptions change
	DV: Maladaptive coping change
	W = Self-compassion change
Direct effect	*b* = .0839
Interaction effect (moderator)	*b* = .-.1375
95% Confidence Intervals	LL: -.2583
	UL: .0110

Note: IV = Independent variable, DV = Dependent variable, t1 = timepoint 1, *W* = Moderator, *b* = unstandardised beta coefficient, LL= Lower limit, UL = Upper limit.

Appendix M (continued)

Hypothesis 3 with Adjusted Coping Measure

Table M7.

Hierarchical multiple regression testing Hypothesis 3b, with adapted 2-item Coping measure

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF from Model 1 (df)	ΔR^2	B	*T*	95% CI for B LB	UB
Model 1 (Controls)		.260	.147	2.308* (7, 46)	N/A	N/A				
	IBD type						-.246	-.593	-1.081	.588
	Number of IBD surgeries						-.297	-.873	-.983	.388
	Stoma / pouch						.012	.067	-.340	.364
	Years since Dx						.009	.383	-.039	.058
	Prescribed IBD medication						.315	.438	-1.133	1.763
	Co-occurring Dx						.472	2.138*	.028	.917
	Current IBD symptoms						.042	3.044**	.014	.069
Model 2		.477	.385	5.139*** (8, 45)	18.73*** (1, 45)	.218				
	IBD type						.014	.038	-.706	.733
	Number of IBD surgeries						-.185	-.636	-.770	.400
	Stoma / pouch						-.082	-.546	-.384	.220
	Years since Dx						.024	1.224	-.018	.066
	Prescribed IBD medication						.549	.894	-.687	1.785
	Co-occurring Dx						.352	1.854	-.030	.734
	Current IBD symptoms						.021	1.643	-.005	.046
	Coping t1						.474	4.328***	.253	.694
Model 3		.484	.378	4.583*** (9, 44)	.546 (1, 44)	.006				
	IBD type						-.023	-.062	-.753	.708
	Number of IBD surgeries						-.190	-.649	-.778	.399
	Stoma / pouch						-.063	-.408	-.371	.246
	Years since Dx						.025	1.209	-.017	.068
	Prescribed IBD medication						.486	.780	-.769	1.740
	Co-occurring Dx						.383	1.961	-.011	.776
	Current IBD symptoms						.019	1.527	-.006	.045
	Coping t1						.444	3.785***	.208	.680
	Self-compassion t1						-.194	-.739	-.722	.334

Note: DV = Coping T2**. Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Appendix M (continued)

Hypothesis 4 (IBD-only cohort) with Adjusted Coping Measure

Table M8.

Results of Serial Mediation Analysis (cross-sectional data) using 2-item IBD-Cope (IBD-only Cohort)

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	.8122***	.6680***	.1442*	.1671*	-.0087	-.0142
95% Confidence Intervals	[0.5946, 1.0299]	[0.4322, 0.9039]	[.0283, .2911]	[.0415, .3087]	[-.0488, .0324]	[-0.0642, 0.0290]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Appendix M (continued)

Table M9.

Results of Serial Mediation Analysis (longitudinal data) using 2-item IBD-Cope (IBD-only Cohort)

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	.5988*	.5442	.0546	.0925	-.0390	.0011
95% Confidence Intervals	[0.0949, 1.1028]	[-.1324 1.2207]	[-.5109, .6547]	[-.4557, .6212]	[-.2345, .1493]	[-0.0929, 0.0781]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Table M10.

Moderation-only Model Testing Hypothesis 2b Cross-sectionally, with adapted 2-item Coping Measure (IBD-only Cohort)

Hypothesis	**Hypothesis 2b**
Variables	IV: Illness Perceptions (t1) DV: Maladaptive coping (t1) *W* = Self-compassion (t1)
Direct effect	*b* = .0158
Interaction effect (moderator)	*b* = .0142
95% Confidence Intervals	LL: -.0211 UL: .0496

Note: IV = Independent variable, DV = Dependent variable, t1 = timepoint 1, *W* = Moderator, *b* = unstandardised beta coefficient, LL= Lower limit, UL = Upper limit.

Appendix M (continued)

Table M11.

Moderation-only Model Testing Hypothesis 2b Longitudinally, with adapted 2-item Coping Measure (IBD-only Cohort)

Hypothesis	**Hypothesis 2b**
Variables	IV: Illness Perceptions change
	DV: Maladaptive coping change
	W = Self-compassion change
Direct effect	*b* = .1436
Interaction effect (moderator)	*b* = -.2190
95% Confidence Intervals	LL: -.4995
	UL: .0616

Note: IV = Independent variable, DV = Dependent variable, t1 = timepoint 1, *W* = Moderator, *b* = unstandardised beta coefficient, LL= Lower limit, UL = Upper limit.

Table M12.

Hierarchical multiple regression testing Hypothesis 3b, with adapted 2-item Coping measure (IBD-only cohort)

Model	**Predictors**	**R^2**	**Adj. R^2**	**F (df)**	**ΔF from Model 1 (df)**	**ΔR^2**	**B**	***t***	**95% CI for B**	
									LB	**UB**
Model 1 (Controls)		.510	.355	3.297 (6, 19)	N/A	N/A				
	IBD type						.049	.096	-1.021	1.119
	Number of IBD surgeries						-.88	-1.92	-1.838	.079
	Stoma / pouch						.519	1.934	-.043	1.081
	Years since Dx						.049	1.25	-.033	.130
	Prescribed IBD medication						-1.07	-1.234	-2.871	.741
	Current IBD symptoms						.061	2.955**	.018	.105
Model 2		.567	.398	3.361* (7, 18)	2.346 (1, 18)	.056				
	IBD type						.173	.345	-.879	1.124
	Number of IBD surgeries						-.876	-1.98	-1.806	.054

Table M12 (continued)

	Stoma / pouch						.469	1.793	-.081	1.018
	Years since Dx						.056	1.477	-.024	.136
	Prescribed IBD medication						-1.118	-1.339	-2.871	.636
	Current IBD symptoms						.074	3.412**	.028	.120
	Coping t1						.362	1.532	-.135	.859
Model 3		.587	.393	3.022* (8, 17)	.846 (1, 17)	.007				
	IBD type						.135	.267	-.929	1.199
	Number of IBD surgeries						-.770	-1.676	-1.739	.199
	Stoma / pouch						.475	1.81	-.079	1.030
	Years since Dx						.055	1.446	-.025	.135
	Prescribed IBD medication						-1.015	-1.201	-2.799	.768
	Current IBD symptoms						.065	2.749*	.015	.116
	Coping t1						.328	1.366	-.179	.835
	Self-compassion t1						-.369	-.920	-1.217	.478

Note: DV = Coping T2**. Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Appendix N

Additional Mediation analyses Testing Hypothesis 1 Longitudinally

Table N1.

Results of Serial Mediation Analysis (Longitudinal data)

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	**.3617***	.2814	.0803	.0780	.0033	-.0009
95% Confidence Intervals	[.1020, .6215]	[-.0139, .5767]	[-.1154, .2832]	[-.0891, .2714]	[-.0818, .0776]	[-.0281, 0.0212]

Note: Total Effect = Total Indirect Effect + Direct Effect. Total Indirect Effect = Sum of indirect effects. Indirect Effect 1 = IBD symptoms change → Illness Perceptions change → QoL change. Indirect Effect 2 = IBD Symptoms change → Coping change → QoL change. Indirect Effect 3 = IBD Symptom change → Illness Perceptions change → Coping change → QoL change (full serial mediation). Figures in bold represent statistically significant results

Appendix O

Serial Mediation Models Testing Hypothesis 1 for both Active IBD vs IBD in Remission

Table O1.

Results of Serial Mediation Analysis (cross-sectional data) for Active IBD

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	.7877***	.6990***	.0887	.1298*	-.0307	-.0104
95% Confidence Intervals	[0.5924, .9830]	[0.4815, 0.9165]	[-.0256, .2141]	[.0174, .2418]	[-.0996, .0240]	[-.0369, .0071]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Table O2.

Results of Serial Mediation Analysis (cross-sectional data) for IBD in Remission

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	2.6812**	2.5781**	.1031	.2043	-.0229	-.0783
95% Confidence Intervals	[1.0863, 4.2761]	[0.8855, 4.2708]	[-.3380, .5666]	[-.2318, .8538]	[-.3061, .2186]	[-.4372, .1949]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Table O3.

Results of Serial Mediation Analysis (longitudinal data) for Active IBD

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	.9038**	.6967***	.2071	.1569	.0119	.0383
95% Confidence Intervals	[.5876, 1.2199]	[0.3379, 1.0554]	[-.0212, .4375]	[-.1162, .3772]	[-.0574, .1450]	[-.1038, .2122]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Table O4.

Results of Serial Mediation Analysis (longitudinal data) for IBD in Remission[1]

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	1.3718	1.3269**	.0448	.0917	-.0561	.0092
95% Confidence Intervals	[-.5546, 3.2981]	[-.7017, 3.3556]	[-.9736, 1.7968]	[-.5404, .1.3666]	[-.7012, 1.0290]	[-.4487, .2789]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$. 1: The sample size for this analysis was $N = 15$, and therefore the analysis was underpowered and unlikely to detect even large effects.

Appendix P

Comparison of T1-only responders against T1 & T2 responders on core variables

Table P1

Independent Samples t-tests Comparing T1-only vs Complete Responders on Core Variables at Baseline

Variable	**Mean (SD) at Baseline**	***t*- statistic**	***p* value (2-tailed)**	**95% Confidence Intervals**
IBD Symptoms	T1-only: 30.22 (19.18) T1+T2:29.02 (16.23)	.386	.70	{-4.96, .7.38}
Illness Perceptions	T1-only: 46.37 (11.20) T1+T2: 49.09 (11.31)	-1.410	.161	{-6.54, 1.09}
Maladaptive Coping	T1-only: 3.87 (1.99) T1+T2: 3.52 (1.87)	1.036	.302	{-0.318, 1.018}
Quality of Life	T1-only: 39.51 (23.92) T1+T2: 40.54 (21.34)	-.262	.794	{-8.86, 6.78}

Appendix Q

Hypothesis 4 Testing

Table Q1.

Results of Serial Mediation Analysis (cross-sectional data) for IBD-only Cohort

	Total Effect	**Direct Effect**	**Total Indirect Effect**	**Indirect Effect 1**	**Indirect Effect 2**	**Indirect Effect 3**
Beta coefficient	.8109***	.6867***	.1242*	.1776*	-.0284	-.0251
95% Confidence Intervals	[0.5917, 1.0301]	[0.4510, 0.9224]	[.0095, .2597]	[.0532, .3239]	[-.1018, .0176]	[-0.0708, 0.0059]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Table Q2.

Results of Serial Mediation Analysis (longitudinal data) for IBD-only Cohort

	Total Effect	Direct Effect	Total Indirect Effect	Indirect Effect 1	Indirect Effect 2	Indirect Effect 3
Beta coefficient	.5988*	.5587	.0401	.0865	-.0596	.0131
95% Confidence Intervals	[0.0828, 1.1148]	[-.1567, 1.2742]	[-.6292, .6858]	[-.5184, .6726]	[-.3086, .1385]	[-0.0744 0.1204]

Note: Total Effect = Sum of Indirect Effects + Direct Effect. Total Indirect Effect = Sum of Indirect Effects. Indirect Effect 1 = IBD symptoms → Illness Perceptions → QoL. Indirect Effect 2 = IBD Symptoms → Coping → QoL. Indirect Effect 3 = IBD Symptoms → Illness Perceptions → Coping → QoL (full serial mediation). Figures in **bold** represent statistically significant results. * denotes $p < .05$, *** denotes $p <. 001$

Appendix Q (continued)

Table Q3.

Hierarchical multiple regression testing Hypothesis 3a for IBD-only cohort

Model	**Predictors**	**R^2**	**Adj. R^2**	**F (df)**	**ΔF from Model 1 (df)**	**ΔR^2**	**B**	***t***	**95% CI for B**	
									LB	**UB**
Model 1 (Controls)		.381	.185	1.948 (6, 19)	N/A	N/A				
	IBD type						2.307	.577	-6.059	10.675
	Number of IBD surgeries						.010	.003	-7.245	7.265
	Stoma / pouch						2.591	1.24	-1.771	6.954
	Years since Dx						-.034	-.116	-.651	.583
	Prescribed IBD medication						-7.998	-1.26	-21.24	5.243
	Current IBD symptoms						.362	2.368*	.042	.682
Model 2		.655	.520	4.874** (7, 18)	14.268** (1, 18)	.274				
	IBD type						1.299	.422	-5.169	7.768
	Number of IBD surgeries						.384	.144	-5.208	5.975
	Stoma / pouch						.476	.281	-3.084	4.036
	Years since Dx						-.071	-.314	-.547	.405
	Prescribed IBD medication						-2.385	-.47	-13.051	8.281
	Current IBD symptoms						.056	.395	-.243	.356
	Illness Perceptions t1						.655	3.78**	.291	1.020
Model 3		.661	.502	4.418** (8, 17)	.333 (1, 17)	.007				
	IBD type						.938	.293	-5.812	7.688
	Number of IBD surgeries						.121	.044	-5.682	5.923
	Stoma / pouch						.089	.048	-3.821	3.998
	Years since Dx						-.071	-.38	-.579	.403
	Prescribed IBD medication						-2.023	-.388	-13.018	8.972
	Current IBD symptoms						.080	.529	-.238	.398
	Illness Perceptions t1						.719	3.448**	.279	1.159
	Self-compassion t1						1.811	.577	-4.811	8.433

Note: DV = Illness Perceptions T2**. Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Table Q4.

Hierarchical multiple regression testing Hypothesis 3b for IBD-only cohort

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF from Model 1 (df)	ΔR^2	B	*t*	95% CI for B LB	UB
Model 1 (Controls)		.287	.049	1.205 (6, 19)	N/A	N/A				
	IBD type						2.307	.577	-6.059	10.675
	Number of IBD surgeries						.010	.003	-7.245	7.265
	Stoma / pouch						2.591	1.24	-1.771	6.954
	Years since Dx						-.034	-.116	-.651	.583
	Prescribed IBD medication						-7.998	-1.26	-21.24	5.243
	Current IBD symptoms						.362	2.368*	.042	.682
Model 2		.547	.361	7.233* (7, 18)	9.77** (1, 18)	.261				
	IBD type						1.299	.422	-5.169	7.768
	Number of IBD surgeries						.384	.144	-5.208	5.975
	Stoma / pouch						.476	.281	-3.084	4.036
	Years since Dx						-.071	-.314	-.547	.405
	Prescribed IBD medication						-2.385	-.47	-13.051	8.281
	Current IBD symptoms						.056	.395	-.243	.356
	Coping t1						.656	3.127**	.213	1.099
Model 3		.555	.333	2.498 (9, 44)	.301 (1, 44)	.008				
	IBD type						.089	.127	-1.397	1.574
	Number of IBD surgeries						-.067	-.103	-1.439	1.305
	Stoma / pouch						.136	.369	-.646	.918
	Years since Dx						.103	1.914	-.011	.217
	Prescribed IBD medication						.522	.489	-1.742	2.786
	Current IBD symptoms						.021	.681	-.045	.088
	Coping t1						.616	2.724*	.137	1.096
	Self-compassion t1						-.365	-.549	-1.774	1.045

Note: DV = Coping T2**. Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics

Table Q5.

Hierarchical multiple regression testing Hypothesis 3c for IBD-only cohort

Model	Predictors	R^2	Adj. R^2	F (df)	ΔF from Model 1 (df)	ΔR^2	B	*t*	95% CI for B LB	UB
Model 1 (Controls)		.382	.186	1.955 (6, 19)	N/A	N/A				
	IBD type						-10.99	-1.4	-27.46	5.488
	Number of IBD surgeries						-2.775	-.407	-17.06	11.509
	Stoma / pouch						-2.228	-.543	-10.82	6.362
	Years since Dx						-.079	-.136	-1.294	1.136
	Prescribed IBD medication						10.549	.847	-15.542	36.621
	Current IBD symptoms						.883	2.94**	.253	1.513
Model 2		.576	.411	3.49* (7, 18)	8,228** (1, 18)	.194				
	IBD type						-5.145	-.735	-19.86	9.565
	Number of IBD surgeries						.954	.160	-11.552	13.46
	Stoma / pouch						-1.47	-.419	-8.829	5.89
	Years since Dx						-.172	-.347	-.1.212	.868
	Prescribed IBD medication						13.843	1.3	-8.562	36.247
	Current IBD symptoms						.069	.181	-.734	.873
	QoL t1						.704	2.868**	.188	1.220
Model 3		.578	.379	2.908 (8, 17)	.086 (1, 17)	.002				
	IBD type						-5.029	-.699	-20.215	10.156
	Number of IBD surgeries						1.156	.188	-11.816	14.127
	Stoma / pouch						-1.311	-.361	-8.982	6.36
	Years since Dx						-.156	-.305	-1.234	.922
	Prescribed IBD medication						13.944	1.273	-9.161	37.049
	Current IBD symptoms						.037	.091	-.823	.897
	QoL t1						.687	2.659*	.142	1.232
	Self-compassion t1						-1.761	-.293	-14.425	10.903

Note: DV = QoL T2**. Key**: R^2 = coefficient of determination; Adj.R^2 = adjusted R^2; F = explained variance; df = degrees of freedom; ΔF= change in variance explained between models; ΔR^2 = change in determination of coefficient between models; B = unstandardized regression coefficient; t = parameter estimate divided by its standard error; p = significance value; CI = confidence interval; LB = lower bound; UB = upper bound; NA = not applicable, *** p<0.001; **p<0.01; *p<0.05. Note: Model used was forced entry or "Enter" method in SPSS statistics