Coping in young people diagnosed with Inflammatory Bowel Disease

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A thesis submitted in partial fulfilment of the requirements for the degree
of Doctor of Clinical Psychology

Doctor of Clinical Psychology
Clinical Psychology Unit
University of Sheffield

May 2017

Declaration

This thesis has not been submitted for any other qualification or to any other academic institution.

Structure and word count

Literature review

Excluding references: 8,337

Including references: 10,620

Research report

Excluding references: 9,940

Including references: 13,075

Total word count

Excluding references and appendices: 18,277

Including references and appendices: 29,984

Abstract

This thesis aimed to explore how young people (YP) cope with inflammatory bowel disease (IBD). First a meta-study was conducted to synthesise existing qualitative studies relating to stress and coping in YP diagnosed with IBD to develop an integrated theoretical understanding. IBD was found to generate stressors which all related to a loss of perceived control and coping mechanisms were conceptualised as efforts to regain control. Escape, isolation, opposition and support-seeking coping mechanisms were described at times of greater stress as ways of quickly regaining control and facilitating a sense of safety. The synthesis was interpreted in the context of the included studies' methodologies and use of theory. It was suggested that future studies could investigate how loss of perceived control relates to psychological distress in this age-group and whether there were factors which could support young people's coping efforts.

To this end, the empirical study investigated whether self-compassion facilitated adaptive coping and in turn reduced psychological distress in YP diagnosed with IBD. A six-week prospective online survey design was utilised to examine the hypothesised relationships over time. Samples of 198 and 105 participants participated at Times 1 and 2 (47% attrition). Self-compassion predicted reduced psychological distress and the direct effect between self-compassion and psychological distress remained significant through avoidant coping. These findings suggested self-compassionate YP may be more able to turn towards difficult feelings linked to their IBD, consider them in context and respond to themselves with self-kindness, which the data suggested would improve their psychological health. However, the relationships were only observed cross-sectionally, not over time, and should be interpreted in the context of the study's limitations.

Acknowledgements

I would firstly like to thank my thesis supervisors Dr Georgina Rowse and Dr Fuschia Sirois for their unwavering support and guidance during this project. I have really enjoyed working with you and hope it may continue.

I am grateful to contributors Dr Alenka Brooks, Dr Jess Hookham, and Dr Paul Norman for their advice and assistance along the way. A big thank you to all the young people who participated and Crohn’s and Colitis UK and Crohn's in Childhood Research Association (CICRA) who kindly advertised the study. You made this thesis possible.

I would also like to thank my family and friends for showing interest in what was keeping me at my desk for so long and willing me to take regular breaks. Finally, to my husband Sam, thank you for being you and supporting and loving me all the way.

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Part One: Literature Review

Stressors and coping in young people diagnosed with Inflammatory Bowel Disease: A systematic meta-study of qualitative research

Abstract

Objectives

To synthesise and critique qualitative studies which focus on stressors young people (YP) diagnosed with Inflammatory Bowel Disease (IBD) experience and how they cope with these, to thereby develop an integrated theoretical perspective.

Design/Methods

Fourteen papers describing eleven studies were included, published between 2002-2016. A meta-study was conducted, which encompassed analysis of included studies' methodology, underpinning theory and a synthesis of available data using meta-ethnography.

Results

YP experienced rapid fluctuations between perceived stressors and coping in the context of IBD. Loss of control was a pivotal stressor and coping mechanisms could be seen as efforts to regain control. Escape, isolation, opposition and support-seeking coping were described by YP at times of greater stress. Stress and coping were described a-theoretically and most studies had practical as opposed to theoretical foci. There was limited consideration of epistemology and reflexivity within the papers.

Conclusions

Perceived control may be of specific relevance to YP diagnosed with IBD and may underpin the stressors they perceive and the coping mechanisms they choose. Normative coping shifts towards greater self-reliant and cognitive coping may be

compromised at times of high illness activity. On-going negotiation of priorities formed an integral part of YP's coping as they moved between situations.

Practitioner Points

- Healthcare professionals should consider ways to empower YP (e.g., ensuring healthcare decisions are made collaboratively).
- Normalising delays to coping transitions in the context of chronic illness may relieve YP's concerns about these delays and improve self-esteem.

Limitations

- Theory and methodology were poorly defined in some of the included studies; therefore, it is possible that the meta-studies' line of argument was impacted by factors unknown to the reviewer.
- The literature search was restricted to peer-reviewed journals and studies published in English which introduced possible publication and language bias, respectively.

Introduction

Living with a chronic illness (CI) can create daily stressors that can be challenging to cope with. Inflammatory Bowel Disease (IBD) refers to a group of CIs which affect the digestive tract. The two most common sub-types of IBD are Crohn's Disease which can affect any part of the digestive system and Ulcerative Colitis which affects the large intestine (Goodhand et al., 2010). The symptoms of IBD include, amongst others, abdominal pain and diarrhoea. IBD can require medical treatment which can be intrusive and body altering (McCombie, Mulder, & Gearry 2013; Taft, Keefer, Leonhard, & Nealon-Woods, 2014). IBD is of particular relevance to young people (YP). Up to a third of individuals diagnosed with Crohn's Disease are diagnosed prior to 21-years-of-age and the peak age of onset for Ulcerative Colitis in the United Kingdom (UK) is between the ages of 15 and 25 (NICE, 2012, 2013). Living with a CI can be particularly difficult for YP as they may also be facing several developmental life stages (e.g., puberty, focus on peer relationships) and be growing into self-management of the condition (Choudhury, Blakemore, & Charman, 2006). However, little is known about how YP approach coping with these stressors.

Stress

Stress is a state of disharmony or threat to living organisms' homeostasis generated by "disturbing forces or stressors" (Chrousos & Gold, 1992, p.1245). Responses to stressors endeavour to maintain homeostasis and may require individuals to make physiological and behavioural adaptations (Mawdsley & Rampton, 2005). The way people respond to stressors (or their mechanisms for coping) can reduce or amplify the psychological and physiological impact of stressors (Skinner, Edge, Altman, & Sherwood, 2003).

Coping

Coping has been conceptualised as cognitive or behavioural “efforts in thought and action to manage specific demands appraised as taxing or overwhelming” (Lazarus, 1993, p.8). Other definitions have emphasised the emotion regulation function of coping and its transactional nature as “reciprocal exchanges between people and context” (Folkman & Lazarus, 1988; Skinner & Zimmer-Gembeck, 2009, p. 7).

A plethora of possible coping mechanisms have been identified which reflect the complexity of the construct (Aldwin & Revenson, 1987; Lazarus, 1993). In response, Skinner et al. (2003) reviewed the available coping literature and proposed 12 families of coping mechanisms organised foremost into three groups of stressful events: threats to relatedness (concerns about attachment relationships), competence (concerns about perceived control); and autonomy (concerns about self-determination; Appendix A). Relatedness, competence and autonomy have long been proposed to be three basic psychological needs which all humans aim to fulfil by self-determination theorists (Deci & Ryan, 2008). Events which impinge on individuals’ ability to enact these needs are proposed to produce stress responses (Skinner & Welbourn, 1994). Skinner et al. (2003) proposed four coping mechanisms (e.g., self-reliance, support-seeking, delegation and isolation) related whether individuals experience a challenge (i.e., an opportunity to prove oneself) or threat (i.e., perceives danger) in relation to relatedness, competence or autonomy and whether the coping mechanism is focused on the self or context (Lazarus, 1993). Skinner et al. (2003) stated that all coping mechanisms have underlying adaptive functions; although, some coping mechanisms may also unintentionally heighten concerns (e.g., avoidance may exacerbate loss of control).

Skinner and Zimmer-Gembeck (2007) proposed that children and YP favoured five of Skinner et al.'s (2003) coping mechanism families: self-reliance, support seeking, problem solving, escape and when escape was not possible, accommodation (specifically distraction). They also proposed several normative coping shifts including; between 14 and 16-years-of-age when coping becomes increasingly self-regulated, cognitive and reflective of YP's personal values and between 18 and 22-years-of-age, when coping starts to reflect YP's long-term goals. These shifts coincide with greater diversity in societal 'roles' (e.g., education, living situation), greater identity formation and higher rates of risk behaviour, a 'distinct developmental' period termed 'emerging adulthood' (aged 18-25) by Arnett (2000). However, this term has been criticised as having no basis in developmental theory or in taking into consideration cultural or socioeconomic diversity (Côté, 2014; Galambos, Turner, & Tilton-Weaver, 2005; Schwartz, 2016). Other definitions of YP have been proposed which take account of cultural diversity. Since 1985, the United Nations has defined 'youth' to encompass YP aged from between 15-24. This age range encompasses the aforementioned life events and takes account of the diverse ages these events occur across cultures and socioeconomic gradients (UNDESA, n.d).

Young people coping with chronic illness

Coping is relevant to all; however, YP diagnosed with CI face prolonged stressors associated with obtaining a diagnosis, ongoing symptoms, extended physical treatments, recovery and risk of relapse (Compas, Jaser, Dunn, & Rodriguez, 2011). In this context, YP's mechanisms of coping are likely to play an important role in how they respond to their CI and their quality of life (Goodhand & Rampton, 2008). However, it has been proposed that coping literature lacks specificity to CI (Schmidt, Petersen, & Bullinger, 2003). Schmidt et al. (2003) highlighted four facets of coping to consider when investigating YP's coping with any CI. Firstly, YP's coping abilities and priorities change over time, from the immediate alleviation of distress to whether coping efforts facilitate adaptive changes (developmental facet). Secondly, the specific nature of the CI impacts the nature of stressors and subsequent coping mechanisms (situational context facet). Thirdly, CI generates stress both within YP and their support system and YP may therefore be more dependent on their parents than their peers which may delay typical coping transitions (interactional facet). Finally, YP are likely to be actively participating in treatment decision-making, which is considered an extension of the coping concept in a healthcare context (healthcare participation facet).

Young people coping with IBD

IBD poses some specific challenges for YP. YP can experience growth failure and pubertal delay which is likely to have important implications for identity development (Pfefferkorn et al., 2009). Flares in symptoms can also lead to absences from education and employment (The IBD Standards Group, 2009). Moreover, some surgeries and treatments can lead to weight-gain and impact on fertility and contraception at a time of sexual exploration (Mahadevan, 2006). Whilst some consideration has been given to how YP cope with CIs, there is a dearth of empirical studies specifically investigating how YP aged 15-24 cope with IBD. YP in this age-group are frequently grouped with adults across the life-span and stratified results according to age are rarely provided to extrapolate whether the findings are applicable to YP (Allison, Lindsay, Gould, & Kelly, 2013). However, a small but increasing number of qualitative studies have been conducted in this field.

Review aims

Considering the body of qualitative studies which has emerged, a review and synthesis of these studies is warranted to develop an integrated theoretical perspective of stress and coping in YP diagnosed with IBD. A focus of this review will be whether YP diagnosed with IBD describe preferences for certain coping mechanisms and whether these correspond with proposed coping shifts (Skinner et al., 2003; Skinner & Zimmer-Gembeck, 2007). A secondary aim of this review is to critique the underlying theory and methods of the included studies which underpins the new theoretical perspective.

It is hoped the new understanding derived from this review can be a valuable clinical resource for healthcare professionals (HCP) who are working with YP diagnosed with IBD. It may be used to inform HCP's understanding of the factors influencing stress and coping in this age-cohort and to develop points of intervention for YP who are experiencing difficulties coping.

Method

Meta-study

Paterson, Thorne, Canam, and Jillings' (2001) meta-study approach was used to structure the review. Within meta-study, data is retrieved followed by a two-stage process: analysis and synthesis. There are three strands of 'analysis': meta-method (i.e., appraisal of studies' methodological characteristics and quality); meta-theory (i.e., analysis of underlying theories to studies) and meta-data-analysis (i.e., synthesising data). Meta-synthesis brings together the ideas developed by these three analysis strands to create a new line of argument (LOA; Noblit & Hare, 1988).

Theoretical frameworks

This review conceptualised stressors as threats to homeostasis and coping as a mediator of emotion and an ongoing series of transactions between individuals and their context (Chrousos & Gold, 1992; Lazarus, 1993; Skinner & Zimmer-Gembeck, 2007, 2009). These theories provided clarity when extracting relevant data from the papers and when synthesising data. Skinner et al.'s (2003) three groups of stressors (relatedness, competence and autonomy) and 12-families of coping were used as a basis to interpret and discuss the data relating to stress and coping mechanisms. To ensure the synthesis focused on the nuances of stress and coping in relation to IBD, Schmidt et al.'s (2003) conceptual model of YP coping with CI (i.e., developmental, interpersonal, situational, healthcare participation facets to coping) informed all phases of the meta-study.

Identifying relevant literature

Search strategy. A search of published studies was undertaken up to 04/12/16. Four electronic databases (PsycINFO, via OVID, Medline, via PubMed, Web of Science and CINAHL via EBSCO) were searched using identical search terms which pertained to the key review areas of IBD, stress, coping and YP (Appendix B). The search terms were derived from preliminary scans of the literature and thesaurus searching the review key components. The Boolean operators 'OR' and 'AND' were used to ensure an exhaustive search and 'NOT' was used to eliminate irrelevant articles relating to conduct disorder which arose from the use of the search term 'CD' (Crohn's Disease). No restriction on publication dates was applied; however, the search was restricted to studies published in English. The search strategy was conducted across titles and abstracts. In Web of Science, the search was conducted across abstract, title and keywords, but was restricted to “social sciences” and “art humanities” domains to enhance precision.

Study selection. Broad inclusion criteria were utilised to increase the likelihood of appropriate studies being retrieved. The inclusion criteria specified that studies; (i) were peer-reviewed journal articles; (ii) used qualitative methodology; (iii) recruited participants with clinical diagnoses of IBD; (iv) included data on stressors YP (aged between 15-24 years) experienced and how they coped with them; and (v) were published in English. Studies that did not meet the inclusion criteria or had findings related to YP or IBD that could not be extracted were excluded. The research supervisors audited the included studies to ensure they fulfilled the inclusion criteria.

Screening. First, papers’ titles were screened and then the abstracts of papers that appeared suitable were assessed according to the inclusion and exclusion criteria. Papers that fulfilled the inclusion criteria were then screened using the full texts to check for final suitability. Citation and ancestry searches, along with searches of Google Scholar and ResearchGate, were conducted to identify additional published and in press articles not retrieved by the initial search.

Meta-synthesis

The meta-synthesis is considered the focal outcome of a meta-study and draws together the insights produced from three analytic processes described hereafter.

Meta-method. Within Paterson et al.’s (2001) meta-study approach, the appraisal of methodological quality is completed as part of ‘meta-method’. This review used the Joanna Briggs Institute Checklist for Qualitative Research (JBI; 2016) as an analytic framework to ensure the appraisal was systematic. The checklist comprises of ten items and studies were rated according to each question; ‘yes’, ‘no’, ‘not applicable’ or ‘not clear’. The JBI has been considered the most coherent freely available critical appraisal tool for assessing validity in qualitative studies (Hannes, Lockwood, & Pearson, 2010). An independent Foundation Year 1 Doctor (MBChB, BMedSci) working in a Gastroenterology department with no prior relationship to the reviewer, rated the included papers against the JBI criteria. The level of inter-rater agreement was measured using Cohen’s kappa (Cohen, 1960).

Meta-theory. A critical appraisal of how major paradigms and theory underpinning the included studies informed the body of data was also conducted. The reviewer: (i) thoroughly read and noted citations of theory in each paper; (ii) investigated the history and underlying assumptions to the theories used; (iii) noted the researchers’ profession and where paper was published as further indicators of theoretical position; and (iv) considered the theories in the wider socio-political context. The use of theory was sometimes overt (e.g., reference citation) or “indirectly discerned” (e.g., from where the study was published; see Appendix C for meta-theory excerpt, Paterson et al., 2001, p. 96).

Meta-data-analysis. First the papers’ ‘data’ (i.e., themes, conclusions) relating to stress and coping were extracted and tabulated according to its source. Paterson et al. (2001) suggests the technique of meta-ethnography developed by Noblit and Hare (1988) as a method for comparing, contrasting and integrating data into higher-order themes. Meta-ethnography is an interpretative synthesis approach which synthesises qualitative findings to generate new theoretical developments (Campbell et al., 2011). Meta-ethnography involves: (i) identifying key metaphors, ideas or and themes in individual studies; (ii) comparing and contrasting studies’ metaphors and ideas; (iii) identifying patterns; and (iv) ‘translating’ them into one another (i.e., creating third-order constructs) to develop a new LOA (see Appendix D for meta-data-analysis excerpt; Campbell et al., 2011; Noblit & Hare, 1988). To increase ‘analytical honesty’, the researcher recorded synthesis decisions in a diary and one research supervisor audited the final synthesis (see Appendix E for diary excerpt; Paterson et al., 2001, p. 64).

Theoretical position and reflexivity

The principal reviewer and the meta-study approach itself are orientated towards an interpretivist epistemological stance, rooted in relativist ontology, which is the belief that is that there is no single external reality, rather individuals construct their own individual realities based on their subjective experiences and these constructions can be multiple and depend on complex interactions between multiple contextual systems (Giacomini, 2010). Within this stance, qualitative reviewers “construct an aggregated account based on their own interpretations” of the data (Paterson et al., 2001, p 6). Therefore, this review’s findings were considered just one possible interpretation of the available data. The principal reviewer had existing knowledge of IBD, derived from personal and professional experiences and used their synthesis diary to monitor the potential influence of their experiences on data-analysis and synthesis (see Appendix E for diary excerpt).

The interpretivist stance was congruent with the reviewer’s beliefs and chosen methodology and contrasts with realism ontology which proposes that data directly corresponds to an objective reality which can be accessed empirically by researchers without influence of bias or values (Giacomini, 2010). Within this school of thought, qualitative synthesis methodologies, such as content analysis, focus on objectively reporting participants’ experiences, meanings and reality, and identifying quantitative patterns within the data (Vaismoradi, 2013).

Results

Literature search

Figure 1 summarises the process of study extraction from database searching. Ancestry and citation searches derived no further articles. Table 1 provides a summary of the 14 included papers, describing 11 studies. The age range in the Allison et al. (2013) paper spanned from 18-25 years; however, this was considered acceptable as it was believed the experiences of a 25-year-old would be unlikely to be substantially different to those of a 24-year-old. Both the Barned, Stinzi, Mack, and Doherty (2016) and Nicholas et al. (2007) papers included children in the sample, but data regarding 15 and 16-year-old YP could be extracted. In the Saunders' papers (2011, 2014) the age range spanned to 29 years; however, data was presented as 'discursive accounts' and only participant accounts which fell into the specified age range were extracted. In the Fletcher and Schneider (2006), Fletcher at al. (2008a, 2008b), Jamieson et al. (2007) and Saunders (2011) papers, IBD data was presented alongside data from participants with other physical conditions (Irritable Bowel Syndrome and Type 1 diabetes) but data relating to IBD participants could be extracted.

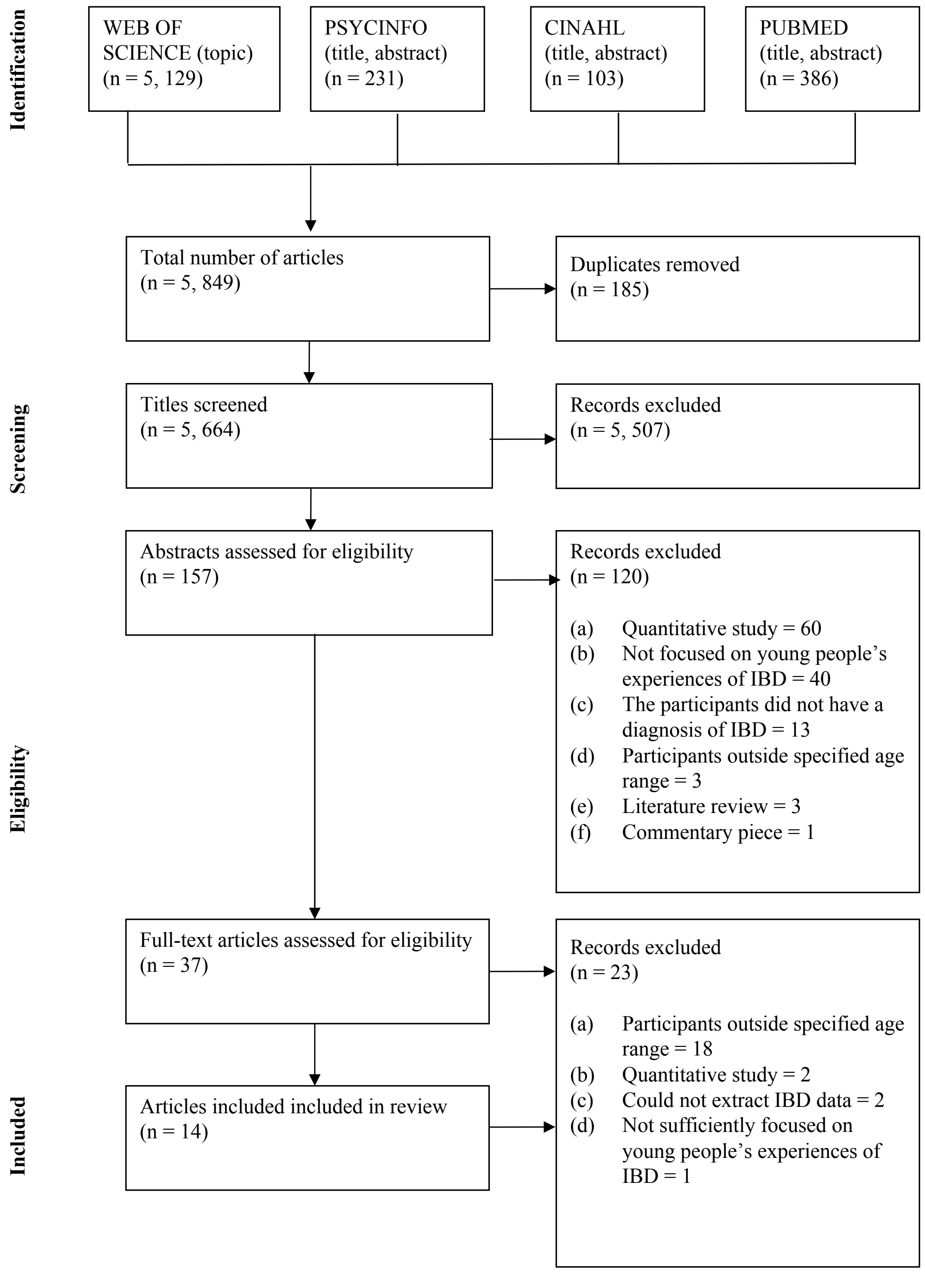

Figure 1. Flow-diagram of article retrieval according to the preferred reporting items for systematic reviews and meta-analyses (PRISMA; Moher, Liberati, Tetziaff, & Altman, 2009).

Table 1

Data extraction table: the methodology and use of theory in included studies

Researcher/s (year) Study location	Sample Size (N) Age range (years) % Female Diagnosis type	Epistemological orientation	Data analysis method	Study focus	Cited theory	Use of theory
1. Alexakis, Nash, Lloyd, Brooks, Lindsay, & Poullis (2015) UK	*N* = 20 16-24 43% CD = 13; UC = 6; Other = 1	Not stated	Thematic analysis	Experiences of YP from BME backgrounds diagnosed with IBD	None cited	N/A
2. Allison, Lindsay, Gould, & Kelly (2013) UK	*N* = 24 18-25 54% CD =17; UC = 7	Narrative	Narrative analysis	Experiences of surgery	None cited	N/A
3. Barned et al. (2016) Canada	*N* = 25 10-17 48% Diagnosis data not provided	Not stated	Thematic analysis	Experiences of IBD disclosure	‘Visible’ and ‘Invisible’ Illnesses (Joachim & Acorn, 2000) ‘Protective disclosing’ or ‘spontaneous disclosing’ (Charmaz, 1997)	Informed research questions and interpretation of findings

(continued)

Table 1 continued

Researcher/s (year) Study location	Sample Size (N) Age range % Female Diagnosis type	Epistemological orientation	Data analysis method	Study focus	Cited theory	Use of theory
4. Daniel (2002) Canada	*N* = 5 18-24 40% Diagnosis data not provided	Phenomenology	Phenomenological descriptive method	Experiences of living with IBD	Theory of Goal Attainment (King, 1981)	Informed research question and the interview guide, analysis of data and presentation of findings
5. Fletcher & Schneider (2006)[a] Canada	*N* = 8 18 – 22 100% UC = 2; UC/IBS = 1; IBS = 5[d]	Phenomenology	Critical content analysis	Relationship between food and IBD and/or IBS	None cited	N/A
6. Fletcher, Jamieson, Schneider, & Harry (2008a)[b] Canada	*N* = 8 18-23 100% CD = 1; UC = 1; CD/UC = 1; IBS = 5 [d]	Phenomenology	Critical content analysis	Dietary patterns before and after diagnosis	None cited	N/A

(continued)

Table 1 continued

Researcher/s (year) Study location	Sample Size (N) Age range % Female Diagnosis type	Epistemological orientation	Data analysis method	Study focus	Cited theory	Use of theory
7. Fletcher, Schneider, Van Ravenswaay, &Leon (2008b)[a] Canada	*N* = 8 18-22 100% UC = 2; UC/IBS = 1; IBS = 5 [d]	Phenomenology	Critical content analysis	Coping strategies when living with IBD/IBS	None cited	N/A
8. Jamieson, Fletcher, & Schneider (2007)[b] Canada	*N* = 8 18-23 100% CD = 1; UC = 1; CD/UC = 1; IBS = 5[d]	Phenomenology	Critical content analysis	Pre and post-diagnosis dietary patterns	Meadow, Lackner, & Belic (1997) grounded theory exploration of patient experience of IBS[e]	Discussion of results
9. Lynch & Spence (2008) New Zealand	*N* = 4 16-21 75% CD = 4	Phenomenology	Thematic analysis	Experiences of living with IBD	None cited	N/A

(continued)

Table 1 continued

Researcher/s (year) Study location	Sample Size (N) Age range (years) % Female Diagnosis type	Epistemological orientation	Data analysis method	Study focus	Cited theory	Use of theory
10. Nicholas et al. (2007) Canada	*N* = 80 7-19 45% CD = 61; UC = 19	Interpretative ethnographic	Content analysis	The meaning YP make of IBD	None cited	N/A
11. Saunders (2011) UK	*N* = 30 18-29 63% IBD = 15 (breakdown not provided) Type 1 Diabetes = 15[d]	Not stated	Discourse analysis	How YP discursively account for social drinking	Three inter-related 'bodies'; 'social body', 'toned body' and 'healthy body' (Balfe, 2009) Two types of 'account', excuses and justifications (Scott & Lyman, 1968) Living 'within' and 'beyond' confines of illness (Sargeant, 2006, as cited in Saunders, 2011, p. 76)	Informed research questions and analysis of findings
12. Saunders (2014)[c] UK	*N* = 16 18-29 38% Diagnosis data not provided	Interaction-based and constructionist perspective	Discourse analysis	How representations of stigma are constructed in talk	Stigma: attribute that is deeply discrediting that arises from undesired differentness (Goffman, 1963) Hidden distress model: enacted and felt stigma (Scambler & Hopkins, 1986) 'Deviance' (Scrambler, 2004)	Theories acted as conceptual frameworks to study (informed research questions and analysis of findings).

(continued)

Table 1 continued

Researcher/s (year) Study location	Sample Size (N) Age range (years) % Female Diagnosis type	Epistemological orientation	Data analysis method	Study focus	Cited theory	Use of theory
13. Savard & Woodgate (2008) Canada	*N* = 6 19-24 83% UC = 6	Hemeneutic phenomenology	Thematic analysis	Experiences of living with IBD and an ostomy.	None cited	N/A
14. Schwenk, Lightdale, Arnold, Goldmann, & Weitzman (2014) USA	*N* = 15 18-24 53% CD = 9; UC = 6	Not stated	Thematic analysis	How going to college shapes health and behaviours	Protection Motivation Theory (Rogers, 1975) Chronic Care Model (Coleman et al., 2009)	Informed the interview guide

Note. CD = Crohn's Disease; UC = Ulcerative Colits; IBS = Irritable Bowel Syndrome; = United Kingdom; USA = United States of America; [a, b] = studies had identical samples; [c] = study uses same IBD sample from paper 11, [d] = data not relating to IBD excluded from analyses; [e] = not analysed as theory related to IBS.

Meta-method

Methodological characteristics. The included studies' sample sizes ranged from 4 – 80 (Table 1). Almost half the studies were conducted in Canada (6:11). Phenomenology (5:11) and thematic analysis (5:11) were the most frequent methodology and data analysis framework adopted, respectively. Participants were purposively recruited and researchers used one-to-one interviews to collect data in all studies.

Six of the included articles described three studies (Fletcher & Schneider, 2006; Fletcher et al., 2008a, 2008b; Jamieson et al., 2007; Saunders, 2011, 2014). This was due to some researchers splitting their findings into separate papers (Fletcher & Schneider, 2006; Fletcher et al., 2008a, 2008b; Jamieson et al., 2007) or presenting different areas of analysis linked to the same sample and set of interviews (Saunders, 2011, 2014). The interpretations drawn from these articles were considered in this context and caution was applied (Thorne et al., 2002).

Methodological quality. A summary of the methodological quality for the papers is provided here. For a full description of the quality ratings for each paper, refer to Appendix F.

Just four papers referenced their underlying philosophical or epistemological perspective (Daniel, 2002; Nicholas et al., 2007; Saunders, 2014; Savard & Woodgate, 2008). Almost all papers reported their methodological orientation; however, a minority of papers simply described their methodology as 'qualitative' (Alexakis et al., 2015; Barned et al., 2016; Schwenk et al., 2014). All studies had specific foci which were also congruent with the chosen methodology. For example, exploring lived experiences of

YP's relationship with food was found to be congruent with phenomenology (Fletcher & Schneider, 2006).

All studies used one-to-one interviews to collect data which was congruent with all methodologies. However, there was a perceived inconsistency between the methodology, phenomenology, and the data analysis approach, critical content analysis, in four papers (Fletcher & Scheider, 2006; Fletcher et al., 2008a, 2008b; and Jamieson et al., 2007). Taking a 'critical' perspective was not considered to be congruent with phenomenology which investigates the meaning people make of their own experiences (Giacomini, 2010). All papers, except the three which did not detail their methodological approach, were found to have interpreted the findings in a way that was congruent with the methodology (Alexakis et al., 2015; Barned et al., 2016; Schwenk et al., 2014).

A significant methodological weakness in the included papers was the lack of consideration of how the researchers' may have influenced the data. Only the Saunders (2014) paper explicitly considered how the wording of their questions may have influenced data collection. All papers provided illustrative quotes to demonstrate the basis of their analysis and to represent their participants in the report. All but two papers included a statement of ethical approval (Fletcher & Scheider, 2006; Jamieson et al., 2007). The paper's conclusions, largely based around implications for clinical practice, were all found to be adequately based on the data collected.

Overall quality. The JBI (2016) provides no defined benchmarks for exclusion. Considering the papers' ratings across the ten JBI (2016) criteria, the Alexakis et al. (2015), Barned et al. (2016) and Schwenk et al. (2014) papers were of the lowest methodological quality based on having the highest frequency of 'no' responses (Appendix F). In contrast, Saunders' (2014), Daniel's (2002) and Savard and

Woodgate's (2008) papers were of higher methodological quality because they made explicit reference to their epistemological positions, and the methodological steps taken were congruent with these positions. Whilst the remaining papers had methodological limitations, all fourteen were considered to have strengths and be valuable based on their contribution to an under-researched area. Accordingly, no papers were excluded.

Inter-rater reliability. There was 'moderate' agreement between the raters: $\kappa = .484$, $p < .001$, according to the benchmarks suggested by Landis and Koch (1977). Disagreements were resolved by discussion which increased the robustness of the quality appraisal.

Meta-theory

Less than half the included studies referenced theory in their studies (Table 1). Whilst the explicit focus of most studies was not stress or coping; almost all researchers used these terms but did not cite how they were conceptualising them. Instead, stress and coping were described as a-theoretical concepts. Any potential conflict between the included studies conceptualisations of these terms and the theoretical frameworks used in this meta-study could not be analysed (Sandelowski, 1993).

In contrast, there was greater consideration of theories relating to CI. Barned et al. (2016) cited the theory of 'invisible illnesses' and types of CI disclosure (Charmaz, 1997; Joachim & Acorn, 2000). These theories defined the phenomena of interest and did not appear to influence the results significantly. In contrast, several theoretical frameworks were embedded into Saunders's (2011, 2014) studies which were focused on identity and social norms in the context of IBD (Table 2). For example, Saunders (2011) referenced Balfe's (2009) theory of 'body projects' which proposed that YP embody 'normal' identities using their bodies (e.g., exercising to achieve ideal 'toned' body). Saunders (2011) used these terms when describing that YP diagnosed with IBD may pursue ‘social bodies’ (e.g., drinking with friends) at the expense of their ‘healthy bodies’ (e.g., minimising symptoms). These theoretical perspectives were influential in shaping the data and offered a theoretical focus of the self, social influences and identity to the synthesis which was considered a strength.

Two nursing studies also cited healthcare participation theories. Daniel (2002) utilised King’s (1992) Theory of Goal Attainment (ToGA) as a conceptual framework for their study. ToGA is a nursing theory which assumes individuals to be social, rational and reactive agents who engage in purposeful behaviour in the pursuit of goals. The ToGA informed Daniel’s (2002) study aims, design and presentation of results. Furthermore, Schwenk et al. (2014) utilised the Protection Motivation Theory (PMT; Rogers, 1975) and the Chronic Care Model (CCM; Coleman et al., 2009) to inform the development of their interview schedule. The PMT proposes that individuals process the potential benefits and harm of a decision to guide their health behaviours (Rogers, 1975). CCM is a model that proposes factors such as ‘decision support’ can improve CI healthcare participation (Coleman et al. 2009). These theories are all notably action-orientated and focused on improving healthcare participation. Although the aforementioned studies were the only nursing studies to explicitly cite healthcare participation theory, other nursing papers also had broader (e.g., exploring YP’s experiences of IBD) and more practical foci (e.g., improving clinical care). This was in starkest contrast to the two sociology studies which had narrower and more theoretical foci. For example, Saunders (2011) investigated how YP discursively account for social drinking and the impact of identity construction and Saunders (2014) investigated how representations of stigma are constructed in talk. Since the majority of studies were conducted in the nursing field (*n* = 8), this may have influenced the data’s overall practical emphasis on action and healthcare participation, as opposed to YP’s broader social and emotional contexts.

The included studies seldom considered the impact of broader socio-economic, cultural or political factors when reporting their results, except for Alexakis et al. (2015) which focused on the experiences of black and ethnic minority YP. Nevertheless, some underlying paradigms to the studies could be discerned by where the studied was conducted (Table 2). All studies were conducted in ‘western’ countries, the majority in Canada (*n* = 6) or the United Kingdom (*n* = 4), which hold biomedical (‘health’ is being free from disease) views of health and illness and where seeking professional healthcare is normalised and free (Skolnik, 2015). Therefore, this review’s findings may be less applicable to countries where accessing healthcare is insurance-based or not culturally normative.

Meta-data-analysis

The final themes derived from the meta-data-analysis were grouped according to the overarching themes of stressors and coping mechanisms. All stressors and coping mechanisms described by the YP centred on losing control and attempts to re-establish control respectively. Tables 2 and 3 provide a summary description of the sub-themes and some illustrative quotes to demonstrate the findings.

Table 2

Description of stressor sub-themes, their corresponding source of threat and illustrative quotes

Subtheme	Brief description	Skinner et al. (2003) perceived threat	Illustrative quotes
Symptomatology	IBD as a relapsing and remitting CI lead YP to feel out of control of their bodies and wider lives. Reductions in symptoms were a relief but YP struggled to relish this as they were unsure of when their next flare-up might occur.	Competency Autonomy	“I really felt like my UC controlled what I could do and where I could go and when I could go…it definitely, um, had a big control over my life (Savard & Woodgate, 2009, p.38) “The paradoxical relationship between hope and fear” (Lynch & Spence, 2007, p. 228). “Like a day to day basis, as if I’m in a stressed out situation...because, a couple, like, two days, and I could have a full-blown flare-up” (Fletcher et al., 2008b, p. 282)
Loss of normality	YP felt sadness and anger towards IBD compromising their ability to live a normal life and fulfil ‘normal roles’ (e.g., such as being a partner, following cultural practices). Hope that YP could one day feel normal facilitated engagement in healthcare. Unsuccessful medical treatments led to fear that normality could not be achieved.	Competency	“You look at other people and you think ‘why did it happen to me?” (Lynch & Spence, 2008, p. 228). “It’s been six years of having abscesses, never being normal, having setons…I want it sorted” (Allison et al., 2013, p. 1570).
Body image	Uncontrollable weight-gain or scarring linked to medical treatment led YP to feel unattractive and/or embarrassed by their body. Body image dissatisfaction threatened YP’s ability to seek interpersonal relationships and explore their sexuality.	Competency Relatedness	“It’s somehow easier to [push him away] than to deal with the guilt of not being able to…you know… be a normal girlfriend for him” (Daniel 2002, p. 88). “It makes you feel unattractive… your confidence is down and your self-esteem goes down” (Allison et al., 2013, p. 1572)

(continued)

Table 2 continued

Subtheme	Brief description	Skinner et al. (2003) perceived threat	Illustrative quotes
Perceptions of others	IBD symptoms posed persistent threats of embarrassment and humiliation for YP. YP feared their identities could be "tarnished" or dominated by IBD and/or that IBD could lead them to be rejected by their family, friends and/or colleagues.	Relatedness Competency	"[Avoiding people] was due to the embarrassment and being afraid of what people would think. I didn't know what was going on…it was gross…" (Lynch & Spence, 2007, p. 226). "As soon as you say 'poo' they go 'ahh no'… 'urggh don't talk to me" (Saunders, 2014, p.1029)
Feeling unsupported	Feeling unsupported by family, HCP and peers exacerbated existing stress. Support and/or treatments were sometimes intrusive and violated YP's desires for privacy and autonomy.	Competency Relatedness	"The Specialist Gastroenterologist…he didn't really give me any suggestions…and I was just like 'ok, but, do you not care?" (Jamieson et al., 2007, p. 156). "My mum comes by when I'm on the toilet to see what is wrong…It's uncomfortable to have my mum watch me on the toilet" (Nicholas et al., 2007; p. 4)

Note. IBD = inflammatory bowel disease; YP = young people; HCP = healthcare professionals

Table 3

Description of coping mechanism sub-themes, their corresponding coping family and illustrative quotes

Subtheme	Brief description	Skinner et al. (2003) coping-family	Illustrative quotes
Implementing restrictions	At times of heightened IBD activity, restrictions to movement, food, relationships and valued activities helped the YP control the impact of flare ups, exposure of symptoms to others and facilitated feelings of safety at times of high illness activity. <u>Trade off:</u> Social exclusion and/or the loss of opportunity.	Escape Isolation	“I can’t really be away from a (laughs) bathroom for more than, like, ten minutes because it’s…scary” (Fletcher & Schenider, 2006, p. 245). “For the last two years literally, I was literally at home unless I had to go to the hospital and I became isolated, so education wise…I’ve lost that” (Alexakis et al.,2015, p. 670).
Concealing/disclosing illness	At times of heightened IBD activity, concealing IBD helped minimised the risks of being teased or ridiculed and IBD influencing other people’s impressions of them. In the context of supportive relationships, disclosure facilitated support and understanding <u>Trade-off:</u> Social isolation	Isolation	“It’s easier to say I’ve got a tummy ache or I’ve got a bug or something” (Saunders, 2014, p. 1029). “It’s not really something that I’d really want to tell very many people about” (Barned et al., 2016, p. 121)

(continued)

Table 3 continued

Subtheme	Brief description	Skinner et al. (2003) coping-family	Illustrative quotes
'Getting on with it'	Some YP described distancing and distracting oneself from the illness at times of high stress. Other YP described living life despite IBD and not dwelling on stress (persistence and perseverance). Trade-off: Lack of support	Accommodation[a]	"Putting on a brave face" (Allison et al., 2013, p. 1573) "You have to have, obviously, a good attitude and obviously mind over matter" (Fletcher et al. 2008b, p. 283)
Taking health risks	Engaging in behaviours which compromised health (e.g., drinking alcohol, medication non-adherence) to retain social status or re-establish autonomy Trade off: Long-term health	Opposition[b]	"It's usually after a night out and then it's quite bad, you know you're up and down [to the toilet] … I can put up with that" (Saunders, 2011, p. 79). "Never played around with that idea [taking vitamins], other than calcium supplements, which I don't take right now, but I should be (laughter)" (Fletcher et al., 2008a, p. 189)
Information seeking	Seeking information from varied sources (e.g., HCP, peer testimonials) to facilitate understanding of the condition and skills of how to manage the illness	*	"The main things that stopped me being afraid of [surgery] was doing research on the operation…testimonials about people that have had it done in the past" (Allison et al., 2013, p. 1572)
Support-seeking	YP appreciated support from family, friends, partners and HCP. However, YP described disliking continued monitoring and intrusion in times of remission. Trade off: Intrusion	*	"Fortunately, I have to some very good friends which happy to drive me [to infusion appointments]" (Schwenk et al., 2012, p. 1624) "Since my operation, I've had my parents on my case…they'll be up in the morning, making my breakfast" (Allison et al., 2013, p. 1573).

(continued)

Table 3 continued

Subtheme	Brief description	Skinner et al. (2003) coping-family	Illustrative quotes
Taking an active position	Being active participants in their healthcare provided YP with a sense of ownership and hope that they may one day have their condition under control.	Problem-solving Self-reliance	“I’ve kind if done it [determined diet] myself. No one’s helped me, like you know what I mean” (Jamieson et al., 2007, p.158). “Hope exists for Sally as long as there are more drugs to try” (Lynch & Spence, 2008, p. 227)
Incorporating IBD into life	Accepting IBD as part of YP which would be with them for the rest of their lives. Finding meaning from having IBD (e.g., having inner strength, compassion for others and greater maturity).	Accommodation	“Taking things as they come and making the best of them” (Nicholas et al., 2007, p. 6). “UC was one of the best things that could have happened to me, because, uh, I found my career path with it and became a better person I think” (Savard & Woodgate, 2009, p. 39)

Note. * = coping strategy belongs to coping family of same name; [a] accommodation coping = adjusting to personal or situational constraints; [b] opposition coping = an active strategy of resisting or combating which “services to warn others about their encroachment on the individuals goals” (Skinner et al., 2003, p. 230); IBD = inflammatory bowel disease; YP = young people.

Meta-synthesis

Based on the three strands of meta-study analysis an integrated model of stress and coping in YP diagnosed with IBD, the stress-coping see-saw, is proposed as a new LOA (Figure 2). Stress was described as an integral part of IBD. IBD led to illness-specific stressors which threatened YP's control over their: bodies, relationships and ability to make normative transitions associated with their stage of development, for example, going to university or entering an intimate relationship (a, Figure 2). Stressors impacted on the YP emotionally (e.g., sadness, anger) and physiologically (e.g., increased pain, exhaustion) which in turn interacted with the YP's appraisals of what threat the stressors posed in the context of the situation, their development and long-term goals (e.g., if I tell my friend about IBD, will they reject me?) (b). Coping mechanisms could be seen to be efforts by YP to readjust the balance of control between themselves and their IBD (c).

The see-saw represents the reciprocal relationship between stress and coping (e). High stress was linked with greater feelings of fear (e.g., of humiliation, being rejected by peers) and in turn greater use of escape, isolation and support-seeking and opposition coping (i.e., resisting or combating) which allowed YP to re-establish control and quickly alleviate distress. In times of relative homeostasis or 'balance' between hope of sustained remission and fear of relapse, YP described lesser use of restrictions, concealment and opposition and greater use of problem-solving, self-reliant and accommodative coping strategies (such as taking an active position and incorporating IBD into life) which were associated with fewer trade-offs. Low stress (generally experienced after surgery or in long-term remission) was associated with greater hope (e.g., of living a healthy and independent life).

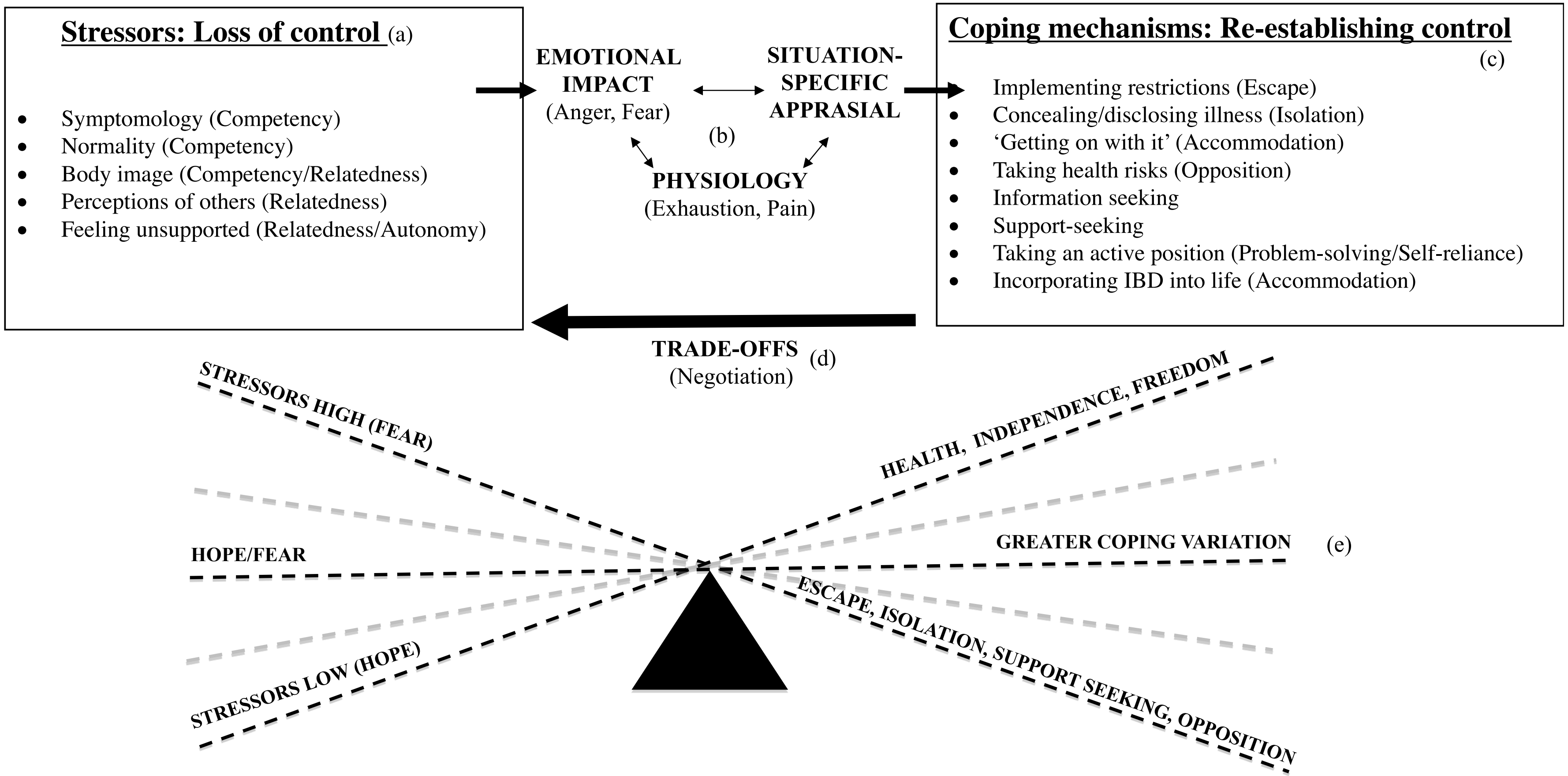

Figure 2. Integrated see-saw model of stress and coping in YP diagnosed with IBD.

This LOA supported Skinner and Zimmer-Gembeck's (2007) proposals that YP's coping becomes increasingly cognitive, self-regulated and reflective of their values between the ages of 14-22 years but suggests normative coping shifts are compromised at times of high illness activity, and YP revert to well-practised behavioural strategies and support-seeking to relieve distress (Schmidt et al., 2003).

YP's efforts to cope with certain stressors sometimes exacerbated stress in relation to other concerns (e.g., adhering to medication may lead to exacerbated stress linked to body image). Negotiating these trade-offs was an essential part of coping for YP as they moved between situations. Negotiating priorities was also an important factor in understanding YP's disengagement from healthcare participation (d).

This LOA should be interpreted in the context of the synthesised studies' underlying theories and methodologies. All studies were conducted in western countries so the LOA is likely to have been influenced by the underlying dominant paradigm of biomedical views of health and illness. Over half the studies were conducted within the field of nursing and these studies had practical clinical foci and cited action-orientated theories which may have influenced the prevalence of striving for illness control as a theme in the data. Greater grounding of qualitative studies in theoretical stances (and greater reporting of this theory) would have improved our understanding of the links between the LOA and theories which underpinned it. Moreover, the LOA should be considered in the context of the methodological limitations identified (i.e., limited descriptions of epistemological stance and processes of reflexivity).

Discussion

The primary aim of this meta-study was to develop a new integrated theoretical understanding of existing qualitative studies relating to stress and coping by YP diagnosed with IBD. The new LOA highlighted that IBD creates stressors which place YP into positions of feeling controlled by their illness. Perceived control has long been considered a “powerful psychological resource” and loss of control to be “universally stressful” (Graff et al., 2009, p. 2960; Skinner & Zimmer-Gembeck, 2011, p. 35). Loss of perceived control has already been highlighted in adult studies as a characteristic IBD stressor (Wolfe & Sirois, 2008). Adults diagnosed with IBD have been found to have a lower sense of control over their lives when compared to a healthy community sample (Graff et al., 2009). Furthermore, perceptions that IBD can be controlled by treatment has been shown to positively predict quality of life in adults diagnosed with IBD (Rochelle & Fidler, 2013). This review has now extended this literature to YP diagnosed with IBD.

YP in this review described using all five of the coping families Skinner and Zimmer-Gembeck (2007) highlighted as prominent for YP. However, escape, isolation, opposition and support-seeking coping mechanisms were described at times of higher stress. This finding corresponds with Zimmer-Gembeck and Skinner’s (2011) proposals that early behavioural forms of coping may be more effective when dealing with high levels of stress. This pattern of findings has also been found within some existing adult quantitative IBD research. Adults in remission have been found to use greater task-orientated coping compared to adults in relapse (Gandhi et al., 2014). Furthermore, adults diagnosed with IBD have been found to make greater use of avoidant coping mechanisms (e.g., avoiding people, sleeping more) at times of heightened illness activity and when they perceive themselves as having less control over their illness

(Graff et al., 2009). Future quantitative studies could seek to verify these qualitative findings in a YP sample and in turn examine the impact of YP's chosen coping mechanisms on important health outcomes (i.e., psychological distress, quality of life).

In contrast, possessing hope was described as supporting greater variation in coping mechanisms and YP's engagement in healthcare decision-making. Hope, regarded as a 'positive' psychological quality has previously been proposed to facilitate coping when individuals are faced with uncertainties (Folkman, 2010; Folkman & Moskowitz, 2000; Wood & Tarrier, 2010). Holding hope of recovery and making future-plans, has also been qualitatively associated with positive adjustment in adults to other CIs (Duggleby et al., 2011; Reynolds & Prior, 2003). Understanding the role of hope in relation to YP diagnosed with IBD could be of clinical value, since cultivating an individual's capacity to remain hopeful in times of high stress could buffer the psychological and physical impact of stressors. Future empirical studies could focus on positive qualities and coping to investigate whether these factors interact to predict positive health outcomes in YP diagnosed with IBD.

Coping was found to be a complex task of negotiation for YP. Some YP described knowingly taking health risks to prioritise their developmental desires to be autonomous or engage in socially normative activities. Brooks, Smith, and Lindsay (2017) highlighted that health-risk behaviours in YP are an unmet need in transition care and that the presence of caregivers at appointments may inhibit exploration of these issues. YP's use of opposition coping, its interaction with healthcare participation and the subsequent impact on long-term health outcomes also appears to be an important gap in the existing literature base (Zimmer-Gembeck & Skinner, 2011).

The second aim of the meta-study was to critique the underlying theory and methodologies of the included studies which underpinned this new understanding.

Meta-method revealed limited definitions of researchers' epistemological stance and how the researchers' cultural position and beliefs may have impacted the data. When epistemology and methodology were defined, some clashes were also identified. Meta-theory also highlighted limited reference to underlying theoretical frameworks. This finding corresponds with other meta-studies and a wider trend observed in qualitative research (Bradbury-Jones, Taylor, & Herber, 2014; Edwards, Pang, Shui, & Chan, 2010; Tamminen & Holt, 2010). The dominance of nursing studies in the included papers, and their focus on action and healthcare participation, may have also led the synthesis to be more focused on actions to 'control' IBD, rather than the emotional and social dimensions to coping.

Clinical implications

YP described loss of control as a recurrent stressor, suggesting that HCP should consider ways to empower YP. Where possible HCP should ensure decisions regarding treatment are made collaboratively. When treatments will knowingly impact areas of developmental priority for YP (e.g., body image), HCP can anticipate this and support YP to negotiate these challenges. Furthermore, coping transitions proposed to occur in youth (e.g., move towards self-reliant coping) may be compromised by illness activity and normalising these delays in the context of CI may minimise the impact of these delays to YP's self-esteem. Moreover, some YP described struggling with ongoing parental monitoring after illness activity had subsided. HCP are in a prime position to identify this dynamic in families and advocate for the benefits of allowing YP space to explore their autonomy at times of low stress, on behalf of the YP. Taking health risks was considered a necessary coping mechanism by YP in response to persistent threats to autonomy. HCP should avoid responding to these behaviours punitively, as this may compound underlying fears of loss of control, and instead sensitively support YP to consider the consequences of these coping mechanisms.

Future directions

There are very few quantitative studies examining control in relation to YP diagnosed with IBD. One study has found YP diagnosed with IBD held greater external locus' of control (the belief that events arise from factors external to an individual) when compared to healthy YP and YP diagnosed with diabetes (Engstrom, 1991). However, future studies should now examine the role of perceived control in relation to YP's coping with IBD in greater depth. Future qualitative studies should also ensure explicit articulation of epistemological and methodological approach to strengthen the integrity of their findings and any future synthesis which may include their findings. Whilst theory is always considered present in studies "in some guise", future studies should explicitly articulate and integrate theory into at all stages of scientific enquiry and increase the ability of qualitative studies to extend and develop new theoretical, as well as practical, understandings (Bradbury-Jones et al., 2014, p. 141).

Strengths and limitations of the review

Qualitative syntheses are dependent on the included studies using robust methodologies. A key finding of this review was that some studies' methodologies and use of theory were poorly defined. These issues signal threats to methodological rigour that may compromise the credibility of the conclusions drawn in this meta-study (Whittermore, Chase, & Mandle, 2001). Furthermore, the reviewer screened thousands of articles independently and human error may have introduced bias into the search. Research supervisors audited inclusion decisions to minimise this risk but an independent-rater could have repeated the literature search to improve the searches' overall reliability. In addition, the search was restricted to studies published in English which introduced language bias and exacerbated concerns raised in meta-theory that the results reflected westernised beliefs and societal structures. Moreover, the search was restricted to peer-reviewed journals and relied on electronic database searching which excludes grey literature. The exclusion of grey literature increased the likelihood of publication bias, in that qualitative studies which do not show “clear, or striking, or easily described findings” are more likely to be remain unpublished (Petticrew et al., 2008, p. 552). Furthermore, relevant dissertation articles which are likely to have described their methodologies and use of theory in greater detail, owing to less word-count restrictions, were also excluded by the search strategy (Paterson et al., 2001). Future reviews may wish to replicate this review and extend the literature search to other techniques of article retrieval (e.g., contacting experts) to minimise the risk of publication bias.

Notwithstanding these limitations, meta-study provided a systematic review structure and incorporated analysis of the included studies’ underlying theories which has been a criticism of other approaches such as thematic synthesis (Campbell et al., 2011). The use of a systematic search process and a critical appraisal tool also further increased the robustness of this meta-study and increased other reviewers’ ability to replicate the review. Furthermore, utilising an entirely independent co-rater to appraise the papers’ methodological quality improved the rigour of the quality appraisal. The broad number of electronic databases searched along with no restrictions to publication date also increased the likelihood that all eligible studies were retrieved and contributed to the new LOA.

Conclusions

Perceived control may be of specific relevance to YP diagnosed with IBD and may underpin the stressors they perceive and the adaptive functions for the coping mechanisms they choose. Normative coping shifts towards greater self-reliant and cognitive coping may be compromised at times of high illness activity and YP may revert to learnt and well-practiced behavioural strategies (e.g., escape, isolation) and support-seeking to alleviate distress. Negotiation of priorities formed an integral part of YP's coping as YP moved between differing situational demands. The current findings may inform HCP's understanding of this age-cohort when working with them clinically. Future qualitative studies should articulate methodological and theoretical positions more clearly to address the limitations identified by this meta-study to ensure future work can make theoretical as well as practical advances in the field.

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Appendix A

Skinner et al.'s (2003) coping families and adaptive functions

	RELATEDNESS		COMPETENCE/CONTROL		AUTONOMY	
	Challenge to		Challenge to		Challenge to	
	Self	Context	Self	Context	Self	Context
	Self-reliance*	**Support-seeking***	**Problem-solving***	**Information seeking**	**Accommodation***	**Negotiation**
Coping description	Reliance on own resources	Seeking support from parents, peers	Select and modify actions to be effective	Attempt to learn more about stressful situation	Adjusting to constraints	Compromise between priorities and constraints
Examples of second-order coping responses	Emotional regulation, emotional expression	Social support, proximity seeking	Instrumental action, strategising, planning	Monitoring, seeking understanding	Distraction, cognitive restructuring	Priority setting, persuasion, trade-offs
Adaptive function	Protect available social resources	Use available social resources	Adjust actions to be effective	Find additional contingencies	Flexibly adjust preferences to options	Find new options
	Threats to		Threats to		Threats to	
	Self	Context	Self	Context	Self	Context
	Delegation	**Isolation**	**Helplessness**	**Escape***	**Submission**	**Opposition**
Coping description	Appointing another as representative	Staying away from others	Relinquishing control	Disengage from stressor	Giving over to stressor	Resisting or combating
Examples of second-order coping responses	Dependency	Social withdrawal, concealment	Passivity, exhaustion, dejection and pessimism	Denial, wishful thinking	Rumination, rigid perseveration	Projection, anger, venting, blaming
Adaptive function	Find limits of resources	Withdraw from unsupportive context	Find limits of actions	Escape environment	Give up preferences	Remove constraints
Adaptive process	Coordinate reliance and social resources available		Coordinate actions and contingencies in environment		Coordinate preferences and available options	

Figure 3. Coping families and their adaptive functions, adapted from Skinner et al. (2003). * refers to coping families commonly used by YP (Skinner and Zimmer-Gembeck, 2007)

Appendix B

Electronic database search terms

Table 4

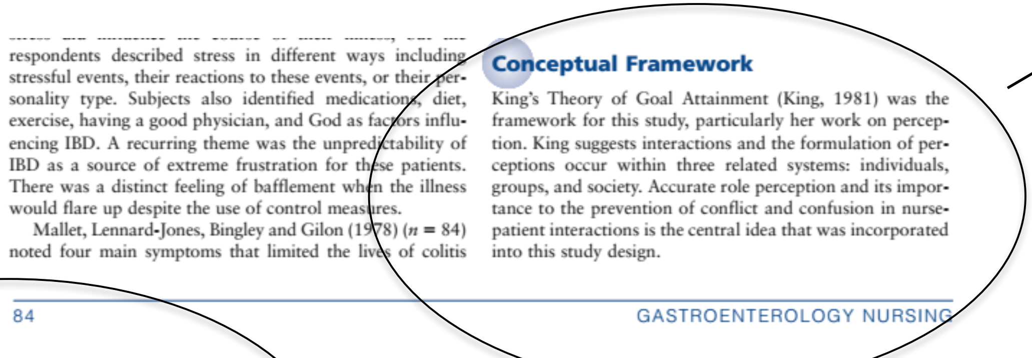
Electronic database search terms

Theme	Search terms
Young people	Adolescen$ OR teen$ OR youth OR young person OR young people OR young adult OR paediatric OR pediatric
	AND
IBD	IBD OR inflammatory bowel disease OR crohn$ OR colitis$ OR CD OR UC OR gastroenterolog$ OR gastrointestinal
	NOT
	Conduct disorder
	AND
Stress/coping	Stress OR struggle$ OR strength$ OR resilien$ OR challenge$ OR cope OR coping OR adapt$ OR impact$ OR change$ OR manage$ OR adjust$ OR quality of life OR change$ OR well-being OR OR wellness OR support OR affect OR concern$ OR issue$ OR need$
	AND
Qualitative	Qualitative OR mixed methods OR interview OR transcrib$ OR focus group OR living OR lived OR experience$ OR account$ OR perspective OR perception$ OR view$ OR narrative$ OR thought$ OR feel$ OR phenomenolog$ OR thematic analysis OR grounded theory OR discourse analysis OR interpretative phenomenological analysis OR IPA OR content analysis OR heuristic OR ethnograph$

Appendix C

Excerpts from meta-theory

Daniel (2002)



respondents described stress in different ways including stressful events, their reactions to these events, or their personality type. Subjects also identified medications, diet, exercise, having a good physician, and God as factors influencing IBD. A recurring theme was the unpredictability of IBD as a source of extreme frustration for these patients. There was a distinct feeling of bafflement when the illness would flare up despite the use of control measures.

Mallet, Lennard-Jones, Bingley and Gilon (1978) (*n* = 84) noted four main symptoms that limited the lives of colitis

Conceptual Framework

King's Theory of Goal Attainment (King, 1981) was the framework for this study, particularly her work on perception. King suggests interactions and the formulation of perceptions occur within three related systems: individuals, groups, and society. Accurate role perception and its importance to the prevention of conflict and confusion in nurse-patient interactions is the central idea that was incorporated into this study design.

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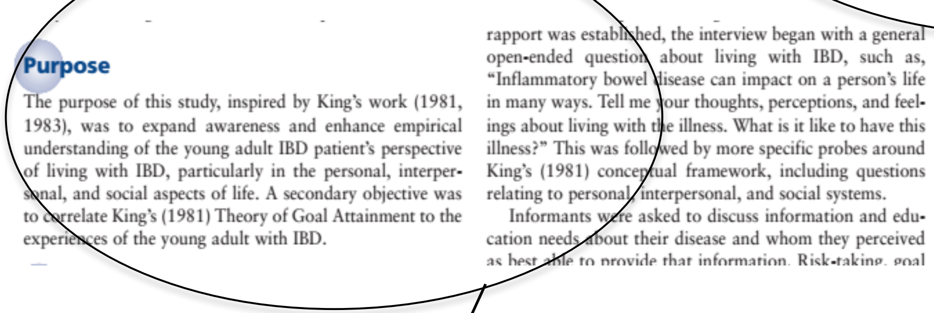
King's theory directly cited. Prominent nursing theory used to understand and improve patient-nurse relationships. Theory proposes that people are "open systems" interacting with their environment. Nursing is proposed to be a process of interaction where individuals perceive one another and using communication agree goals and ways to achieve these goals (King, 1981). Theory has been critiqued for being constricted to Western views of 'sickness' and viewing the individual as an isolated system, not within wider context. But is also an action-orientated theory, aimed at improving outcomes (Carter & Dufour, 1993)



Purpose

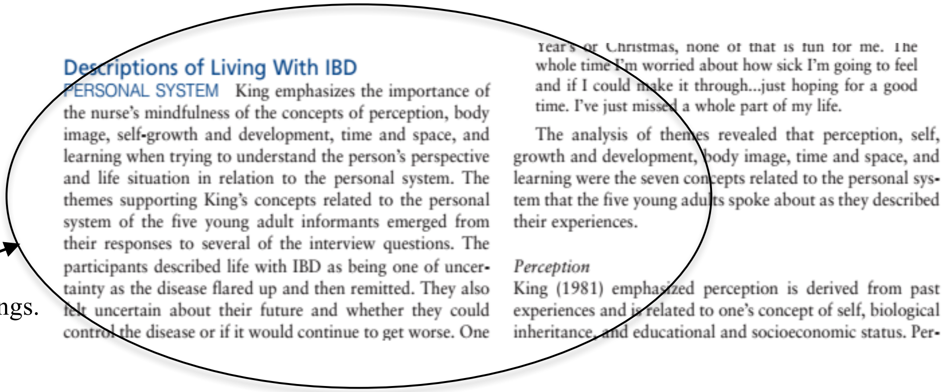
The purpose of this study, inspired by King's work (1981, 1983), was to expand awareness and enhance empirical understanding of the young adult IBD patient's perspective of living with IBD, particularly in the personal, interpersonal, and social aspects of life. A secondary objective was to correlate King's (1981) Theory of Goal Attainment to the experiences of the young adult with IBD.

rapport was established, the interview began with a general open-ended question about living with IBD, such as, "Inflammatory bowel disease can impact on a person's life in many ways. Tell me your thoughts, perceptions, and feelings about living with the illness. What is it like to have this illness?" This was followed by more specific probes around King's (1981) conceptual framework, including questions relating to personal, interpersonal, and social systems.

Informants were asked to discuss information and education needs about their disease and whom they perceived as best able to provide that information. Risk-taking, goal

King's theory cited as an aim of the study. One aim was to correlate the data to the theory, meaning the data is likely to have been analysed through the lens of the theory and influenced the resulting data

King's theory fully embedded into the description of the findings.



Descriptions of Living With IBD

PERSONAL SYSTEM King emphasizes the importance of the nurse's mindfulness of the concepts of perception, body image, self-growth and development, time and space, and learning when trying to understand the person's perspective and life situation in relation to the personal system. The themes supporting King's concepts related to the personal system of the five young adult informants emerged from their responses to several of the interview questions. The participants described life with IBD as being one of uncertainty as the disease flared up and then remitted. They also felt uncertain about their future and whether they could control the disease or if it would continue to get worse. One

Year's or Christmas, none of that is fun for me. The whole time I'm worried about how sick I'm going to feel and if I could make it through...just hoping for a good time. I've just missed a whole part of my life.

The analysis of themes revealed that perception, self, growth and development, body image, time and space, and learning were the seven concepts related to the personal system that the five young adults spoke about as they described their experiences.

Perception

King (1981) emphasized perception is derived from past experiences and is related to one's concept of self, biological inheritance, and educational and socioeconomic status. Per-

cont. Schwenk et al. (2014)

The term coping used in the title of article but not referred to until results and not theoretically defined at this stage either. Term is used a-theoretically.

Coping with College and Inflammatory Bowel Disea

Implications for Clinical Guidance and Support

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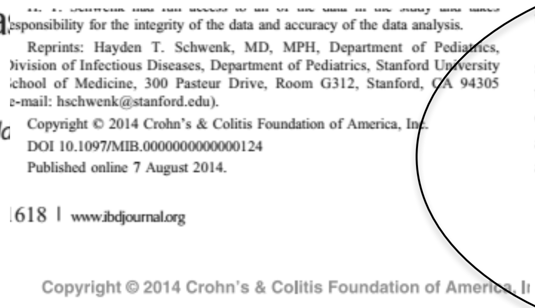
Donald A. Goldmann, MD,[*,†,¶] and Elissa R. Weitzman, ScD, MSc[†,**,††]



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esponsibility for the integrity of the data and accuracy of the data analysis.

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DOI 10.1097/MIB.0000000000000124

Published online 7 August 2014.

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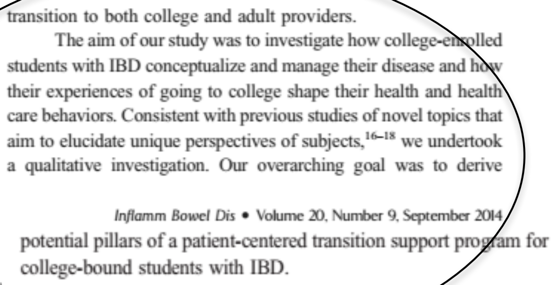

transition to both college and adult providers.

The aim of our study was to investigate how college-enrolled students with IBD conceptualize and manage their disease and how their experiences of going to college shape their health and health care behaviors. Consistent with previous studies of novel topics that aim to elucidate unique perspectives of subjects,[16–18] we undertook a qualitative investigation. Our overarching goal was to derive

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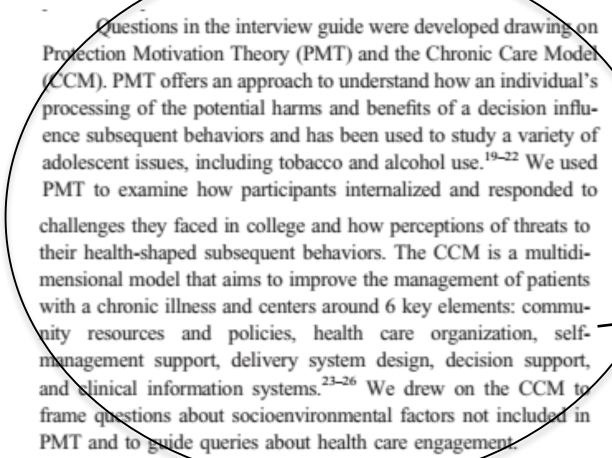
potential pillars of a patient-centered transition support program for college-bound students with IBD.

Practical focus to understand how YP conceptualise and manage their IBD in relation to 'college', in order to inform the development of a support programme.



Questions in the interview guide were developed drawing on Protection Motivation Theory (PMT) and the Chronic Care Model (CCM). PMT offers an approach to understand how an individual's processing of the potential harms and benefits of a decision influence subsequent behaviors and has been used to study a variety of adolescent issues, including tobacco and alcohol use.[19–22] We used PMT to examine how participants internalized and responded to challenges they faced in college and how perceptions of threats to their health-shaped subsequent behaviors. The CCM is a multidimensional model that aims to improve the management of patients with a chronic illness and centers around 6 key elements: community resources and policies, health care organization, self-management support, delivery system design, decision support, and clinical information systems.[23–26] We drew on the CCM to frame questions about socioenvironmental factors not included in PMT and to guide queries about health care engagement.

PMT and CCM both theories which are action-orientated and seek to understand adherence/nonadherence and barriers to healthcare.

PMT has been critiqued for not playing attention to the origin of beliefs and other factors which may impact adherence such as seeking social acceptance (Munro, Lewin, Swart, Volmink, 2007). The theory assumes that individuals will take the action which will protect them from harm, which was not found in other included studies (Saunders, 2011).

In the CCM, there is a lot of emphasis on what the clinician can do to improve outcomes, less about the client's system. These theories informed data collection, therefore likely data from this study focused on actions to improve adherence rather than seeking to understand emotional or social stressors and their context to coping.

Appendix D

Excerpt of meta-data-analysis

Table 5

Meta-data-analysis process

Theme	Sub-theme	Source	Raw data	Theme
Stressors				
	Symptomatology	Alexakis et al. (2015)	Fears of public incontinence Fears that may have to interrupt worship to find toilet	Prominence of the emotion fear, link to anxiety
		Allison et al. (2013)	Appreciating improvement but fearing it wouldn't last Lack of control around timing of surgery Stuck in a cycle or recurrent disease and multiple operations Those who had ongoing problems described feeling pessimism about the future Concerns about sexuality, concerns about conception, pregnancy, delivery and raising a child	Ongoing symptoms reduced hope
		Daniel (2002)	Emotional effects of having IBD which never goes away (anger, depression, self-blame, guilt, mood swings) Feeling damaged, physically diminished, loss of control, uncertainty related to flare-ups and physiological responses to food/activities. Loss of control of body functions Fear and humiliation around bowel incontinence and concerns Idea of having to live with IBD forever Disease would remain a part of them for their entire lives was a major aspect of the disease for the participants to come to terms with and accept Fear and humiliation of losing bowel control in public Fears of surgery if disease got worse	Lack of control over symptoms/when they will get another flare. Constant uncertainty

(continued)

Table 5 continued

Theme	Sub-theme	Source	Raw data	Theme
		Fletcher et al. (2008a)	Lack of control further fuelled by insurmountable levels of stress	Feeling stuck and powerless in cycle involving stress and IBD.
			Vicious cycle involving stress, lack of control and gastrointestinal discomfort	
			All women reported the negative consequences that stress had on the condition.	
			Believing themselves to not cope well with stress	
			Not knowing what might trigger it or a flare-up drives me nuts	
			Worrying about being in stressful situations or being busy because worry could have a full-blown flare-up.	
		Lynch and Spence (2007)	Knowing stress triggers disease, must get used to what can’t change	
			Moved out of home, moved back and then got sick again. Got to get used to it, you can’t change it, it just flares up when it wants to	
			Stress caused by anger and frustration reached point where exhausted physically and mentally	
			Combination of symptoms and stress appears to engender anger, depression, mood swings	
			Stress brings on CD, not getting enough sleep, thinking too much	
			Getting worried and that wasn’t helping	
			It just flares up when it wants to	
			You could think you are getting your life back and then it flares up again	
			Investing considerable time and energy to cope with pain and get life back on track yet normal life may only last for a short time	
			Times of normality, times when plagued with symptoms, living simultaneously with hope and fear	IBD relative homeostasis, living in fear or relapse but hope of continued remission
			Fear is experienced when symptoms create knowns and unknowns	
			Scared something will go wrong if had an operation	
		Nicholas et al. (2007)	Reduced control over many elements of their life	Emotional and physiological impact of symptoms: Feeling emotionally exhausted/depleted and anger/frustration/ embarrassment
			The disease elicited uncertainties about what adolescents lives would hold on a daily basis	
			Never know when I’m going to get fat again	
			Never know what’s going to happen	
			Decreased control over possibility disease could flare up at any time	
			Never know when I’m going to have the pain	
			Loss of control of certain aspects of life	
			Feeling weak internally	

(continued)

Table 5 continued

Theme	Sub-theme	Source	Raw data	Theme
		Savard and Woodgate (2008)	Illness caused great stress and anxiety on daily basis Feeling controlled by UC UC had big control over my life Frustrated by needing to be in hospital Frustrated by being told how to use stoma, were upset at having it, not ready to take responsibly for it Physical and emotional pain from illness Worst thing about IBD was the pain have to endure Embarrassed about nature of symptoms and prenisone adverse effects	
		Schwenk et al. (2014)	Lack of control intensified when women left comfort of their homes and went to places where perceived control was diminished. The inability to maintain control became all consuming Unable to anticipate disease flare ups contributed to feeling of having little control over lives Difficulty locating bathrooms and embarrassment related to frequent and unpredictable bathroom use were stressors Unable to anticipate disease flare ups contributed to feeling of having little control over lives	

Appendix E

Excerpts from record of synthesis decisions

Excerpt 1: Translation decision involving ‘getting on with it’ sub-theme

….‘Persisting’ theme collapsed into ‘getting on with it’. Both themes reflect desire to want to continuing living life despite illness. Both refer to distraction and distancing self from living with CI and not letting IBD limit them. However, some of the data in this theme is more indicative of avoidance than others. Some data refers to themes of ‘putting on a brave face’ or not ‘dwelling’ on illness. This appears more avoidant than data relating to persistence and perseverance which also encompasses some accommodative coping or cognitive reappraisal (i.e., acknowledging illness but not seeing illness as something to be restricted by)….

Excerpt 2: Decision to use concept of see-saw as underlying concept to model

…. A see-saw is a “long plank balanced in the middle on a fixed support” with people or objects on each side and the seesaw “swings up and down”. A see-saw “changes rapidly and repeatedly from one position, situation or condition to another and back again” (dictionary definitions). This concept appears to reflect what YP are describing: living with stress is part of their lives and whether they feel in or out of control of their IBD is constantly changing and tipping in either direction according to factors such as the demands of the situation, underlying support from others and levels of personal resource.…

Excerpt 3: Reflection on prominence of control in meta-synthesis

…. Control’s prominence in the data might be linked to the majority of studies being conducted in the field of nursing (and associated foci on adherence to healthcare which involves engaging in medication to obtain illness control). The underlying theories of some of these nursing nurses (e.g., PMT) may exacerbate this. Feeling out of control and striving for illness control is also a theme I have observed in my experiences of IBD in my personal life. I have reflected on whether control has emerged as a key theme due to my experiences and associated expectations. I have checked data to ensure this theme’s prominence is warranted across the raw data, which I think it is….

Appendix F

Table of study ratings according to the JBI (2016) criteria

Table 6

Appraisal of methodological quality using the JBI (2016)

Is there congruity between . . .	1	2	3	4	5	6	7	8	9	10	11	12	13	14
The stated philosophical perspective and the research methodology?	N	NC	N	Y	NC	NC	NC	NC	NC	Y	NC	Y	Y	N
The research methodology and the research question or objectives?	NC	Y	NC	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	NC
The research methodology and the methods used to collect data	NC	Y	NC	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	NC
The research methodology and the representation and analysis of the data?	NC	Y	NC	Y	N	N	NC	Y	Y	Y	Y	Y	Y	NC
The research methodology and the interpretation of results?	NC	Y	NC	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	NC
Is there a statement locating the researcher culturally or theoretically?	N	N	N	N	N	N	N	N	N	N	N	N	N	N
Is the influence of the researcher on the research and vice-versa, addressed?	N	N	N	N	N	N	N	N	N	N	N	N	N	Y
Are participants, and their voices, adequately represented?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is the research ethical and is there evidence of ethical approval?	Y	Y	Y	Y	N	Y	Y	N	Y	Y	Y	Y	Y	Y
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Note. 1 = Alexakis et al. (2015); 2 = Allison et al. (2013); 3 = Barned et al. (2016); 4 = Daniel (2002); 5 = Fletcher & Schneider (2006)[a]; 6 = Fletcher et al. (2008a); 7 = Fletcher et al. (2008b); 8 = Jamieson et al. (2007); 9 = Lynch & Spence (2008); 10 = Nicholas et al. (2007); 11 = Saunders (2011); 12 = Saunders (2014); 13 = Savard & Woodgate (2008); 14 = Schwenk et al. (2014). Y = Yes; N = No; NC = Not Clear; NA = Not applicable

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Part Two: Research Report

Self-compassion, coping and psychological distress in young people diagnosed with Inflammatory Bowel Disease.

Abstract

Objective

To investigate whether dispositional self-compassion in young people (YP) diagnosed with inflammatory bowel disease (IBD) predicts adaptive coping responses and coping flexibility, and less use of avoidant coping responses and psychological distress.

Design

A six-week prospective online survey design was utilised to examine the hypothesised relationships over time.

Method

A sample of 198 YP completed measures of self-compassion, coping response, coping flexibility, and psychological distress at baseline. Self-compassion and psychological distress measures were repeated six to eight weeks later by 105 participants (47% attrition).

Results

Self-compassion and avoidant coping responses were the only significant predictors of psychological distress over and above the variance explained by illness activity in the cross-sectional analyses, but not the prospective analyses. The indirect effect of Time 1 self-compassion on Time 1 psychological distress through lower avoidant coping was significant.

Conclusions

These findings suggest that self-compassion may be an important quality for facilitating psychological health in YP diagnosed with IBD. Avoidant coping was the only coping factor to make a significant and robust contribution to explaining Time 1 psychological distress variance which highlighted its importance to IBD coping. However, these relationships were only observed cross-sectionally, not over time, and should be interpreted in the context of the study's limitations. Future studies may wish to examine whether other factors can further explain the relationship between self-compassion and psychological distress and whether cultivating self-compassion can reduce the use of avoidant coping and distress felt by YP.

Practitioner Points

- Facilitating YP's ability to be self-compassionate may in turn improve their ability to cope with their IBD and reduce the distress they feel, both during relapse and remission of IBD.
- Avoidant coping may exacerbate psychological distress and strategies to bring the use of avoidance to the attention of YP and support to consider alternative strategies may reduce the distress they feel.

Limitations

- The six-week interval between Time 1 and Time 2 data collection was likely too short to measure meaningful changes in psychological distress in a chronic illness sample.
- A high rate of attrition was found in this study which may have impacted the validity of the findings.

Introduction

Inflammatory Bowel Disease (IBD) is a broad term used to refer to a group of chronic and relapsing-remitting conditions that affect the digestive system, Crohn's Disease (CD) and Ulcerative Colitis (UC) being the two most common (Goodhand et al., 2011). It is estimated that 240,000 people in the United Kingdom are diagnosed with IBD (146,000 being diagnosed with UC) and IBD has no known aetiology or cure (NICE, 2012, 2013). Twenty-five percent of individuals are diagnosed by the age of 16 (The IBD Standards Group, 2009). IBD causes the lining of the digestive system to become inflamed which can cause recurrent abdominal pain, fatigue, weight loss and diarrhoea. UC affects the large intestine whereas CD can affect any part of the digestive system (McCombie, Mulder, & Gearry 2013). IBD treatment aims to relieve symptoms (gain remission) and prevent relapse. Depending on the age of the individual and illness severity, IBD can be treated by medical treatment (e.g., corticosteroids, 5-aminosalicylate), tube feeding, and in some cases surgery (NICE, 2012, 2013). IBD symptoms can be highly embarrassing for individuals and the illness is associated with reduced quality of life and psychological wellbeing in adults (Lu & Markowitz, 2011; Graff, Walker, & Bernstein, 2009).

IBD has particular relevance to young people (YP; aged 15-24 years) at a time when they are establishing their autonomy, identity and forming relationships (Arnett, 2000; Goodhand, Hedin, Croft, & Lindsay, 2010; UNDESA, n.d). IBD poses many developmental challenges for YP including delays to physical growth, puberty and psychological development (Loonen, Grootenhuis, Last, Koopman, & Derkx, 2002). For example, a study found impaired motor functioning and reduced autonomy in YP diagnosed with IBD (Pfefferkorn et al., 2009). IBD medical treatments can also impact YP's body image. Corticosteroid treatment can result in weight gain and acne. Some YP also need to have surgery which may result in ileostomies (Greenley et al., 2010; Mackner & Crandall, 2007). These challenges to YP's physical appearance may in turn impact YP psychosocially as they may look different to their peers and appear less mature which may lead some YP to withdraw socially (Lu & Markowitz, 2011). Despite these challenges, there are fewer studies focusing on the impact of IBD on YP, compared to adults.

Several studies have found higher incidences of depression and anxiety amongst YP with IBD when compared to their healthy peers (Raymer, Weiniger, & Hamilton, 1984; Mackner, & Crandall, 2006). A recent review focused on factors which increased the risk of psychological distress in YP diagnosed with IBD and found that increased illness activity, being diagnosed older, having lower socioeconomic status, parental stress and being prescribed corticosteroids were all risk factors (Brooks et al., 2016). Depression symptoms have also been found to predict self-reported abdominal pain in YP (aged 9-17 years) diagnosed with both CD and UC (Srinath et al., 2014). However, it is not clear whether psychological distress is a product or precursor of IBD symptoms, as research on this topic has had methodological weaknesses (Mikocka et al., 2007). Nevertheless, the proposed adverse links between psychological distress and symptom severity, and the associated costs of relapse to the National Health Service (NHS) is causing attention to be increasingly paid to the factors which could facilitate coping with IBD (Ghosh & Purushothaman, 2015).

Coping

Coping refers to "cognitive or behavioural efforts to manage specific external or internal demands (and the conflicts between them) that are appraised as taxing or exceeding the resources of the person" (Lazarus, 1993; p. 237). The methods (e.g., planning, distraction) individuals use to cope with chronic illnesses (CI) such as IBD have been identified as important determinants of quality of life, psychological adjustment and functioning (Crane & Martin, 2004; Parekh et al., 2015). Several taxonomies of coping have been proposed; one of the most recognised being the distinction between ‘problem-focused’ and ‘emotion-focused’ coping (Lazarus, 1993). Problem-focused coping methods include planning and taking action whereas emotion-focused coping strategies attempt to regulate the emotional distress caused by the stressful event (e.g., positive reframing and distraction). Emotion-focused coping has frequently been found to be associated with poorer quality of life and adjustment in adults (Kinash, Fischer, Lukie, & Carr, 1993; Smolen & Topp, 1997) and in YP diagnosed with IBD (McCombie et al. 2013). The outcomes associated with problem-focused coping are less clear; some studies have found problem-focused coping to be associated with better quality of life and positive affect in adults diagnosed with IBD (Pellissier, Dantzer, Canini, Mathieu, & Bonaz, 2010; Kinash et al., 1993) but other studies have not (Snolen & Topp, 1997). Moreover, distinctions have been drawn between two types of emotion-focused coping, one involving an attempt to understand an emotional response to a stressor, and the other involving attempts to avoid or escape it (Skinner, Edge, Altman, & Sherwood, 2003).

Avoidant coping responses have been consistently associated with poorer adjustment to CI and higher levels of psychological distress (Carver et al., 1993; Crane & Martin, 2004; Desmond, 2007; Dorrian, Dempster, & Adair, 2009). Research has found that both adults (Jones, Wessinger & Crowell, 2006) and YP diagnosed with IBD (Van der Zaag-Loonen, Grootenhuis, Last & Derkx, 2004) make greater use of avoidant coping styles when compared to healthy controls. However, a minority of studies have reported no differences (Calsbeek, Rijken, Bekkers, van Berge Henegouwen, & Dekker, 2006). In view of the aforementioned findings, research has focused on factors which may predict greater or lesser use of avoidance. Higher IBD illness activity has been linked with greater use of avoidant strategies and in turn poorer psychological adjustment (Voth & Sirois, 2009). Furthermore, the avoidant coping strategy of decreasing activity, was also found to mediate the relationship between perceptions of control over IBD and poorer mental health (Van Erp et al., 2017). Moreover, some researchers have suggested that physicians may actively encourage avoidance by advocating restricted activity levels to manage symptoms (Crane & Martin, 2004).

Avoidance is typically regarded as 'maladaptive' in view of its association with poorer psychological health outcomes. Other researchers have defined coping to be 'adaptive' when the external or internal demands remain present but the individual is less distressed by them (Lazarus, 1993; McCombie et al., 2013). However, one approach to coping is unlikely to be effective in reducing distress in every scenario and instead individuals are likely to require a diverse set of coping strategies, ready to deploy according to the demands of the situation (Sirois, Molnar, & Hirsch, 2015).

Coping flexibility

Coping flexibility has been conceptualised several ways (Cheng, Lau, & Chan, 2014) including; individuals having a 'broad repertoire' of coping strategies (Lykes, 1983); using a balance between problem and emotion-focused coping (Kaluza, 2000); being able to alter strategies according to the demands of the situation (Lazarus, 1993); and, being able to match a coping response to the situation (Cheng, 2003). Another measure of coping flexibility is individuals' own appraisal of their ability to cope across situations, measured using self-report tools (Gignac, Cott, & Badley, 2000). A meta-analysis found stronger links between coping flexibility and higher levels of psychological adjustment when coping flexibility was conceptualised and measured as the ability to match a coping strategy to the situation or based on individual's perceived ability to cope flexibly (Cheng, Lau, & Chan, 2014). One proposal for measuring individuals' perceived ability to cope flexibly is Brandtstäudter's (2009) dual-process theory of coping. This theory proposes that individuals who are able to cope flexibly, adjust their coping goals according to the situational stressor. Kato (2012) extended the dual-process theory of coping by proposing that individuals who cope flexibly must first be able to recognise that a coping strategy is ineffective before they are able to consider an alternative, a cognitive process called 'evaluation coping', the first component to Kato's (2012) 'coping flexibility hypothesis'. The second component is the ability to be able to consider viable alternatives until the desired outcome is achieved, called 'adaptive coping' in the hypothesis. Greater coping flexibility, measured using Kato's (2012) Coping Flexibility Scale, has been found to be significantly associated with reduced depression symptoms in a female YP sample ($M_{age\,=}$ 20.5 years) who were experiencing chronic headaches (Kato, 2015). However, this hypothesis and measure has not yet been examined in relation to IBD.

Self-compassion

A growing body of literature has also highlighted the potential for 'positive' traits to improve psychological health (de Ridder, Green, Kuijer, & van Midendorp, 2008). One such trait is self-compassion conceptualised by Neff (2003) to comprise of three qualities; 'self-kindness' (responding to self in a non-judgemental way); 'common humanity' (recognising that negative events is common to human kind); and 'mindfulness' (taking a balanced and thoughtful view of ones' difficulties). The concept of self-compassion originates from Buddhist psychology and in essence involves treating oneself with kindness and compassion (in contrast to criticising or blaming oneself) when in challenging or uncontrollable circumstances (Sirois & Rowse, 2016). Higher levels of self-compassion have consistently been associated with reduced psychological distress in healthy adults (Neff, Pisitsungkagarn & Hseih, 2008) and YP

(Neff & McGehee, 2010; Sirois, 2015). A meta-analysis revealed a large effect size for the relationship between increased self-compassion and reduced psychopathology in adult studies (*r* = -.54) (MacBeth & Gumley, 2012).

The reported benefits of self-compassion in reducing psychological distress have also been proposed to extend to individuals with CIs (Sirois & Rowse, 2016). The aforementioned researchers proposed that self-compassionate individuals may be more able to "[frame hardship] as the common human experience of imperfection" and take a balanced view of the limitations associated with their CI (p. 522). Higher self-compassion has been associated with lower stress and anxiety in adults diagnosed with HIV (Brion, Leary & Drabkin, 2013) and depression in adults diagnosed with cancer (Matos, Pinto-Gouveia, & Duarte, 2013). Terry and Leary (2011) also proposed positive links between self-compassion and adaptive coping in CI. These researchers proposed that self-compassionate individuals may be better able to regulate negative emotions linked to experiencing a CI and take a thoughtful, flexible and balanced approach to coping. Sirois et al. (2015) recently examined the impact of self-compassion on coping in adults diagnosed with IBD. They found self-compassionate adults made greater use of adaptive coping strategies (e.g., active coping, positive reframing) and less use of avoidant coping strategies which was in turn linked to greater coping efficacy and less perceived stress. However, this study was limited by its cross-sectional design therefore it is unclear whether these associations hold over time. Furthermore, no studies have yet examined the impact of self-compassion on coping and distress in YP diagnosed with IBD.

The Present Study

IBD is a CI which can follow an uncertain course of relapse and remission and higher illness activity has been found to predict greater psychological distress in YP

(Brooks et al., 2016). Existing research has suggested self-compassion is a quality which can cultivate psychological health in response to uncontrollable circumstances (Sirois & Rowse, 2016). Recent research has found that self-compassion can facilitate adaptive coping strategies (e.g., positive reappraisal, acceptance) and in turn reduce perceived stress in adults diagnosed with IBD (Sirois et al., 2015). This study aims to expand on this research by examining the replicability of Sirois et al.'s (2015) findings in a YP IBD sample to examine whether these relationships hold within YP's developmental context. This study also addresses the limitations of existing research by employing a prospective design to analyse the hypothesised relationships over time and aims to increase the reliability of findings by controlling for IBD type (e.g., CD, UC), illness activity and gender, as previous research have found these factors can covary with the independent and/or dependent variables in this study (Brooks et al., 2016; Neff & McGehee, 2010; Yarnell et al., 2015). Age and age at diagnosis were not covariates due to the relatively small sample age range.

This study aims to test the efficacy of self-compassion in facilitating adaptive coping and reducing psychological distress in YP diagnosed with IBD using a robust methodological design. It is hoped that the results will provide a foundation for targeted clinical intervention to improve the psychological health of YP diagnosed with IBD.

Hypotheses

It is hypothesised that in a sample of YP diagnosed with IBD;

i. Higher dispositional self-compassion, measured at Time 1 (T1), will be associated with;

- Reduced psychological distress at T1 and Time 2 (T2)
- Greater use of adaptive coping strategies
- Lesser use of avoidant coping strategies
- Greater coping flexibility.

i. T1 self-compassion, coping response, coping flexibility (controlling for gender, illness activity and illness type) will significantly predict T1 psychological distress (cross-sectional analysis).
ii. T1 self-compassion, coping response, coping flexibility (controlling for gender, illness activity and illness type and baseline levels of psychological distress) will significantly predict T2 psychological distress (prospective analysis).

iii. There will be significant indirect effects of T1 self-compassion on T1 and T2 psychological distress through coping mechanisms and coping flexibility.

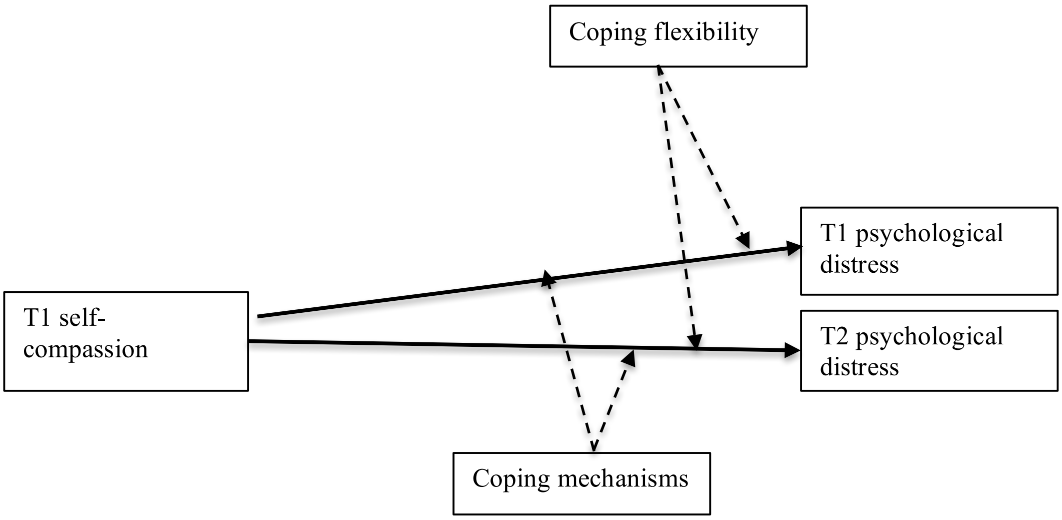

Figure 1. Proposed indirect directs of T1 self-compassion on T1 and T2 psychological distress through coping mechanism and coping flexibility

iv. There will be significant indirect effects of coping mechanisms on T1 and T2 psychological distress through coping flexibility.

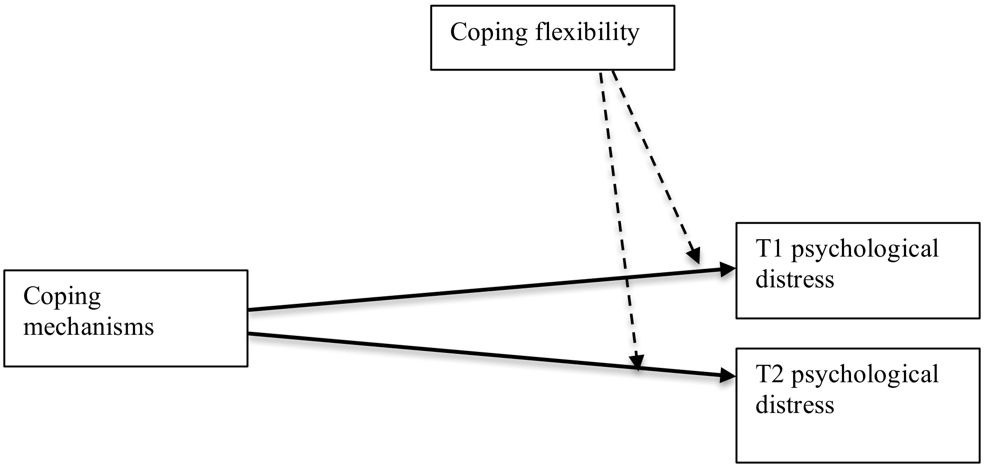

Figure 2. Proposed indirect effect of coping mechanism on psychological distress through coping flexibility

Method

Design

A 6-week prospective online-survey design was utilised to examine the hypotheses both cross-sectionally and prospectively. The T1 survey obtained self-report measurements of the control variables (demographic variables and subjective health status), the three independent variables (self-compassion, coping response and coping flexibility) and the dependent variable (psychological distress). The T2 survey was completed between six to eight weeks later, and measured the independent variable, self-compassion, to assess the stability of the construct over time, and the dependent variable, psychological distress, to facilitate the prospective analyses.

Participants

To ensure the study was adequately powered, an estimate of required sample size based on multiple regression analyses was conducted using G*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009). Previous studies have found medium to large effect sizes between self-compassion and negative affect in healthy YP (r = -.46; Sirois, 2015) and perceived stress in adults diagnosed with IBD (r = -.56; Sirois et al. 2015). Therefore, to achieve 80% power, based on a medium effect size of $F^2 = 0.15$, a significance level of alpha = .05, an estimated 6 tested predictors and 13 total predictors (including all covariates), a sample size of 98 was found to be required (Cohen, 1992). A sample size of around 130 was targeted to achieve adequate power and to take account of likely attrition, estimated to be at least 30% based on attrition found in online longitudinal viability studies (Musch & Reips, 2000; Hiskey & Troop, 2002).

YP aged between 16-24 years, diagnosed with Inflammatory Bowel Disease, including Crohn's Disease, Ulcerative Colitis and other less common sub-types of IBD (e.g., IBD not otherwise specified) were invited to participate. The age range was chosen to reflect the United Nations' (UNDESA, n.d) definition of 'youth' which specifies 15-24 years; however, 16 was chosen as a lower limit to reflect the age when YP are typically considered for transition from the child gastroenterology service to adult services. Transition occurs when YP are considered prepared and ready to make independent healthcare decisions (Brooks et al., 2017) and thus this was considered an appropriate lower-age limit to ensure the focus of the study was YP as opposed to a paediatric population.

One hundred and ninety-eight participants residing in the United Kingdom completed the T1 survey. Of these participants, 184 consented to be contacted regarding the T2 survey and 109 participants completed this; however, 4 participants' T2 data was excluded as they had not completed the second survey within the 6-8 week window, resulting in 105 completed responses at T1 and T2 (47% attrition).

Recruitment

The majority of participants (*n* = 193) were purposively recruited by online advertisement of the study by the third-sector organisations Crohn's and Colitis UK and Crohn's in Childhood Research Association (CICRA) and the online campaign group '#GetYourBellyOut'. A small number of participants were recruited via face-to-face advertisement of the study at an IBD event conducted by CICRA (*n* = 3) and by contacting individuals who had participated in IBD-related research at the University of Sheffield previously and consented to be contacted about future IBD studies (*n* = 2).

Ethical considerations

Ethical approval was granted by the Brent NHS Research and Ethics Committee, reference number 16/LO/0530 on March 21, 2016 (Appendix A). The University of Sheffield provided research governance sponsor status on July 28, 2016 (Appendix B). Informed consent to participate was ensured by providing all participants with information about the study either by providing them with the paper information sheet (Appendix C) or a summary of the information sheet on the first page of the online survey (Appendix D). It was explained to participants at the beginning of the survey that they would be invited to provide their email address so they could be contacted about the T2 survey and that this information would be kept confidential. Identifiable information was kept in an encrypted password protected database and was only visible to the lead researcher.

Procedure

Participants recruited online responded to a study advertisement (see Appendix E) distributed by the supporting charities, which included a link to the online survey developed using the Qualtrics© 2015 software, Version 08/2016. All survey responses were submitted directly into the software. Six weeks after participants had completed the T1 survey, individual emails were generated and sent by the Qualtrics© email system to alert participants to complete the T2 survey. In this email, each participant was provided with a unique number to input into the first page of the T2 survey to allow the researcher to link T1 and T2 data anonymously.

Participants who had consented to be contacted about future University of Sheffield IBD studies were contacted by email which included a link to the online survey and the study information sheet (Appendix B).

Participants recruited face-to-face at IBD charity events were provided with a 'research pack' which included the study information sheet, consent form (Appendix F), survey and a stamped addressed envelope to enable them to return the survey to the lead researcher. Two of the three participants who participated in this way chose to receive and return their T2 survey via post whilst the third completed the T2 survey online.

Measures

Demographic information. Participant characteristics (i.e., age, gender, diagnosis, approximate date of diagnosis and self-reported relapse or remission) were collected using a brief demographic questionnaire (Appendix G).

The Inflammatory Bowel Disease Questionnaire (IBDQ; Guyatt et al., 1989; Appendix H). Participants' IBD severity and quality of life was measured using the

IBDQ, a 32-item self-report measure, at T1. The measure is a widely used and validated measure of IBD-related health quality of life (Alrubaiy, Rikaby, Dodds, Hutchings, & Williams, 2015). Participants rated themselves on items such as, “how frequent have your bowel movements been during the last two weeks?” according to varying Likert scales, lower scores indicating poorer health status. The measure yields four subscale scores (bowel symptoms, systemic symptoms, emotional function and social function) as well as a global subjective health status score. Changes in the bowel symptom subscale of the IBDQ have been shown to correlate with changes in illness activity indexes in individuals diagnosed with CD and UC (Guyatt et al., 1989; Han, McColl, Steen, Barton & Welfare, 1998; McColl, Han, Barton, & Welfare, 2004). The bowel subscale score has therefore previously been used as a proxy measure for IBD severity (Voth & Sirois, 2009; Gick & Sirois, 2010). For the purposes of this study the bowel subscale score is used as a covariate. The bowel subscale has been found to have acceptable to excellent internal consistency in samples of adults diagnosed with IBD: $\alpha = 0.78$ (Cheung, Garratt, Russell, & Williams, 2000) and $\alpha = 0.89$ (Gick & Sirois, 2010). In this sample, the bowel subscale had good internal consistency ($\alpha = 0.85$).

The Self-Compassion Scale-Short Form (SCS-SF; Raes, Pommier, Neff, & Gucht, 2011; Appendix H). Dispositional self-compassion was measured using the SCS-SF, a 12-item self-report scale at T1 and T2, to assess the stability of the construct over time. The SCS-SF is a shortened version of the well-validated 26-item Self-Compassion Scale (Neff, 2003). Participants rated themselves on items such as, “when something painful happens I try to take a balanced view of the situation” according to a 5-point scale ranging from ‘‘almost never’’ to ‘‘almost always’’ with higher scores representing greater self-compassion. The measure yields six subscale scores and a total self-compassion score; for the purposes of this study, only the total self-compassion score was used. Neff and McGehee (2010) found the SCS-SF total score to have good to excellent internal consistency in non-clinical samples of adolescents (M_{age} = 15.2 years, α = 0.90) and young adults (M_{age} = 21.1 years, α = 0.93). In the current sample, the total SCS-SF score had good internal consistency at T1 (α = 0.83) and T2 (α = 0.86).

The Coping Flexibility Scale (CFS; Kato, 2012; Appendix H). The CFS, a 10-item self-report scale, was used at T1 to measure participants' coping flexibility. The measure yields two subscale scores; evaluation coping (i.e., recognition that a coping strategy is ineffective and consideration of an alternative) and adaptive coping (i.e., the consideration of a viable alternative until the desired outcome of reduced psychological distress is obtained). Both subscales consist of five items such as, "I only use certain ways to cope with stress" and participants rated how much each item applied to them on a 3-point Likert scale ranging from 0 "not applicable" to 3 "very applicable". For a sample of students (M_{age} = 19.8 years), the Cronbach's alphas for the evaluative coping items and adaptive coping items were 0.91 and 0.86 respectively, indicating good to excellent internal consistency (Kato, 2012). In this sample, the adaptive coping subscale had good internal consistency (α = 0.82); however, the evaluation coping subscale's internal consistency was inadequate (α = 0.41).

The Brief COPE (Carver, 1997; Appendix H). The Brief COPE, a 28-item self-report measure, was used at T1 to measure participants' coping responses. The Brief COPE is a shortened version of the original 52-item COPE measure (Carver, Scheier, & Weintraub, 1989). Participants rated themselves on items about how often they had used different coping styles such as, "I've been saying to myself, this isn't real" since they found out they had been diagnosed with IBD on a 4-point Likert scale ranging from 1 "I haven't been doing this at all" to 4 "I've been doing this a lot". The Brief COPE consists of 14 scales, of two items each (i.e., self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame). The authors of the scale recommend the use of exploratory factor analysis to determine whether a second-order factor structure could be supported, as many previous studies have found (Benson, 2010; Kiebles, Doerfler, & Keefer, 2010; Lawrence & Fauerbach, 2003). Brief COPE subscales has been found to have acceptable to excellent internal consistency in an adult IBD sample (α = .73-.94, Voth & Sirois, 2009). In the current sample, internal consistency scores for the higher-order coping factors ranged from acceptable to good: support-seeking coping (α = .87); avoidant coping (α = .80); and active coping, (α = .77).

The Depression Anxiety Stress Scales-Short Form (DASS-21; Lovibond & Lovibond, 1995; Appendix H). The DASS-21, a 21-item self-report measure, was used at T1 and T2 to measure participants' psychological distress. Participants rated how much statements like, "I found it hard to wind down" applied to how they had felt in the past week on a 4-point Likert scale ranging from 0 "not at all' to 3 "very much or most of the time". The DASS-21 produces 3 subscale scores for anxiety, depression and stress and a total composite score; the latter was used in this analysis. Higher scores indicate greater psychological distress. The DASS-21 scale score has been found to have good internal consistency in a non-clinical sample of UK adults (α =.93; Henry & Crawford, 2005). In this sample, the total psychological distress score had excellent internal consistency at T1 (α = 0.94) and T2 (α = 0.94).

Data analysis

All data was analysed using SPSS statistical software (Version 23; IBM Corp, 2013).

Data screening. Because the T1 (*n* = 198) and T2 (*n* = 105) samples were sufficiently powered for the analyses, almost all cases with missing data were excluded. The exception was one case that included two missing values both within the BCOPE measure. These were assessed to be missing seemingly at random (Graham, 2009). Each BCOPE subscale has two items and the missing values occurred in different subscales, therefore the value of the corresponding subscale item was used as a substitute for the missing values.

Preliminary analyses. Differences between the T1 baseline responders and T2 completers were assessed using *t*-tests, chi-square and Fisher's exact tests. Paired sample *t*-tests were used to examine whether there were changes in self-compassion and psychological stress from T1 to T2. Differences between the model variables according to the three categorical covariates (gender, diagnosis type and whether participants were in relapse or remission) were tested using *t*-tests and ANOVA tests.

Brief COPE second-order factor structure. As recommended by the authors of the BCOPE scale, an exploratory factor analysis was conducted to explore whether any of the 28 items measured in the Brief COPE (Carver, 1997) were correlated and therefore potentially measuring similar underlying coping dimensions. The resulting factors were then used as coping predictors in the multiple regression analyses.

T1 cross-sectional analyses. Bivariate correlational analyses for T1 were first conducted to measure whether self-compassion significantly correlated with the coping variables and psychological distress. Regression analyses were used to determine the extent to which the proposed model of self-compassion, coping mechanisms and coping flexibility explained variance in psychological distress. Variables were entered into the regression model using the hierarchical method based on past research, the a-priori hypotheses and the hypothesised direction of the relationships. Indirect effect analyses were conducted using the PROCESS macro in SPSS (Hayes, 2013). The hypothesised indirect effects are both regarded as simple indirect effect models involving a single independent variable (IV), mediator (M) and dependent variable (DV). Significance tests of the indirect effects can produce the following results; a 'total effect' (IV – DV, the c path), a 'direct effect' (IV on DV through M, the c' path) and an 'indirect effect': the product of the a (IV - M) and b-paths (M – DV; Preacher & Hayes, 2004). The PROCESS macro tests the significance of the indirect effect using a bootstrapping resampling procedure which creates 5,000 bootstrapped samples from the data to estimate the indirect effect for each of the resampled data sets. This widely used method accounts for non-normality in the sampling distribution and it can be applied to smaller samples with greater confidence (Preacher & Hayes, 2004).

T2 prospective analyses. Regression analyses were next conducted to examine the extent to which the variables measured at T1 (self-compassion, coping response and coping flexibility) explained variance in psychological distress at T2, controlling for baseline levels of psychological distress. Variables were entered into the regression in the same order as the test of the T1 model, with the addition of T1 psychological distress as a control variable. Follow-up indirect effect analyses (Preacher & Hayes, 2004) were again conducted to test whether the hypothesised indirect effects held prospectively.

Results

Exploratory factor analysis of the Brief COPE

The Kaiser-Meyer Olkin measure verified the sample adequacy for the analysis, KMO = 0.75, a score which is considered 'good' (Kaiser & Rice, 1974). Bartlett's (1950) test of sphericity χ^2 (378) = 2612.34, $p < .001$, indicated that correlations between the items were sufficiently large to conduct Principal Components Analysis. An initial analysis was run to obtain eigenvalues for each component in the data. Items were retained in the analysis if they loaded onto a factor above 0.5, considered a ‘strongly’ loading item (Costello & Osborne, 2005). Eight components had eigenvalues over Kaiser’s (1960) criterion of 1; however, the scree plot showed a clear break after three factors, before several smaller factors with less than three items, typically considered ‘weak factors’ (see Appendix I; Cattell, 1966; Cattell & Jaspers, 1967; Costello & Osborne, 2005). On examination of the three-factor structure, the first and third factors were not conceptually consistent (Appendix J). The first factor included active coping, planning and positive reframing. Positive reframing was conceptually inconsistent and loaded weakly in comparison to the other items. In the third factor, self-blame clustered together with venting and behavioural disengagement and there was a spread of loading scores suggestive of a necessary spilt. Given the poor loadings, the self-blame and positive reframing items were removed and the factor analysis was re-run. Acceptance items then loaded weakly with avoidant coping items (denial and behavioural disengagement), which was also conceptually inconsistent. Acceptance items were then also excluded and the analysis was re-run again. Three conceptually consistent factors (Table 2) were then derived and retained. These three retained factors explained 43.3% of the variance.

Preliminary analyses

Multicollinearity between variables was examined by inspecting the correlation matrix, which revealed no highly correlated relationships (r = > .8). Additional multicollinearity statistics (variance inflation factor and tolerance) did not suggest multicollinearity was biasing the model. The Durbin-Watson value, testing the assumption of independent errors, was 2.06 which falls above the upper critical limit of

1.82, based on six independent variables, which suggested the data was not serially correlated (Durbin & Watson, 1971; Savin and White, 1977). The assumption of normally distributed errors was examined using histograms and normal probability plots. The histogram demonstrated some non-normality by positive skew in relation to T1 and T2 psychological distress but the P-P plots did not suggest these were substantial deviations from normality (Field, 2009). Finally, the assumptions of homoscedasticity and linearity were examined using regression plots, which did not raise concern.

Table 1

Factor loadings for the three coping variables

Item	Support-seeking coping	Avoidant coping	Active coping
5. I've been getting emotional support from others	.80		
10. I've been getting help and advice from other people	.83		
15. I've been getting comfort and understanding from someone	.83		
23. I've been trying to get advice or help from other people about what to do	.80		
2. I've been saying to myself "this isn't real"		.78	
6. I've been giving up trying to deal with it		.74	
8. I've been refusing to believe that it has happened		.84	
16. I've been giving up the attempt the cope		.76	
2. I've been concentrating on doing something about the situation I'm in			.70
7. I've been taking action to try and make the situation better			.72
14. I've been trying to come up with a strategy about what to do			.77
25. I've been thinking about what steps to take			.61
% of variance (total 43.33)	20.30	13.72	9.30

Since the evaluation coping CFS subscale's internal consistency was inadequate, this variable was excluded from subsequent analyses.

Descriptive analyses

No significant differences between participants who completed just the baseline survey (*n* = 91) and participants who completed both surveys (n = 105) were found across all demographic variables and model predictors (Table 2).

Average T1 and T2 psychological distress fell in the 'moderate' range (Lovibond & Lovibond, 1995). Of the 105 participants who completed the baseline and follow-up survey, paired *t*-tests revealed no significant change in their average psychological distress between T1 and T2; however, self-compassion was found to be on average significantly lower at T2 when compared to T1 (Table 3).

Table 4 summarises the descriptives for each of the categorical variables. Illness activity, as measured by the IBDQ bowel subscale, was found to be higher in females. Levels of self-compassion did not differ according to gender. Males reported greater use of active coping strategies and females reported greater use of avoidant coping strategies. As expected, those in relapse reported higher levels of bowel activity. Psychological distress did not significantly differ according to whether participants were in relapse or remission. No differences in model variables according to illness type were found.

Table 2

Demographic characteristics of the baseline and completer samples and T-tests for all study measures

	Baseline (T1)	Completers (T1 and T2)	χ^2	*p*
N	91	105		
Gender (%)			.03	.50
Male	22.0	21.0		
Female	78.0	79.0		
Diagnosis (%)			1.86	.39
CD	57.1	62.9		
UC	36.3	33.3		
Other	6.6	2.9		
Illness status (%)			2.65	.07
Relapse	33.0	44.8		
Remission	65.9	55.2		
Location (%)			2.54	.84
England	83.5	80.0		
Scotland	11.0	10.5		
Wales	2.2	6.7		
Northern Ireland	4.4	2.9		
Ireland	1.1	1.0		
			t	*p*
Age (M, SD)	21.09 (2.28)	20.76 (2.44)	-0.96	.34
Range	16-24	16-24		
Diagnosis length (M, SD)	4.20 (3.70)	4.47 (4.16)	0.48	.64
IBDQ Bowel subscale score (M, SD)	3.36 (1.14)	3.33 (0.18)	0.17	.86
T1 Total Self-compassion (M, SD)	2.57 (0.63)	2.65 (0.70)	0.74	.46
T1 Psychological distress (M, SD)	1.54 (1.52)	1.31 (1.52)	-1.04	.30
Active Coping (M, SD)	9.38 (3.01)	9.21 (2.73)	-0.43	.67
Support-seeking Coping (M, SD)	8.73 (3.19)	8.76 (3.24)	0.08	.94
Avoidant Coping (M, SD)	7.11 (2.99)	6.50 (2.90)	-1.46	.15
Evaluative Coping (M, SD)	12.46 (2.48)	12.70 (2.12)	-0.74	.46
Adaptive Coping (M, SD)	11.51 (3.04)	12.22 (2.84)	1.70	.10

Notes. CD = Crohn's Disease; UC = Ulcerative Colitis; M = mean; SD = standard deviation; psychological distress composite scores computed by transforming the subscale scores into z-scores using Australian normative data for a 19-29 population (Lovibond & Lovibond, 1995) and then averaged.

Table 3

T-Tests for self-compassion and psychological distress at baseline and 6-week follow-up

	Baseline (N = 105)	Follow-up (N=105)	t	*p*
Psychological distress (M, SD)	1.31 (1.52)	1.37 (1.42)	-0.62	.54
Self-compassion (M, SD)	2.64 (0.70)	2.54 (0.66)	2.22	.03*

Note. M = mean; SD = standard deviation; * *p* < .05

Correlational analyses

Psychological distress at T1 and T2 was found to correlate with all the T1 predictors except support-seeking (Table 5). No significant correlations were also found between support-seeking coping and self-compassion; therefore, support-seeking coping was excluded as a predictor in the subsequent analyses.

In support of hypotheses 1a and 1b, higher T1 self-compassion was significantly correlated with lower psychological distress at T1 (*r* = -.57) and T2 (*r* = -.47) and less use of avoidant coping strategies (*r* = -.41). T1 self-compassion was significantly correlated with greater use of active coping strategies (*r* = .26) and greater coping flexibility (*r* = .46) and evaluative coping (*r* = .23). Avoidant coping strategies were also associated with higher psychological distress at T1 (*r* = .55) and T2 (*r* = .41), whilst active coping strategies were associated with lower psychological distress at T1 (*r* = -.16) and T2 (*r* = -.24). Higher levels of illness activity were significantly associated with higher psychological distress at T1 (*r* = -.53) and T2 (*r* = .39) and use of avoidant coping strategies (*r* = -.41). Illness activity was significantly associated with lower T1 self-compassion (*r* = -.16); adaptive coping (*r* = -.27); evaluative coping (*r* = -.27) and use of active coping strategies (*r* = -.16) (Table 5).

Table 4

Study variables according to the three categorical covariates

	Gender				Illness activity				IBD Type				
	Male	Female	t	*p*	Relapse	Remission	t	*p*	CD	UC	Other [a]	F	*p*
T1 (N)	42	154			77	118			118	68	9		
Ill Act (M, SD)	2.96 (1.10)	3.44 (1.15)	-2.48	.02*	3.94 (1.06)	2.94 (1.05)	6.46	.00**	3.31 (1.13)	3.36 (1.18)	3.76 (1.38)	0.63	.53
T1 PDis (M, SD)	1.14 (1.40)	1.49 (1.55)	-1.40	.17	1.60 (1.51)	1.31 (1.53)	1.27	.21	1.51 (1.61)	1.28 (1.38)	1.22 (1.48)	0.61	.55
T1 SC (M, SD)	2.72 (0.67)	2.58 (0.67)	1.16	.25	2.59 (0.67)	2.62 (0.66)	-.23	.82	2.56 (0.67)	2.68 (0.66)	2.88 (0.61)	1.41	.25
Act C (M, SD)	10.26 (3.31)	9.03 (2.68)	2.23	.03*	8.87 (2.95)	9.54 (2.78)	-1.60	.11	8.95 (2.70)	9.82 (3.10)	9.56 (2.70)	2.26	.10
Sup C (M, SD)	8.69 (3.31)	8.76 (3.19)	-0.12	.90	8.71 (3.17)	8.74 (3.25)	-0.05	.96	8.42 (3.09)	9.15 (3.31)	10.33 (3.50)	1.37	.26
Avo C (M, SD)	5.45 (1.82)	7.14 (3.09)	-4.50	.00**	7.27 (3.16)	6.48 (2.77)	1.79	.08	7.05 (3.21)	6.34 (2.42)	6.33 (2.87)	2.08	.13
Eva C (M, SD)	12.64 (2.23)	12.58 (2.32)	0.17	.87	12.39 (2.19)	12.69 (2.35)	-.92	.36	12.75 (2.31)	12.31 (2.30)	12.67 (2.29)	0.78	.46
Ada C (M, SD)	12.26 (3.26)	11.79 (2.85)	.86	.39	11.35 (3.11)	12.24 (2.80)	-2.02	.05	12.08 (2.78)	11.47 (3.07)	12.78 (3.96)	1.34	.27
T2 (N)	22	83			47	58			66	35	3		
T1 PDis (M, SD)	1.82 (1.36)	1.43 (1.44)	-0.74	.46	1.39 (1.27)	1.37 (1.54)	0.06	.95	1.52 (1.44)	1.20 (1.42)	0.68 (0.95)	0.95	.39
T2 SC (M, SD)	2.65 (0.62)	2.51 (0.67)	0.90	.37	2.57 (0.62)	2.52 (0.69)	0.39	.70	2.51 (0.69)	2.58 (0.62)	2.75 (0.75)	0.27	.76

Notes. [a] = ‘Other’ encompassed Indeterminate Colitis, both Crohn’s and Ulcerative Colitis, Inflammatory bowel disease unclassified and Ulcerative Proctitis; [b] = Bowel IBDQ subscale score. Ill act = illness activity; PDis = psychological distress; SC = self-compassion; Act C = active coping; Sup C = seeking-support coping; Avo C = avoidant coping; Eva C = evaluative coping; Ada C= adaptive coping. * $p < .05$; ** $p < .001$.

Table 5

Descriptive statistics and bivariate correlations for the model variables

Variable	1	2	3	4	5	6	7	8	9
1. T1 Psychological distress[a]	-	-.74***	-.57***	-.52***	-.05	.55***	-.16*	-.39***	.53***
2. T2 Psychological distress[a]		-	-.47***	-.60***	-.14	.41***	-.24**	-.34***	.39***
3. T1 Self-compassion			-	.74***	.10	-41***	.26***	.46***	-.16
4. T2 Self-compassion				-	.13	-.35***	.31***	.44***	-.07
5. Support-seeing Coping					-	-.07	.47***	.17*	-.06
6. Avoidant Coping						-	-.30***	-.36***	.41***
7. Active Coping							-	.34***	-.16*
8. Adaptive Coping								-	-.27**
9. Bowel Activity									-
N	196	105	196	105	196	196	196	196	196
Mean	1.42	1.38	2.61	2.54	8.74	6.78	9.29	11.89	3.34
SD	1.52	1.42	0.67	0.66	3.21	2.95	2.86	2.94	1.16
Min	-1.09	-0.87	1.08	1.25	4	4	4	5	1
Max	5.41	4.72	4.58	4.42	16	16	16	20	6.80

Note. * $p < .05$, ** $p < .01$; *** $p < .001$; DV = dependent variable; IV = independent variable; C = covariate; SD = standard deviation; C alpha = Cronbach's alpha. [a] scores were converted to z-scores to compute composite score; Dis = distress

Regression analyses

The results from the cross-sectional and prospective regression analyses are presented in Table 6.

Table 6

ΔR^2 and standardized beta coefficients for each hierarchal regression step in cross-sectional and prospective analyses

Block	ΔR^2	Step 1 β	Step 2 β	Step 3 β	Step 4 β
DV: T1 PDis					
Step 1	0.32***				
Gender		-0.03	-0.05	-0.07	-0.07
CD - UC		-0.09	-0.05	-0.03	-0.05
CD - Other		-0.08	-0.03	-0.02	-0.02
Relapse/remission		0.16*	0.14**	0.13*	0.14**
Bowel Activity		0.62***	0.54***	0.46***	0.45***
Step 2	0.24***				
T1 SC			-0.50***	-0.43***	-0.41***
Step3	0.04***				
Active Coping				0.08	0.09
Avoidant Coping				0.24***	0.23***
Step 4	0.00				
Adaptive Coping					-0.07
DV: T2 PDis					
Step 1	0.56***				
Gender		-0.07	-0.07	-0.07	-0.01
CD - UC		0.01	0.01	0.01	-0.01
CD - Other		0.01	0.01	0.01	0.01
Relapse/remission		0.07	0.07	0.08	0.08
Bowel Activity		0.03	0.05	0.04	0.03
T1 PDis		0.75***	0.71***	0.71***	0.71***
Step 2	0.00				
T1 SC			-0.05	-0.04	-0.01
Step 3	0.00				
Active Coping				-0.02	-0.02
Avoidant Coping				-0.01	-0.02
Step 4	0.00				
Adaptive Coping					-0.08

Notes. DV = dependent variable; PDis = psychological distress; SC = self-compassion; * $p < .05$; ** $p < .01$; *** $p < .00$; PDis = psychological distress. The cross-sectional findings did not substantially differ when the covariates were excluded, the finding was not reliant on the presence of covariates (Simmons, Nelson, & Simonsohn, 2011). The overall model explained 46.2% of the variance, self-compassion ($\Delta R^2 = .33$) and coping styles ($\Delta R^2 = .16$) were significant predictors, avoidant coping was the only significant individual predictor at Step 4 ($\beta = .38$). When the covariates were excluded in the prospective analysis, the overall model explained 29.0% of the variance and self-compassion was the only significant predictor ($\Delta R^2 = .22$).

The model (T1 self-compassion, coping styles and coping flexibility and covariates) accounted for 58.1% (adjusted R^2) of the variance in T1 psychological distress. The first step of the regression analyses, which included the covariates, explained a significant proportion of variance, $\Delta R^2 = 0.32$, $F(5,188) = 17.97$, $p <.001$. However; as shown in Table 6, the Bowel IBDQ subscale ($\beta = 0.45$, $p <.001$) and relapse/remission ($\beta = 0.14$, $p <.05$) scores were the only significant predictors at Step 4. The addition of T1 self-compassion produced a significant increment in explained variance, $\Delta R^2 = 0.24$, $F(1,187) = 99.44$, $p <.001$. The coping variables also resulted in a significant increment of explained variance, $\Delta R^2 = 0.04$, $F(2,185) = 8.91$, $p <.001$; however, avoidant coping was the only significant individual predictor ($\beta = 0.23$, $p <.001$) at Step 4. Coping flexibility, measured by the adaptive coping subscale was non-significant, $\Delta R^2 = 0.00$, $F(1,184) = 1.36$, $p = .25$.

With T2 psychological as the outcome, the overall model accounted for 52.2% (adjusted R^2) of T2 psychological distress variance. The first step in the regression (the covariates) explained a significant proportion of variance, $\Delta R^2 = 0.56$, $F(6,97) = 20.83$, $p <.001$; however, T1 psychological distress was the only significant covariate, $\beta = 0.72$, $p <.001$. The addition of self-compassion, coping mechanisms and coping flexibility did not explain significant additional variance.

Given that T2 self-compassion was significantly higher than T1, the T2 regression was conducted using T2 self-compassion data, still controlling for T1 psychological distress. The pattern of results was very similar to those observed in the T1 cross-sectional data. The overall model accounted for 59.3% (adjusted R^2) of the overall variance, the covariates accounted for the largest proportion of variance $\Delta R^2 = 0.56$, $F(6,97) = 20.87$, $p <.001$ and the addition of self-compassion resulted in a small but significant increment in explained variance $R^2 = 0.07$, $F(1,96) = 17.17$, $p <.001$.

Indirect effects

The total model of the effects of self-compassion through avoidant coping was significant, F(6, 187) = 39.40, *p* <.001 and explained 55.83% of the overall variance in T1 psychological distress. Self-compassion was significantly associated with the mediator avoidant coping (a path) and avoidant coping was significantly associated with the outcome psychological distress (b path; Table 7). After accounting for the indirect effects through the avoidant coping (c' path), the direct effect between self-compassion and T1 psychological distress remained significant, *b* = -0.97, *t*(193) = -8.23, *p* <.001. The completely standardised indirect effect was significant as the 95% confidence intervals did not pass zero (*b* = -0.09; 95% CI: -0.16; -0.04).

Table 7

Indirect effect of self-compassion on T1 psychological distress through avoidant coping

Path	*b* (SE)	*t*	Indirect effect[a]	LLCI	ULCI
SCO – PDis (c)	-1.14 (.11)	-9.97**		-1.36	-0.91
SCO – AVC (a)	-1.47 (.27)	-5.40**		-2.01	-0.94
AVC – PDis (b)	0.12 (.03)	3.91**		0.06	0.17
SCO – AVC – PDis (c')	-0.97 (.12)	-8.19**		-1.20	-0.74
			-0.09 (.03)	-0.16[b]	-0.04[b]

Note. The *b* path coefficients were all unstandardised. [a] = completely standardised indirect effect; [b] = bias corrected confidence intervals calculated using 5000 bootstraps; ** *p* <.001; SCO = T1 self-compassion; PDis = psychological distress; AVC = avoidant coping; LLCI = lower level confidence interval; ULCI = upper level confidence interval.

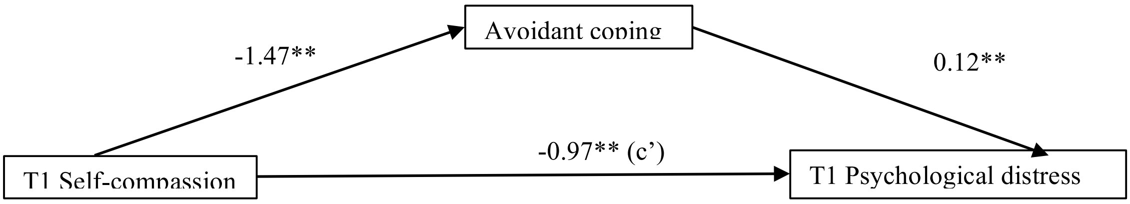

Figure 1. Unstandardised indirect effect path co-coefficients of T1 self-compassion on T1 psychological distress through avoidant coping. **all paths *p* <.001.

Following the recommendations of Simmons et al. (2011) regarding the importance of testing for false positive results, the analysis was also conducted without the covariates. The re-analysis found that indirect effect remained when the covariates were excluded (*b* = -0.15; 95% CI: -0.23; -0.09).

Analysis of the indirect effect between coping style and psychological distress through coping flexibility was not tested since coping flexibility was not a significant predictor of psychological distress at T1 or T2.

Discussion

The current findings replicate and extend previous research on the benefits of self-compassion for coping with IBD (Sirois et al., 2015), by examining the role of self-compassion in adjustment to IBD in a sample of YP. Self-compassion explained significant incremental variance in T1 psychological distress in YP diagnosed with IBD, even when accounting for variance explained by other factors such as illness activity. This finding supports previous research which suggests that self-compassion may enable individuals with threats to their health to regulate negative emotions which arise as a result (Terry, Leary, Mehta, & Henderson, 2013).

The effectiveness of problem-focused coping in reducing psychological distress in individuals diagnosed with IBD has been mixed (McCombie et al. 2013). This study found that the problem-focused coping strategy, active coping, was negatively associated with psychological distress at T1. This finding echoes that of Kinash et al. (1993) and Pellissier et al. (2010) who found this association in adults. The current finding that self-compassion was positively associated with active coping at T1 also replicates evidence that self-compassion is associated with proactive attempts to manage health (Terry et al., 2013; Sirois et al., 2015). However, active coping did not explain significant proportions of variance in T1 or T2 psychological distress; therefore, conclusions regarding its value in facilitating reduced psychological distress, after taking into account other factors, cannot be drawn.

The current study also replicates findings that self-compassion is negatively related to avoidant coping (Neff, Hsieh, & Dejitterant, 2005). Avoidant coping (i.e., denial and behavioural disengagement) was the only coping factor to make a significant and robust contribution to explaining psychological distress at T1 (Crane & Martin, 2004; Van der Zaag-Loonen et al., 2004). This study also found that avoidant coping indirectly linked self-compassion and T1 psychological distress. Considering this finding in the context of self-compassion theory, self-compassionate YP may have a coping advantage in that they may be less likely to deny difficult feelings and disengage from attempting to cope with their symptoms, which would in turn heighten psychological distress (Allen & Leary, 2010). Self-compassionate YP may be more able to turn towards difficult feelings or behaviours linked to their IBD, consider them in the context of others diagnosed with IBD and respond to themselves with self-kindness despite their difficulties, which the results of this study suggest could improve their psychological health.

After accounting for the indirect effect of avoidant coping, the direct cross-sectional relationship between self-compassion and psychological distress remained significant. This indicates that self-compassion may be linked to psychological distress through factors beyond coping. Further research is required to examine other potential mediating variables. Illness perceptions may be one potential mediator. Illness perceptions feature in the Common Sense Model (CSM) of illness which proposes that psychological outcomes in individuals with CIs are predicted by illness severity, illness perceptions and coping mechanisms (Leventhal, Diefenbach, & Leventhal, 1980).

Illness perceptions are “organised cognitive representations or beliefs” about illnesses and can include beliefs about the range of symptoms associated with illnesses or the consequences the illness holds for individuals (Petrie, Jago, & Devcich, 2007, p. 163). Illness perceptions have been found to play a crucial role in explaining psychological distress outcomes across a range of CIs (Dempster, Howell, & McCorry, 2015). Furthermore, illness perceptions have been found to account for 11 to 21% of the variance in quality of life of individuals’ with IBD (Han et al., 2005; Dorrian et al., 2009; Van der Have et al., 2015). Recent evidence provides support for the CSM in relation to adjustment to IBD. Stronger illness activity, ‘negative’ illness perceptions (i.e., IBD as chronic and uncontrollable) and greater use of maladaptive coping responses (i.e., denial, behavioural disengagement) have been found to predict poorer psychological health in adults with IBD (Zhang et al., 2016). Furthermore, van Erp et al. (2017) recently found that perceptions of more serious consequences, stronger personal control and a lack of personal understanding of IBD were associated with greater use of the avoidant coping strategy, decreasing activity, in adults which in turn was associated with poorer mental health. However, less is known about how self-compassion relates to the CSM of illness; therefore, examining the additional impact of illness perceptions on the relationships observed in this study in both YP and adults diagnosed with IBD would be a fruitful area for future research.

In accordance with the hypotheses, coping flexibility was associated with greater self-compassion and reduced psychological distress. This finding supports earlier studies that self-compassion facilitates greater coping efficacy (Sirois et al., 2015). Although the bivariate correlations suggested a positive impact, contrary to the hypotheses, coping flexibility did not explain a significant increment of variance in T1 or T2 psychological distress. This finding is in contrast with previous studies (Kato, 2015). It is possible that other factors are more important than coping flexibility in IBD samples, or that YP or those relatively new to the diagnosis, are less capable of coping flexibly. Cheung, Lau and Chan (2014) found that the relationship between coping flexibility and psychological adjustment was stronger in adults (over-30-years-of-age) compared to younger people (under 30-years-of-age) which suggests coping flexibility develops with age. Furthermore, the weak links between coping flexibility and psychological distress observed in this study are possibly due to YP being less focused on whether their coping strategies produce adaptive changes and more focused on the immediate alleviation of distress. This coincides with Schmidt, Petersen, and Bullinger's (2003) proposal that the YP's approach to coping with CI begins with obtaining 'technical competence', which focuses on gaining skills in alleviating distress using strategies such as avoidance, problem-solving and acceptance (Fournet, Wilson, & Wallander, 1998). They also suggest that adaptive and flexible coping gradually develops as YP begin to activate their individual resources in accordance with the demands of the situation and develop the capacity for independent action. For the current sample of YP, technical competence may have remained a priority. Focus on technical competence could also explain why avoidant coping was the strongest predictor of psychological distress in this sample, as avoidant-coping can be effective in alleviating distress in the short-term (Roth & Cohen, 1986).

Study strengths and limitations

The current findings should be interpreted in the context of the study's methodological limitations. The relationships between self-compassion, coping and psychological distress were only observed cross-sectionally, when the variables were measured simultaneously. Therefore, inferences about the impact of self-compassion and coping on psychological distress over time and direction of causality, made using prospective analyses, cannot be made. This may reflect either a true effect, that self-compassion does not predict changes in psychological distress over time or, limitations of the six-week time interval used. T1 and T2 mean psychological distress scores were too highly correlated ($r = .74$) to show variation and thus could not facilitate an analysis of change over time. Six weeks was likely too short to measure meaningful changes in psychological distress in a CI sample, whose circumstances may not have changed in such a short period of time. Other prospective studies with IBD populations have utilised time intervals of six months (Sirois et al., 2015; Sirois & Wood, 2017). Future research should replicate the current study using longer intervals between data collection and more data collection time points to improve methodological robustness.

A high rate of attrition was found in this study; although, this is not uncommon in online longitudinal studies (Musch & Reips, 2000; Hiskey & Troop, 2002). No significant differences between the baseline and completer samples were found across model variables, however, it is likely that attrition of the size observed will have impacted the validity of the study. Participants who completed both the T1 and T2 survey may have held certain characteristics, which were not measured, which may have impacted the results. In addition, whilst key variables known to covary with the focal model variables were controlled for (e.g., illness activity), factors such as current medical treatment were not accounted for. Recent research has suggested that being prescribed corticosteroids is a key risk factor for psychological distress in YP diagnosed with IBD (Brooks et al., 2016). Future studies should control for current medication treatment to limit the impact of confounding effects.

Whilst the analyses conducted were sufficiently powered, the high rate of attrition meant that the sample size was relatively small at T2. This restricted the number of variables that could be examined and meant that the individual components of self-compassion (self-kindness, mindfulness and common humanity) and psychological distress (depression, anxiety and stress) could not be analysed separately in the regression analyses. Instead overall scores were analysed. Examining the relationships between individual components of these key constructs with larger sample sizes would be a crucial area of further research to extrapolate key dimensions of self-compassion for clinical intervention.

Illness-related variables were measured by self-report. Recruiting from a clinical setting and obtaining physician reports of illness-related factors (e.g., illness activity), may have improved accuracy of diagnosis and illness activity data. Though, self-reports of illness activity have been found to be comparable to physician reports (Randell et al., 2014).

The Brief COPE measures a broad spectrum of potential coping mechanisms which are applicable to wide-ranging groups. This limits the tools' ability to measure the nuances of coping with a CI such as IBD (e.g., being near a toilet). An IBD coping measure has recently been developed which includes IBD-specific coping responses for example, "have you altered your diet in an attempt to improve your IBD? (IBD-Cope, McCombie et al., 2016). However, the breadth of coping responses in the IBD-Cope measure are limited and that there is currently no data validating its use with YP (McCombie et al., 2016). However, future studies could consider examining the relationships between self-compassion, psychological distress and coping as measured by the IBD-Cope, possibly as a supplement to a broader coping measure.

Despite these limitations, this study responded to important gaps in the existing literature base. This study was the first to examine the role of self-compassion in YP diagnosed with IBD, and to study self-compassion in relation to coping with IBD using a prospective design. Furthermore, through using exploratory factor analysis on responses to the Brief COPE measure, this study identified an underlying coping factor structure relevant to this sample. Three conceptually distinct coping strategies were extracted, which were subsequently used as predictors in this study. Recruitment from online charity advertisements also resulted in a nationwide UK sample that increased the generalisability and clinical applicability of the findings. In addition, this study controlled for key variables known to covary with the outcome (e.g., illness activity), strengthening the robustness of the findings.

Clinical implications

Notwithstanding the limitations identified, self-compassion has been found to negatively predict psychological distress over and above the impact of illness activity in the cross-sectional analyses. This suggests that cultivating self-compassion may help increase psychological wellbeing in this population at times of both remission and relapse. This cross-sectional finding provides preliminary evidence for the efficacy of self-compassion targeted clinical interventions for this population. However, further robust prospective research, taking into account the limitations of the current study, investigating these relationships over time is required to strengthen this case.

Self-compassion interventions developed thus far have typically focused on supporting individuals to acknowledge and notice their tendencies to be self-critical and inducing a self-compassionate mind-set in which individuals respond to themselves with self-kindness (Gilbert & Proctor, 2006; Neff, Kirkpatrick, & Rude, 2007). Intervention studies to date have found self-compassion interventions to be associated with reduced depression in undergraduate students ($M_{age} = 21.05$ years; Neff et al., 2007) and adults diagnosed with personality disorders (Gilbert & Proctor, 2006). Other intervention studies have also focused on specific elements of self-compassion (e.g., mindfulness and common-humanity) and found reductions in depression in clinical psychology trainees ($M_{age} = 32.61$ years) which were maintained over a three-month follow-up (Finlay-Jones, Kane, & Rees, 2016). However, less research has been conducted on self-compassion interventions with CI populations. Chapin et al., (2014) found that adults with chronic pain reported reduced depression and pain scores after completing a compassion meditation course which encompassed two sessions on self-compassion when compared to their baseline scores. Therefore, it is possible that interventions, with self-compassion components, may facilitate improved psychological health in YP diagnosed with IBD and support them to reduce their use of avoidant coping; however, this requires investigation in future research.

Finally, whilst not examined in this study, current research is linking self-compassion to improved health behaviours (Sirois & Rowse, 2016). A recent meta-analysis found that self-compassion was positively associated with health-promoting behaviours in non-clinical samples, albeit with a small effect size ($r = .25$; Sirois et al., 2015). Sirois (2015) also found self-compassion to be positively associated with intentions to engage in health-promoting behaviours in YP aged 18-25. Nevertheless, there is no current research on the impact of self-compassion on health-promoting behaviours in YP diagnosed with IBD; but this is a crucial area for future research to extend the clinical rationale for cultivating self-compassion in this population.

Conclusions

These findings suggest that self-compassion may be an important quality for facilitating psychological health in YP diagnosed with IBD. Self-compassion was found to directly and indirectly, through avoidant coping, be associated with psychological distress in the cross-sectional analyses. However, these relationships were not observed prospectively when controlling for baseline levels of psychological distress at the 6-week follow-up. Future studies may wish to; (i) replicate the existing study with a longer time interval to test whether the observed relationships can be observed prospectively; (ii) examine whether how a young person perceives their IBD (e.g., how serious the consequences of the illness are) which may further explain the relationships between self-compassion, avoidant coping and psychological distress; and (iii) examine whether cultivating self-compassion reduces the use of avoidant coping, improves health-promoting behaviours and reduces the distress YP diagnosed with IBD experience.

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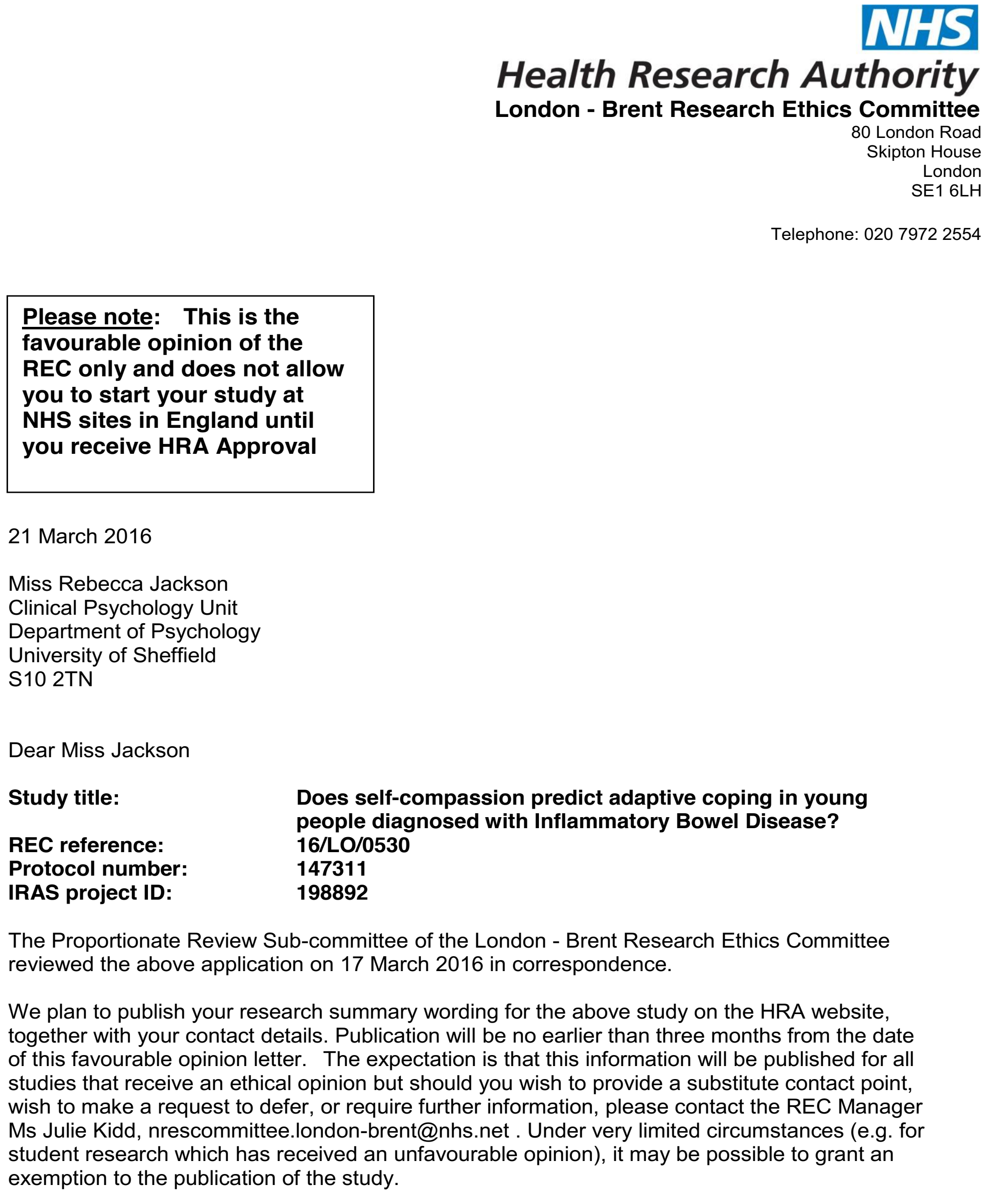
Appendix A

NHS ethical approval letter



NHS
Health Research Authority
London - Brent Research Ethics Committee
80 London Road
Skipton House
London
SE1 6LH

Telephone: 020 7972 2554

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

21 March 2016

Miss Rebecca Jackson
Clinical Psychology Unit
Department of Psychology
University of Sheffield
S10 2TN

Dear Miss Jackson

Study title:	**Does self-compassion predict adaptive coping in young people diagnosed with Inflammatory Bowel Disease?**
REC reference:	**16/LO/0530**
Protocol number:	**147311**
IRAS project ID:	**198892**

The Proportionate Review Sub-committee of the London - Brent Research Ethics Committee reviewed the above application on 17 March 2016 in correspondence.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Ms Julie Kidd, nrescommittee.london-brent@nhs.net . Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion").

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Online advertisement materials]	V1	26 February 2016
Covering letter on headed paper [Covering letter]	V1	26 February 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor insurance]	V1	26 February 2016
IRAS Checklist XML [Checklist_08032016]		08 March 2016
IRAS Checklist XML [Checklist_10032016]		10 March 2016
Letter from sponsor [Scientific approval letter which also confirms sponsorship]	V1	01 March 2016
Letters of invitation to participant [Invitation letter for NHS participants]	V1	01 March 2016
Letters of invitation to participant [Invitation letter for people on existing UoS database]	V1	01 March 2016
Participant consent form [Consent form for NHS participants]	V1	01 March 2016
Participant consent form [Consent form for UoS database participants]	V1	02 March 2016
Participant information sheet (PIS) [Information sheet for University of Sheffield and NHS participants participating via post]	V1	01 March 2016
Participant information sheet (PIS) [Information sheet for online version of survey]	V1	01 March 2016
REC Application Form [REC_Form_08032016]		08 March 2016
Referee's report or other scientific critique report [Scientific approval letter]	V1	26 February 2016
Research protocol or project proposal [Thesis proposal]	V2	26 February 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	V1	01 March 2016
Summary CV for student [Dr Fuschia Sirois Summary CV (2nd academic supervisor)]	V1	01 March 2016

Summary CV for supervisor (student research) [Dr Georgina Rowse CV (1st academic supervisor)]	V1	01 March 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research flowchart]	V1	01 March 2016
Validated questionnaire [Copies of validated questionnaires being used in survey]	V1	26 February 2016

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

16/LO/0530 **Please quote this number on all correspondence**

Yours sincerely

PP

G Kidd.

Vice Chair
Mrs Sunder Chita

Email: nrescommittee.london-brent@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

"After ethical review – guidance for researchers"

Copy to: *Dr Andrew Thompson*
Ms Wendy Swann, Sheffield Children's Hospital NHS Foundation Trust

Appendix B

Research governance sponsorship letter

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research
training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Address:
Rebecca Jackson
Trainee Clinical Psychologist
Department of Psychology
Western Bank

Clinical Psychology Unit
Department of Psychology
Western Bank
Sheffield

Date 29/09/2016

Telephone: 0114 22 26650
Fax: 0114 22 26610
Email: a.sinha@sheffield.ac.uk

Project title: Does self-compassion predict adaptive coping in young people diagnosed with Inflammatory Bowel Disease (IBD)?

URMS number: 147311

Dear Rebecca,

LETTER TO CONFIRM THAT THE UNIVERSITY OF SHEFFIELD IS THE PROJECT'S RESEARCH GOVERNANCE SPONSOR

The University has reviewed the following documents:

1. A University approved URMS costing record;
2. Confirmation of independent scientific approval;
3. Confirmation of independent ethics approval.

All the above documents are in place. Therefore, the University now **confirms** that it is the project's research governance sponsor and, as research governance sponsor, **authorises** the project to commence any non-NHS research activities. Please note that NHS R&D/HRA approval will be required before the commencement of any activities which do involve the NHS.

You are expected to deliver the research project in accordance with the University's policies and procedures, which includes the University's Good Research & Innovation Practices Policy: www.shef.ac.uk/ris/other/gov-ethics/grippolicy, Ethics Policy: www.sheffield.ac.uk/ris/other/gov-ethics/ethicspolicy and Data Protection Policies: www.shef.ac.uk/cics/records

Your Supervisor, with your support and input, is responsible for providing up-to-date study documentation to all relevant sites, and for monitoring the project on an ongoing basis. Your Head of Department is responsible for independently monitoring the project as appropriate. The project may be audited during or after its lifetime by the University. The monitoring responsibilities are listed in **Annex 1**.

Yours sincerely

Dr Andrew Thompson
Director of Research Training, Clinical Psychology Unit

cc. Supervisors: Georgina Rowse & Fuschia Sirois
Head of Department/School: Glenn Waller

Information Sheet

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Telephone: 0114 2226650

Email: rjackson7@sheffield.ac.uk

Information sheet

1. Research Project Title:

Understanding how young people cope with IBD.

2. What does participation in the research project involve?

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with other people if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

3. What is the project's purpose?

This study aims to explore what factors impact how young people cope with IBD.

4. Why have I been chosen?

You have been chosen because you are aged between 16-24 and you have a diagnosis of IBD and this is the group of people we're interested in, in this study. Approximately, 120 other people will also be recruited to take part in this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and you can still withdraw at any time without it affecting your care or the benefits that you are entitled to in any way. You do not need to give a reason.

6. What will happen to me if I take part?

If you choose to take part, you will be asked to complete an online survey, which will take approximately 15 minutes to complete. You will also be asked whether you consent to be contacted in six weeks time to complete a shorter 5-minute survey.

7. What do I have to do?

In the survey you will be asked questions about how you feel emotionally and physically and how you cope with IBD and respond to stress.

8. What are the possible disadvantages and risks of taking part?

Some of the questions in the survey will ask you about how you feel physically and emotionally and how you respond to stress, which may make you feel embarrassed and/or uncomfortable. If you feel distressed at any stage, you can pause the survey or withdraw from the project completely.

9. What are the possible benefits of taking part?

Whilst there are no immediate benefits to participating in the project, it is hoped that this work will inform the help and support young people are given when they are coping with IBD.

10. What if something goes wrong?

If after participating, you decide that you would like to withdraw your data from the study please email rjackson7@sheffield.ac.uk, quoting the unique survey number allocated to you at the end of the study. You do not need to provide a reason for withdrawing from the study.

If you feel distressed after participating you can contact your GP, ChildLine (on 0800 1111) or Crohns and Colitis UK (on 0121 737 9931).

If after participating in the study, you wanted to raise a complaint, you can do this by contacting Dr Georgina Rowse, Research Supervisor at the University of Sheffield by telephone on 0114 2226574 or by email on g.rowse@sheffield.ac.uk . However, if you do not feel your complaint has been handled in a satisfactory way, you can also contact the University's Registrar and Secretary.

11. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any reports or publications.

13. What type of information will be sought from me and why is the collection of this information relevant for achieving the research project's objectives?

Information about your age, gender, ethnicity and your diagnosis of IBD will be collected because this will help the researcher see whether these factors impact how people cope with IBD.

14. What will happen to the results of the research project?

The results of this study will be published in 2018 in a peer-reviewed scientific journal. You will be not be identifiable in any report or publication of these results. The lead researcher will write up the results of this study and this will form part of her DClinPsy (Clinical Psychology doctorate) qualification.

If you decide after participating that you would like to withdraw your responses from the study, you can email the Lead Researcher and your data will be removed.

15. Who is organising and funding the research?

The University of Sheffield is organising and funding this research.

16. Who has ethically reviewed the project?

This project has been ethically approved via the NHS Research and Ethics Committee.

17. Contact for further information

If you would like any further information you can contact Rebecca Jackson (Lead Researcher) by email: rjackson7@sheffield.ac.uk.

Thank you for taking part in the project.

Appendix D

Summary of information sheet included at the front of the online survey

You are being invited to take part in a survey which aims to understand how young people (16-24 year olds) cope with IBD. It is hoped that this work will help inform the support young people are given when they are coping with IBD. The study is being organised by the University of Sheffield.

Before you decide to take part it is important for you to understand what it will involve. Take time to decide whether or not you wish to take part.

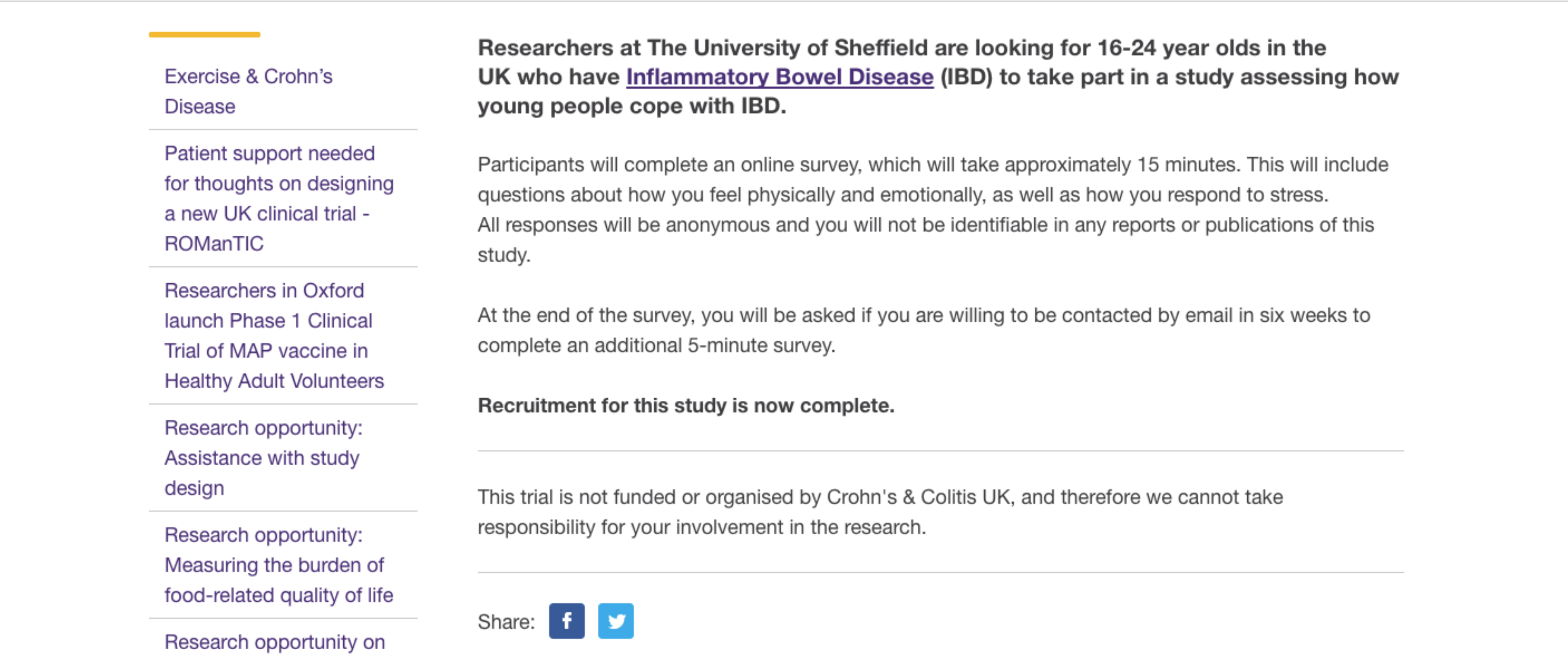
You will be asked to answer some questions which will take approximately 15 minutes to complete.
Some of the questions in the survey will ask you about how you feel physically and emotionally and how you respond to stress, which may cause you some distress. Your responses will be anonymous and you will not be identifiable in any reports or publications of this study.

At the end of the survey you will be asked whether you are willing to be contacted by email in six weeks about completing a short 5-minute survey. All the information that we collect about you during the course of the research will be kept strictly confidential. If you would like any further information you can contact Rebecca Jackson (Lead Researcher) by email: rjackson7@sheffield.ac.uk.

If you consent to participating, you can click ‘Yes I agree to participate’ and you will be taken to the first page of the survey.

Appendix E

Online advertisement of the study



Exercise & Crohn's Disease

Patient support needed for thoughts on designing a new UK clinical trial - ROManTIC

Researchers in Oxford launch Phase 1 Clinical Trial of MAP vaccine in Healthy Adult Volunteers

Research opportunity: Assistance with study design

Research opportunity: Measuring the burden of food-related quality of life

Research opportunity on

Researchers at The University of Sheffield are looking for 16-24 year olds in the UK who have Inflammatory Bowel Disease (IBD) to take part in a study assessing how young people cope with IBD.

Participants will complete an online survey, which will take approximately 15 minutes. This will include questions about how you feel physically and emotionally, as well as how you respond to stress.
All responses will be anonymous and you will not be identifiable in any reports or publications of this study.

At the end of the survey, you will be asked if you are willing to be contacted by email in six weeks to complete an additional 5-minute survey.

Recruitment for this study is now complete.

This trial is not funded or organised by Crohn's & Colitis UK, and therefore we cannot take responsibility for your involvement in the research.

Share:

Appendix F

Consent Form

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Telephone: 0114 2226650

Email: rjackson7@sheffield.ac.uk

Title of Research Project: Understanding how young people cope with IBD.

Name of Researcher: Rebecca Jackson

Participant Identification Number for this project: Please

initial box

I confirm that I have read and understand the information sheet explaining the above research project and I have had the opportunity to ask questions about the project. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. You may contact the researcher Rebecca Jackson on rjackson7@sheffield.ac.uk to discuss this further if you would like. ☐

I understand that my responses will be kept strictly confidential. ☐

I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

I agree for the data collected from me to be used in future research

☐

I agree to take part in the above research project.

I agree to share my contact details with Rebecca Jackson so she can contact me in six weeks time to complete a second survey which will take 5 minutes to complete. ☐

Name of Participant	Date	Signature
Rebecca Jackson Lead Researcher	Date	Signature

Appendix G

Demographic Questionnaire

These questions will ask you to describe yourself. This information will help the researcher to see whether these factors impact how people cope with IBD.

1. Where do you live?
    England
    Scotland
    Wales
    Ireland
    Northern Ireland
    Other (specify)

2. How old are you? (in years, 16-24)

3. What is your gender?
    Male
    Female

4. What is your diagnosis? (free-text)

5. How old were you when you were diagnosed with IBD? (in years, 1-24)

6. Would you consider yourself to be in relapse or remission right now?
    Relapse
    Remission

Appendix H – Copies of measures

Removed for copyright reasons

Appendix I

Scree Plot

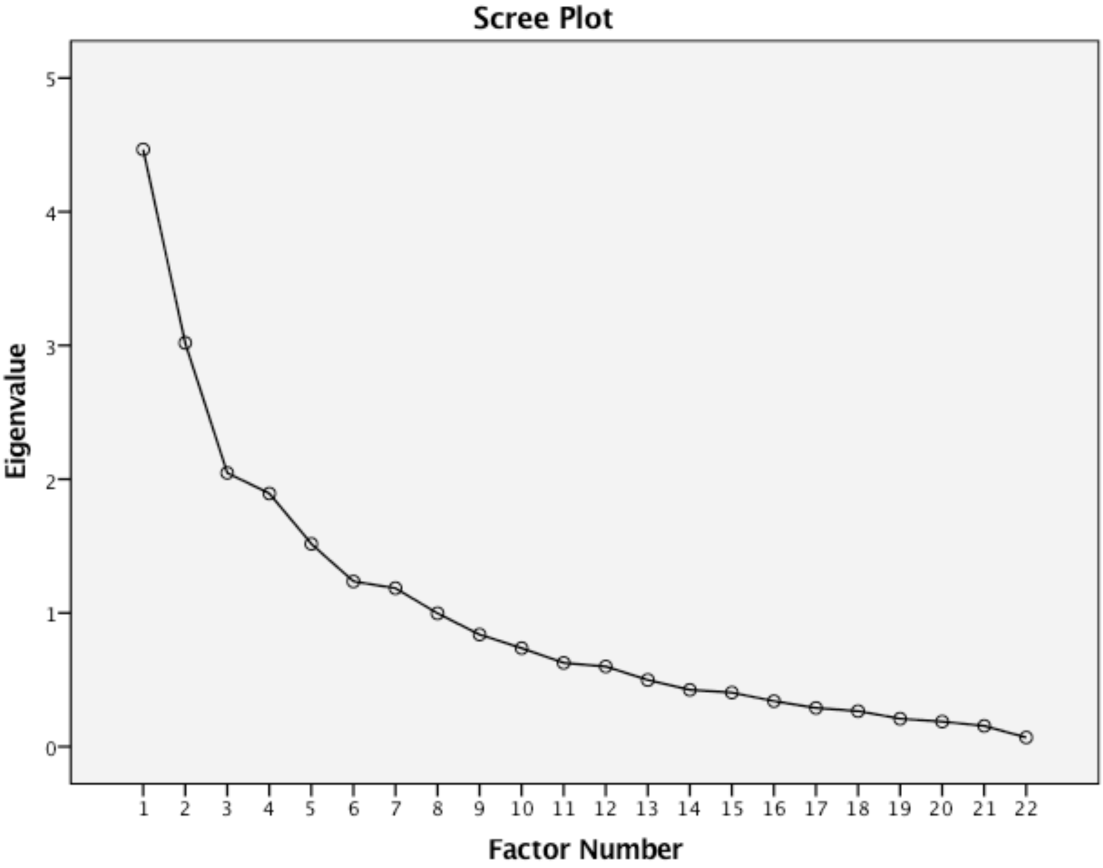


Figure 2. Brief COPE exploratory factor analysis scree plot

Appendix J

Initial three factor structure prior to removing items

Table 8

Factor loadings for the three coping variables

Item	Factor 1	Factor 2	Factor 3
14. I’ve been trying to come up with a strategy about what to do (P)	.76		
25. I’ve been thinking hard about what steps to take (P)	.70		
7. I’ve been taking action to try and make the situation better (AC)	.69		
2. I’ve been concentrating my efforts on doing something about the situation I’m in (AC)	.61		
17. I’ve been looking for something good in what is happening (PR)	.59		
12. I’ve been trying to see it in a different light, to make it seem more positive (PR)	.59		
10. I’ve been getting help and advice from other people (IS)		.83	
5. I’ve been getting emotional support from others (ES)		.82	
15. I’ve been getting comfort and understanding from someone (ES)		.82	
13. I’ve been trying to get advice or help from other people about what to do (IS)		-.78	
13. I’ve been criticising myself (SB)			.73
26. I’ve been blaming myself for things that have happened (SB)			.68
16. I’ve been giving up the attempt to cope (BD)			.66
9. I’ve been saying things to let my unpleasant feelings escape (V)			.61
6. I’ve been giving up trying to deal with it (BD)			.54
% of variance (total 41.60)	20.19	13.50	7.90

Key. P = planning; AC = active coping; PR = positive reframing; IS = use of instrumental support; ES = use of emotional support; SB = self blame; BD = behavioural disengagement; V = venting.